Patient and Public Awareness of the NHS Constitution

The Patients Association

December 2014
1. CONTENTS

1. Contents Page 1
2. Foreword Page 2
3. Executive Summary Page 3
4. Calls to Action Page 5
5. Introduction Page 6
   5.1 NHS Constitution Page 6
   5.2 Background Page 6
   5.3 Legal Status Page 7
   5.4 Current Policy Page 8
6. Methodology Page 10
7. Results Page 11
   7.1 Experience of the NHS and awareness of the NHS Constitution Page 11
   7.2 Understanding of the NHS Constitution and using it Page 14
   7.3 Perception of the NHS Constitution Page 16
8. Conclusion Page 30
   Appendix A: February – June survey questions Page 34
   Appendix B: August survey questions Page 38

Written by Katherine Murphy, Chief Executive, The Patients Association
2. FOREWORD

Katherine Murphy, Chief Executive of the Patients Association

“The NHS belongs to the people”. This is the fundamental truth outlined by the NHS Constitution, and with which we began our 2012 report ‘NHS Constitution: Fact or Fiction? We stand by that truth, and our belief that the NHS Constitution remains a key resource to help patients exercise their rights to excellent care, within a compassionate, respectful National Health Service.

Since our last report, our follow-up research has shown a significant increase in patient and public awareness of the NHS Constitution itself, despite there being much room for improvement. There continues to be much goodwill amongst patients, and positive stories about their experience of the NHS.

That said, the universal application of the Constitution’s values and pledges is still very much a work in progress. Our findings show that the reality on the ground is often far removed from these ideals and patients’ legal rights are not consistently upheld. Whilst the significant financial challenges and re-organisation of the NHS may offer some explanation for poor care experiences, there is never an excuse for failure to uphold basic patient rights.

Even in these times of immense pressure on NHS services, there are many positive steps that can be taken to make the principles of the NHS Constitution the reality everywhere. Here we have outlined a number of achievable, common sense recommendations for how the NHS could best embed the Constitution in everyday practice, and raise patients and the wider public’s understanding of the values it espouses. No matter whether we currently consider ourselves patients, carers, family members or NHS staff, at some point we are all patients. It is in our interest to use the NHS Constitution as the tool it deserves to be, to give us the NHS we all deserve.

Katherine Murphy
Chief Executive, Patients Association
3. EXECUTIVE SUMMARY

The NHS Constitution is a single document covering the principles and values of the NHS, as well the rights and responsibilities of patients and staff within the NHS. The most important rights of patient care relevant to the NHS Constitution include being involved in decisions about treatment; being given information about treatment; and being treated with dignity and respect.

In 2012 the Patients Association conducted a survey to study what the NHS Constitution meant to patients and the public. The results showed a low awareness from the public at only 24.0%, with 98.1% reporting they had been treated by the NHS without being notified of the Constitution’s existence by staff, or via information sources such as leaflets.ii

Based on the findings of this survey, and in collaboration with the NHS and other organisations, the Patients Association in 2012 delivered a number of public awareness initiatives including designing the GP checklist, a tool for shared decision-making.iii

In 2014, the Patients Association measured the impact that these initiatives have had on public awareness of the NHS Constitution by conducting a follow-up survey, which showed an increase in awareness of the NHS Constitution over the last two years. In 2014, out of 986 respondents, 60.4% stated they were aware of the NHS Constitution compared to just under 24% in 2012.iv

Crucially, whilst awareness of the Constitution may be slowly increasing, there appears to be in many cases an absence of in-depth understanding of the Constitution and how to use it effectively.

When patients were asked which issues they thought were the most important for the NHS Constitution to cover, the highest priority was given to rights to be treated with dignity and respect (78.0%), closely followed by rights to be given information about your treatment (76.5%) and rights to be involved in decisions about your treatment (76.2%)

When asked what the important responsibilities for patients should be in the NHS Constitution, respondents identified the most important ones (for patients) as treating NHS staff and other patients with respect, and the importance for patients to keep appointments or cancel within a reasonable time.

Nearly a third of respondents said they would be very likely to read and try to
understand the Constitution if they were not already using NHS services. However, if they were about to embark on a period of care this increases to 47.4%.

The need for greater awareness and promotion of the NHS Constitution was highlighted, with 63% of respondents choosing to make a comment and suggest ways in which such promotion may occur. Approximately 25% of those who knew what the Constitution was suggested a name change for the document, in order for this to be more meaningful, for example ‘Rights and Responsibilities’.

**Nearly half (47.9%) of respondents found out about the NHS Constitution through using another service, for example, the Patients Association.**
4. CALLS TO ACTION

The Patients Association calls upon the NHS, the Government and all health and social care professionals to:

- actively raise awareness of the NHS Constitution among patients and staff through effective media campaigns and personally informing patients of their rights during all stages of care;
- ensure that all patients are not only aware of the NHS Constitution’s existence, but also have a sound knowledge of its working and how to use it effectively to protect their rights and ensure satisfactory outcomes;
- consider a more user friendly name-change;
- not underestimate the primary importance of being treated with dignity and respect, which some patients consider more important than safety;
- not underestimate the patient’s need and desire to be given appropriate information and be involved in decisions about their care and treatment;
- allow patients to acknowledge and understand their own responsibilities and take responsibility for their health and social care and relationship with provider services;
- take extra measures to promote the NHS Constitution among the young (including school children) through formal education and social media campaigns;
- extend the duty to promote the NHS Constitution to all NHS bodies, including NHS Foundation Trusts and Monitor;
- establish an annual audit by NHS England to assess how the NHS Constitution is being promoted and the level of public and staff awareness;
- clarify and define the enforceability of the NHS’ pledges within the NHS Constitution.
5. INTRODUCTION

5.1 The NHS Constitution

The NHS Constitution establishes the principles and values of the NHS in England, setting out the rights to which patients, the public and staff are entitled, as well as their responsibilities to one another. The document also states pledges the NHS is committed to achieving. The Constitution and its pledges are neither legally binding nor enforceable alone, but the Secretary of State for Health, all private and voluntary sector bodies proving NHS services, and all NHS bodies are legally obliged to uphold the NHS Constitution in their decisions and actions. The patients’ rights outlined are legal entitlements derived from legal obligations imposed on NHS bodies and other healthcare providers.

The two key principles of the NHS Constitution, underpinning core NHS values, are “reassuring the public and patients about the NHS” and “empowering patients and the public by setting out what they are entitled to”, what they can expect from the NHS, and what their responsibilities are as patients.

The Secretary of State for Health must review the NHS Constitution and publish an updated version every 10 years. It is to be accompanied by a Handbook to the Constitution, renewed at least every three years. Changes to the NHS Constitution are subject to wide consultation, including patients, healthcare professionals, and carers.

Some of the rights to which patients in England are entitled include:

- Universal access to free NHS services, excluding some limited exceptions sanctioned by Parliament;
- The right to be treated with dignity and respect, and the right to privacy and confidentiality;
- The right to nationally approved treatment, drugs and programmes recommended by the National Institute for Health and Clinical Excellence for use in the NHS.

5.2 Background

In 2007, then Parliamentary Undersecretary of State for Health, Professor Lord Darzi, was asked to undertake a review of the course of the NHS for the next ten years. In June 2008, Lord Darzi presented the ‘High Quality Care for All’ report, along with his recommendations to the then Prime Minister, Gordon Brown and Secretary of State for Health, Alan Johnson. As part of this report, and as a product of extensive consultation, the NHS Constitution was established.

In January 2009 the proposed NHS Constitution was put before Parliament as part of the Health Bill which received Royal Assent the following November, becoming the Health Act 2009.
5.3 Legal Status

Since the Health Act 2009 came into force, the role of the NHS Constitution within the wider health landscape has been uncertain, due in part to widespread confusion of its legal enforceability. While the Health Act (revised by the Health and Social Care Act 2012) ensures that all providers of NHS services take the Constitution into consideration, and many of the described ‘rights’ are underpinned by current legislation, the NHS Constitution is not in itself legally enforceable, including the NHS’ pledges within the document.

However, the rights outlined gain legal standing from other pre-existing statutes, regulations, and case law. Below are examples of statutes and case law from which some of the Constitution’s rights obtain their legal credibility and enforceability.

- ‘You have the right to access NHS services. You will not be refused access on unreasonable grounds.’

Patients are protected from discrimination through legislation such as the Sex Discrimination Act 1975, and the Equality Act (Sexual Orientation) Regulations 2007. Such laws prohibit discrimination on grounds of gender, sexual orientation, religion, disability, or race. These rights also stem from the principles of Administrative Law that governs public bodies such as the NHS to act in accordance with their statutory duties to be reasonable and procedurally fair.

- ‘You have the right to be treated with dignity and respect, in accordance with your human rights.’

Patients are legally protected from administrative decisions potentially infringing upon their dignity and human rights. This is supported by the Human Rights Act 1998 which applies the European Convention of Human Rights (ECHR) in UK law. The relevant articles applicable to these specific rights are Article 2: the right to life; Article 3: the right not to be subject to inhuman or degrading treatment and Article 8: the right to a family and private life. Furthermore, individual practitioners must be regulated by the appropriate regulatory body.

- ‘You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests.’

If a patient undergoes examination or treatment without expressing prior consent, it may be considered assault and/or battery under the Offences Against the Person Act 1861. There are some exceptions, for example where consent is implied if a patient is unconscious and requires immediate medical intervention. Mental capacity will also be taken into account in establishing consent; in such cases a guardian or carer must provide consent on behalf of the patient.
• ‘You have the right to have access to your own health records. These will always be used to manage your treatment in your best interests.’

In most circumstances, patients have the right to access their health records and any information which relates to them, enforced by the Data Protection Act 2007.

• ‘You have the right to be given information about the test and treatment options available to you, what they involve and their risks and benefits’

The Common Law of Negligence compels healthcare professionals to ensure that patients receive enough information in order to give informed consent. Failure to provide such relevant information, or to give insufficient information, would be a breach of their duty of care. If a patient would not have given consent had they received adequate information and the patient comes into physical harm as a result of the treatment, they may be entitled to take legal action against the medical professional responsible, and in some cases may have a vicarious claim against the hospital or Trust.

5.4 Current Policy

The healthcare landscape has seen dramatic change in recent years following NHS reforms with the ‘Equity and Excellence’ White Paper, launched in 2010, and the introduction of the crucially influential Health and Social Care Act 2012 which ensured elements of the NHS Constitution were prioritised and enforced.

Since the NHS Constitution’s publication in 2009, there have been three public consultations that have proposed improvements to the Constitution, such as adding new patient and staff rights and staff duties.

In March 2010, the Constitution was updated to include new patient rights, including the rights:

• for patients to start consultant-led non-emergency treatment within a maximum period of 18 weeks of a GP referral, and for the NHS to take all reasonable steps to offer a range of alternatives if this is not possible;

• to be seen by a specialist within a maximum of two weeks from GP referral for urgent referrals where cancer is suspected.

In March 2012 the Department of Health requested an in-depth review of the NHS Constitution by the NHS Future Forum. The review aimed to investigate whether there were any ways in which the Constitution could be strengthened. A public consultation was also announced alongside the reviewed Constitution, including new provisions on whistleblowing. Amendments were made as part of a series of measures intended to highlight the importance of whistleblowing in the NHS. The newly revised Constitution included:

• an expectation that staff should raise any concerns at the earliest opportunity;
• a pledge that NHS organisations should support staff when raising concerns;

• clarification of existing legal rights for staff to raise concerns about safety, malpractice or other wrong doing without suffering any detriment.

In April 2013 the NHS Constitution was further updated. xxv The most significant changes were:

• patient involvement; rights to information and their role in decision making during their own treatment;

• patient and staff feedback; in particular the efficiency of the feedback procedure and the effectiveness of its results;

• duty of candour;

• enhancing standards of end of life care;

• integrated care;

• improvements in access to and dealing with complaints procedures;

• access to patient information;

• dignity, respect and compassion in all elements of care.
6. METHODOLOGY

This report is based on findings from a survey carried out by the Patients Association in England, aimed to assess awareness amongst patients and the public of the NHS Constitution’s existence and content.

The survey consisted of 18 questions, and was distributed to the Patients Association’s e-Member database (which includes patients, staff and other supporters), Twitter followers, and other members of the general public. 1007 responses were collected between February and June 2014. A similar survey was carried out in 2012. The 2012 survey was also distributed to the same audiences, with 1,336 responses between March and May 2012.

This report details responses to these 18 questions in the 2014 survey. Where appropriate in the context of policy changes, the report makes meaningful comparisons with the 2012 survey to demonstrate the effect the NHS Constitution has had on the NHS landscape, and make recommendations for the future.

A third survey is introduced towards the end of this report which considers respondents' perception of the NHS Constitution, and is drawn from a sample of 493 respondents from the same sources. This was undertaken over August 2014.
7. RESULTS

7.1 Experience of the NHS and awareness of the NHS Constitution

Q.1 Are you completing this questionnaire for yourself?

The first question asked respondents if they were completing the questionnaire for themselves. The vast majority (96.1% out of a total of 988) completed this on behalf of themselves, with only 3.9% who answered the questionnaire on behalf of someone else, indicating that they may be a carer.

Q.2 Have you ever heard of the NHS Constitution?

60% of respondents (986 answered the question) said they had heard of the NHS Constitution in the 2014 survey. This illustrates a significant improvement in awareness since our last survey on the NHS Constitution held in 2012, in which just 24% of respondents reported that they were aware of the document before their recent experience of NHS services. Indeed, during 2010 the Department of Health surveyed patients about their awareness of the NHS Constitution and only 22% were aware of the NHS Constitution. However, awareness of the NHS Constitution should in theory be much more widespread now, considering that:

(a) The Health and Social Care Act 2012 requires all providers of NHS care not only to have an obligation to regard the NHS Constitution in their work, but also a duty to inform patients in their care of the NHS Constitution and their rights, and
(b) 97.4% of respondents (N= 993) had used NHS services in the last two years.

Quotes from respondents included:

“But it will only give power to patients and carers if enough people are aware of it. BUT most patients (including me) have no idea what rights and responsibilities it brings”.

“It sounds good. It is no good if it is not implemented. Most NHS users do not know what it says unless they research it like I did. The general public have even less knowledge until they become patients.”

“I’ve heard of it but haven’t taken a great deal of notice of it-I’ve been happy with my NHS dealings.”
Q.3 Have you used any NHS services in the last 2 years? (e.g. GP, Hospital, Community Services, NHS dentist, Pharmacist etc.)

In the 2014 survey of the 97.4% of respondents who said they had made use of NHS services in the last two years, the vast majority (90.7%) of patient interactions were with GPs and/or services provided by local practices, followed by 65.2% attending an appointment in an outpatients department in hospital.

Q.4 Which NHS services have you used in the last 2 years?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was staying in hospital as an in-patient</td>
<td>29.6%</td>
<td>283</td>
</tr>
<tr>
<td>I was attending an appointment in an outpatients department in hospital</td>
<td>65.2%</td>
<td>623</td>
</tr>
<tr>
<td>I was visiting my GP, Nurse and/or other services at my local practice</td>
<td>90.7%</td>
<td>867</td>
</tr>
<tr>
<td>I was using the services of community practitioners in my home, such as district nurses, matrons, podiatrists, occupational therapy or other community services</td>
<td>13.2%</td>
<td>126</td>
</tr>
<tr>
<td>I was visiting an NHS Dentist</td>
<td>46.3%</td>
<td>443</td>
</tr>
<tr>
<td>I was visiting/seeking advice from a Pharmacist</td>
<td>37.7%</td>
<td>360</td>
</tr>
<tr>
<td>I was using another service – please explain</td>
<td>12.2%</td>
<td>117</td>
</tr>
<tr>
<td>answered question</td>
<td></td>
<td>956</td>
</tr>
<tr>
<td>skipped question</td>
<td></td>
<td>51</td>
</tr>
</tbody>
</table>

The top three contacts with NHS services in the last two years were visiting a GP, outpatient appointment and visiting an NHS dentist.

Q.5 Had you heard of the NHS Constitution before you used these services?

Respondents were then asked if they had heard of the NHS Constitution before they used these services. 53.6% out of 954 respondents said they had.

In comparison, the results from the 2012 survey showed that only 1.8% of respondents had been made aware of the NHS Constitution during the course of their treatment.

Q.6 What information have you had, or seen, about the NHS Constitution in the last 2 years?

In our 2014 survey, we asked respondents about the information they have seen concerning the NHS Constitution.
What information have you had, or seen, about the NHS Constitution in the last 2 years? (please tick all that apply)

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>78.7%</td>
<td>586</td>
</tr>
<tr>
<td>A healthcare professional spoke to me about it</td>
<td>2.7%</td>
<td>20</td>
</tr>
<tr>
<td>I picked up or saw a leaflet about it</td>
<td>13.8%</td>
<td>103</td>
</tr>
<tr>
<td>I saw a poster about it</td>
<td>8.2%</td>
<td>61</td>
</tr>
<tr>
<td>Other (please state)</td>
<td></td>
<td>250</td>
</tr>
</tbody>
</table>

answered question 745
skipped question 262

The number of respondents claiming to have received information about the NHS Constitution directly from a healthcare professional is incredibly low. As of 2012, the Health and Social Care Act requires healthcare professionals to provide this information by law¹, and while 97.4% of respondents have used healthcare services in that time, the fact that just 2.7% received this information directly from their healthcare provider shows just how little regard there is for this element of the Act.

However, there has been an improvement, since our 2012 survey revealed that just 1.8% of respondents had received any information regarding the NHS Constitution, including through leaflets and posters.

“I am quite astounded that despite the fact I accessed numerous outpatient appointments I have not come across any information about this. The term sounds familiar but I have not received any information verbally or otherwise. I will however be looking into this and what my rights are as a patient. There should definitely be more awareness around this. What’s the point in having these things if patients like me don’t know about them?”

“I don’t think the NHS really wants people to know about this. It feels like a token gesture. If they are so keen to improve things then why is this so under the radar?”

250 respondents chose to detail under ‘other’ methods of receiving information and left written comments offering more information on where they heard about the NHS Constitution. Many explained that they are only aware of the NHS Constitution through independent research or because they work for, or are affiliated to, the NHS or relevant health related bodies.

These people had reason to seek out information regarding the NHS Constitution and found it online or through other material.

“someone told me about it”.

“Via work, I work clinically within NHS organisations”.

“From the Patients' Association Newsletter”.

¹ Health and Social Care Act 2012, Chapter A1, Section 13C – Duty to Promote the NHS Constitution
“It is being mentioned in correspondence from my GP (verbatim) and also outpatient correspondence.”

“Downloaded from Thyroid UK’s website.”

“Found it on internet whilst pursuing NHS complaint.”

“I heard a reference to it on the radio.”

It makes sense to raise awareness of the NHS Constitution in spaces where patients engage with the NHS. Airports in the European Union are required by law\textsuperscript{xxvi} to display posters detailing airline passengers’ rights in cases of delay or cancellation. This could be a potential model for the NHS to follow in promoting its Constitution within healthcare environments. Displaying a simple, informative poster in a GP’s surgery is a clear, effective, non-invasive way to ensure that patients are aware of their rights.

7.2 Understanding of the NHS Constitution and using it

Q.9 Have you made use of the NHS Constitution in any way in the last 2 years?

We asked if respondents had made use of the NHS Constitution.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Count</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had never heard of it before taking this survey</td>
<td>35.6%</td>
<td>340</td>
</tr>
<tr>
<td>No</td>
<td>51.4%</td>
<td>491</td>
</tr>
<tr>
<td>Yes, in what way did you do this? Please describe below</td>
<td>13.0%</td>
<td>124</td>
</tr>
</tbody>
</table>

Although just 13% of respondents have made use of the NHS Constitution in the last two years, this is a significant increase since our last survey on the matter, in which just 3.6% had actively used the NHS Constitution to challenge the NHS.

Many of the respondents also chose to elaborate on the ways in which they have utilised it. Some responses include passive use of the document, mainly in order to educate themselves of their rights as patients. Others have actively applied the legal framework of the document in pursuing complaints against healthcare providers and defending their rights during the process. Those who felt confident enough in their understanding of the NHS Constitution to put it into practice provided positive feedback of their experience, indicating the potential for this document to be an effective tool in empowering patients.

“Asserting my rights of access to a GP when I needed one.”
“Tried to get estimate of waiting time for operation. Was told that the Constitution was only a target. Never got a proper response.”

“To obtain medical records.”

“To persuade my GP practice manager that I had a legal right to visit the hospital and hospital consultant of my, not their (GP practice manager) choosing.”

“I have quoted it in trying to resolve a complaint and state my rights as a patient. It seems that NHS staff either don't know about the Constitution or ignore it.”

“I bore it in mind when I wrote to the hospital to state my view of the quality of care received.”

“I challenged patient choice but was told there is no patient choice, we have to have what is offered.”

Despite a great increase in the level of awareness of the NHS Constitution, in order for it to be truly effective, patients must not only be aware but also have a comprehensive understanding of how it can be put into practice for their benefit, and the confidence to do so when necessary. One of the worrying trends in the comments from this survey is the lack of confidence patients have in their abilities to defend their own rights, and indeed of staff’s awareness or adherance to the Constitution. Many find the NHS complaints procedure an intimidating and arduous process and are consequently reluctant to go through it. By ensuring that patients have a full understanding of the NHS Constitution and the rights they are entitled to, they can be empowered to utilise the document to guide them through seemingly complicated bureaucratic procedures with confidence.

There is still a fear of complaining as patients/relatives are frightened that a complaint will have a detrimental effect on their treatment.

“Although my own doctor is caring and gives a good service, it is too difficult to get appointments and many of the stories I hear from friends often makes me afraid that although I have good health, I will fall into uncaring and neglectful hands if I become heavily dependent on others.”

“Most people still do not know the best way to complain about health and social care services. Even the advice when given can be confusing. Serious consideration needs to be given to how public knowledge can be improved.”
7.3 Perception of the NHS Constitution

Q.10 Which of the following phrases best describes what you think of the NHS Constitution?

We asked what respondents thought of the NHS Constitution.

One can see from the above chart that nearly a quarter (24.2%) believe the NHS Constitution to be pretty meaningless.

“Documents such as the NHS Constitution are just window dressing - another example of ‘involving’ patients with no intention of taking any real action.”

“The NHS Constitution is a well-meaning but perhaps too subtle instrument to address a deeply dysfunctional culture amongst NHS staff. I have heard of it but never read it - so no opinion except that I would not expect it to be the most exciting document I have ever read!”

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>2014 Response Percent</th>
<th>2014 Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had never heard of it before taking this survey</td>
<td>43.9%</td>
<td>383</td>
</tr>
<tr>
<td>Pretty meaningless</td>
<td>24.2%</td>
<td>211</td>
</tr>
<tr>
<td>A helpful statement of principles</td>
<td>23.8%</td>
<td>208</td>
</tr>
<tr>
<td>A great way of giving power to patients and carers</td>
<td>8.0%</td>
<td>70</td>
</tr>
<tr>
<td>Other (please state)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

answered question 872
skipped question 135
The 2012 survey shows that 48.3% indicate the NHS Constitution can be described as serving some positive purpose (a helpful statement of principles or a great way of giving power to patients and carers), whereas in the 2014 survey this proportion dropped to 31.9% indicating that confidence in the Constitution may have decreased over the last two years.

“If nobody knows about it, and services don’t follow it, it serves no purpose”

“Most of the medical practitioners I have encountered seem to ignore the constitution, largely because I believe so few patients and their carers know about it and doctors still routinely ignore patient wishes and nursing staff, frequently neglect patients and their carers....it would be great if this had improved, but from what I experienced and have heard about from friends and family, sadly this is not the case!”

“I actually don’t know enough about it to have an opinion. I did look at it but can’t remember exactly what it was all about.”

Looking specifically at the proportion of respondents who said they had used the NHS Constitution (N=135) in the 2014 survey, 22% of these said they thought it pretty meaningless and 58% gave a positive response (a helpful statement of principles or a great way of giving power to patients) indicating that for those who have used the NHS Constitution then a more positive opinion of it is formed. As the previous table shows 31.9% of the whole sample (both those who had used the NHS constitution and those who had not) gave a positive response.

“I have told other people about it and spoken of how good it is.”

“I think the NHS Constitution is one of the best statements to be brought out by any organisation. If only they had the staff and funding to make it work.”

“A good idea in principle... but it will only give power to patients and carers if enough people are aware of it.”

The general consensus appears to be that the Constitution may be good in theory, but in practice it lacks effectiveness. This is due to the fact that most people are unaware of its existence (staff and patients alike), and even if they are aware then they are unlikely to know much more.

Q.7 Which NHS services were you using when you heard about the NHS Constitution?
Which NHS services were you using when you heard about the NHS Constitution?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was staying in hospital as an in-patient</td>
<td>10.8%</td>
<td>36</td>
</tr>
<tr>
<td>I was attending an appointment in an outpatients department in hospital</td>
<td>23.2%</td>
<td>77</td>
</tr>
<tr>
<td>I was visiting my GP, Nurse and/or other services at my local practice</td>
<td>34.6%</td>
<td>115</td>
</tr>
<tr>
<td>I was using the services of community practitioners in my home, such as district nurses, matrons, podiatrists, occupational therapy or other community services</td>
<td>4.5%</td>
<td>15</td>
</tr>
<tr>
<td>I was visiting an NHS Dentist</td>
<td>9.0%</td>
<td>30</td>
</tr>
<tr>
<td>I was visiting/seeking advice from a Pharmacist</td>
<td>6.6%</td>
<td>22</td>
</tr>
<tr>
<td>I was using another service - please explain</td>
<td>47.9%</td>
<td>159</td>
</tr>
</tbody>
</table>

answered question 332
skipped question 675

Some respondents chose multiple options in this question, showing they were engaged in a variety of NHS services at the time they heard about the Constitution. Although 52.1% of respondents indicated they found out about the NHS Constitution by using a variety of NHS services, a staggering 47.9% found out about the NHS Constitution through another method - because they wanted to and being to some degree proactive rather than finding out about it in a reactive way. Some of the responses are highlighted below. It must be remembered that the answers to these questions are the respondents’ perceptions; it may be that NHS staff are making patients aware but it is the patients’ perception that they are not.

“I work with the NHS.”

“Not using any services just heard it mentioned either in media or social media.”

“The Patients Association.”

“Via National Carers Network and Local Action Group.”

“I wasn’t using NHS services when I heard about the NHS Constitution, it’s something I’ve heard about in news coverage of health service issues.”

“I have some family members who work for the NHS who explained details.”

Q.8 How often have you accessed the services of an NHS healthcare professional over the last 2 years?
How often have you accessed the services of an NHS healthcare professional over the last 2 years? (you can be approximate)

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>1.8%</td>
<td>17</td>
</tr>
<tr>
<td>Once or twice</td>
<td>15.0%</td>
<td>140</td>
</tr>
<tr>
<td>3-6 times</td>
<td>27.9%</td>
<td>261</td>
</tr>
<tr>
<td>6 - 12 times</td>
<td>27.4%</td>
<td>256</td>
</tr>
<tr>
<td>12 - 24 times</td>
<td>17.5%</td>
<td>164</td>
</tr>
<tr>
<td>More than 24 times</td>
<td>10.5%</td>
<td>98</td>
</tr>
</tbody>
</table>

answered question 936
skipped question 71

More than 83% of respondents have accessed NHS services more than three times in the last two years with 15% accessing treatment once or twice. The sample consists generally of people that do use NHS services fairly frequently. It is reasonable to assume that these patients would have more opportunities to find out, and have an interest in finding out about the NHS Constitution than perhaps those who do not frequently use NHS services.

Q.11 What do you think the NHS Constitution contains?

<table>
<thead>
<tr>
<th>What do you think the NHS Constitution contains? (please tick all the options that you think are included)</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>A list of legal rights for patients</td>
<td>61.3%</td>
<td>334</td>
</tr>
<tr>
<td>A description of how the NHS works</td>
<td>33.8%</td>
<td>184</td>
</tr>
<tr>
<td>A guide to NHS complaints</td>
<td>34.5%</td>
<td>188</td>
</tr>
<tr>
<td>Responsibilities for NHS staff</td>
<td>64.4%</td>
<td>351</td>
</tr>
<tr>
<td>Responsibilities for patients</td>
<td>54.9%</td>
<td>299</td>
</tr>
<tr>
<td>A guide to NHS departments</td>
<td>9.4%</td>
<td>51</td>
</tr>
<tr>
<td>Don’t know</td>
<td>15.4%</td>
<td>84</td>
</tr>
<tr>
<td>Other (please state)</td>
<td></td>
<td>42</td>
</tr>
</tbody>
</table>

answered question 545
skipped question 462
The most popular responses to the question were:

- responsibilities for NHS staff
- a list of legal rights for patients
- responsibilities for patients

It is reassuring to note that of those who answered the question (N=545) they got the answers largely correct and do have a fairly good understanding of what the NHS Constitution contains. A few respondents questioned the ‘legal’ nature of the document:

“Except that the legal rights are illusory.”

“There is a significant issue concerning the status of the ‘pledges’, and the vagueness about how binding these ‘pledges’ are is a significant weakness in the Constitution.”

“Are they legal rights? There is a difference of opinion amongst us over how the ‘rights’ are viewed in law and how meaningful the ‘pledges’ are. It also contains ‘rights’ of staff which are certainly not being met currently.”
Q.12 How likely are you to read the NHS Constitution and try to understand it if you are NOT already using or expecting to use NHS services?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already read it</td>
<td>14.1%</td>
<td>119</td>
</tr>
<tr>
<td>Not at all likely</td>
<td>20.1%</td>
<td>170</td>
</tr>
<tr>
<td>Very likely</td>
<td>28.4%</td>
<td>240</td>
</tr>
<tr>
<td>Don't know</td>
<td>16.5%</td>
<td>140</td>
</tr>
<tr>
<td>Not applicable</td>
<td>20.9%</td>
<td>177</td>
</tr>
</tbody>
</table>

answered question: 846
skipped question: 161

With 14.1% having already read the NHS Constitution, 28.4% said they were very likely to read it.

Q.13 How likely are you to read the NHS Constitution and try to understand it if you ARE already using or expecting to use NHS services?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already read it</td>
<td>17.3%</td>
<td>151</td>
</tr>
<tr>
<td>Not at all likely</td>
<td>15.4%</td>
<td>135</td>
</tr>
<tr>
<td>Very likely</td>
<td>47.4%</td>
<td>414</td>
</tr>
<tr>
<td>Don't know</td>
<td>15.8%</td>
<td>138</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4.1%</td>
<td>36</td>
</tr>
</tbody>
</table>

answered question: 874
skipped question: 133

This question is hypothetical, in that we already know almost all the survey respondents are using NHS services. However nearly a third of respondents said they would be very likely to read and try to understand the NHS Constitution if they were not already using NHS services. This shows a highly motivated and resourceful group of people. The responses show very nearly half (47.4%) say they would be very likely to read the NHS Constitution and try to understand it if they were using or expecting to use NHS services. Not surprisingly, interest in becoming more knowledgeable about something that is increasingly likely to affect you is apparent.
Q.14 Which of the following issues do you think are the most important issues for the NHS Constitution to cover for patients and carers?

<table>
<thead>
<tr>
<th>Answer Options (tick all that apply)</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rights to maximum waiting times for your treatment</td>
<td>55.0%</td>
<td>485</td>
</tr>
<tr>
<td>Rights to choose treatment by an independent private provider if waiting times exceed guidelines set out in the Handbook to NHS Constitution</td>
<td>45.4%</td>
<td>400</td>
</tr>
<tr>
<td>Rights to be offered the most appropriate treatment or medication as recommended by National Institute of Clinical Excellence (NICE)</td>
<td>63.8%</td>
<td>563</td>
</tr>
<tr>
<td>Rights to be treated with dignity and respect</td>
<td>78.0%</td>
<td>688</td>
</tr>
<tr>
<td>Rights to choose where you will be treated</td>
<td>56.5%</td>
<td>498</td>
</tr>
<tr>
<td>Rights to choose who will treat you</td>
<td>52.7%</td>
<td>465</td>
</tr>
<tr>
<td>Rights to be involved in decisions about your treatment</td>
<td>76.2%</td>
<td>672</td>
</tr>
<tr>
<td>Rights to be given information about your treatment</td>
<td>76.5%</td>
<td>675</td>
</tr>
<tr>
<td>Rights not to be treated in mixed sex accommodation</td>
<td>49.8%</td>
<td>439</td>
</tr>
<tr>
<td>Rights to be treated in a safe environment and in a safe way</td>
<td>73.6%</td>
<td>649</td>
</tr>
<tr>
<td>Rights to complain and have that complaint dealt with properly</td>
<td>73.1%</td>
<td>645</td>
</tr>
<tr>
<td>Responsibility for patients and carers not to miss appointments without good reason / notice</td>
<td>61.6%</td>
<td>543</td>
</tr>
<tr>
<td>Responsibility to give feedback - both positive and negative - about your experience and the treatment and care you have received</td>
<td>59.2%</td>
<td>522</td>
</tr>
<tr>
<td>All of the above</td>
<td>45.4%</td>
<td>400</td>
</tr>
<tr>
<td>None of the above</td>
<td>0.9%</td>
<td>8</td>
</tr>
</tbody>
</table>

answered question 882
skipped question 125

The top answers here were:
- 78% Rights to be treated with dignity and respect
- 76.5% Rights to be given information about your treatment
- 76.2% Rights to be involved in decisions about your treatment

“The Constitution is a great idea, however it is a great pity that the staff in the NHS seem to be totally oblivious about it. Reception staff in hospitals and doctors surgeries seem to forget that patients are unwell when they visit the hospital or surgery. Medical and nursing staff need to remember that not all patients are articulate and should not come away from treatment or a consultation feeling they have been dismissed.”

However least popular were those responses concerning waiting times and those concerning single sex accommodation.
In comparison the 2012 survey asked respondents the same question, and the priorities expressed were:

- 65.8% Rights to be involved in decisions
- 60.6% Rights to information about your treatment
- 57% Rights to be treated with dignity and respect

In two years it appears priorities have changed slightly with the Right to be treated with dignity and respect now being the single most important issue. It is not possible from the data to say why. However, it can be speculated that the media’s coverage of stories relating to dignity and respect issues have become more commonplace, and therefore service level expectations raised and noticed and noted when lacking.

Q.15 How could awareness of the NHS Constitution be improved?

<table>
<thead>
<tr>
<th>How could awareness of the NHS Constitution be improved?</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know</td>
<td>35.6%</td>
<td>311</td>
</tr>
<tr>
<td>Don’t think it needs to be improved</td>
<td>3.3%</td>
<td>29</td>
</tr>
<tr>
<td>I have some suggestions - please complete the box below with your comments</td>
<td>62.7%</td>
<td>548</td>
</tr>
</tbody>
</table>

While just 3% or respondents believe that there is no need to enhance awareness of the NHS Constitution, an amazing 63% of respondents took the time to make some suggestions as to how it could be improved.

“Greater awareness among the younger generation is needed, perhaps through effective use of social media.”

“Promotion via national media through NHS Organisations and the government.”

“I would like to see copies of the Constitution in all GP surgeries and in hospital public areas so that patients can be reminded of their rights and responsibilities whenever they need to be.”

“A leaflet drop, posters in GP surgeries, and in magazines in waiting rooms.”

“Every healthcare professional should refer to it when treating a patient.”

“Needs to be part of school education for the next generation.”

“I have visited my local GP and I am not aware of seeing information about the NHS
Constitution. I would prefer better visibility of this information, perhaps in the form of posters and leaflets.”

“Spread through as many NHS venues and websites as possible.”

“A leaflet could be provided every time a prescription is issued by a GP. Failing that the same leaflet could come with the medication picked up from a Pharmacy. Similarly, when filling in forms in a hospital.”

“Doctors and other NHS staff should mention it at every consultation: "Have you heard about the NHS Constitution? Here’s a copy. Please read it, you may find it very helpful..." sort of thing.”

Too complicated. To be useful as a "Constitution" it needs to be a short list of short statements. The Constitution adds lots of provisos and clauses to its statements.

“It should be shown in every Healthcare setting including private settings. Copies should be in all waiting areas and in libraries and perhaps village halls.”

“Encourage much more press and TV coverage.”

“Have leaflets available in every hospital department/ward, GP surgery/pharmacy etc...”

“Use Patients Association website.”

Besides more leaflets and posters in healthcare settings and through GP surgeries, the most frequent suggestions were relating to publicity campaigns via national media outlets. Interestingly there also appears to be a great emphasis on a need to promote awareness of the NHS Constitution among the younger generation, with such suggestions as increased presence in social media campaigns, formal education on patients’ rights in schools, and use of modern technology such as creating an NHS Constitution Smart Phone App. This has the potential to be the most effective method of ensuring a positive future for the Constitution.

“It certainly needs more publicity; very few members of the public (and indeed staff) have any real awareness of the Constitution”

“There has to be more emphasis on NHS staff as public servants, and an attempt at breaking down the ‘them v. us’ attitudes so prevalent amongst staff. I am a nurse (not in the NHS) and have never heard of it! This sounds so important, why has it been missed?”
“An almost impossible task. Start in schools perhaps. Roll out information on a very localised basis. Do not use jargon and keep information short and to the point with no gimmicks.”

A follow-up survey was sent out in August 2014 to the same audiences asking patients and the public what they would like to see in the NHS Constitution. Of the slightly less than half who said they knew about the NHS Constitution:

- 87% said they understood that the NHS Constitution was a document establishing and setting out patients’ rights and responsibilities within the NHS;
- 8% said they understood it was a document summarizing the services offered by the NHS;
- 5% gave some other suggestion – some of which are detailed below.

“Having read this document carefully it sounds wonderful, however experience is somewhat different. We have a fragmented NHS where in spite of the above Constitution there exists a postcode lottery, care varies greatly from one area to another. People are often scared when going into hospital, often staff are indifferent to patient concerns.”

“Patient’s right to expect certain standards and obligations in the delivery of care by clinical staff in the NHS.”

“It aims to put patients at the heart of everything.”

“It also makes promises on waiting times, patient choice and standards of patient care.”

We asked respondents which priorities they would like to see most in the NHS Constitution. Looking at the highest two scores (9 and 10) only, their priorities are ranked below:

1. Rights to be treated with dignity and respect (87%).
2. Rights to be treated in a safe environment and in a safe way (84%).
3. Joint third: Rights to be involved in decisions about your treatment and Rights to be given information about your treatment (both 82%).
4. Rights to complain and have that complaint dealt with properly (77%).
5. Responsibility for patients and carers not to miss appointments without good cause or reason (75%).
7. Rights to be offered the most appropriate treatment as recommended by the National Institute of Clinical Excellence (NICE) (70%).

8. Responsibility to give feedback both positive and negative about your experience and the treatment and care you have received (65%).

9. Rights to maximum waiting times for your treatment (58%).

10. Rights to choose treatment (57%).

It is worth highlighting that being treated with dignity and respect came first, even above safety.

Other comments are listed below:

“Right to be allowed to die with dignity, and without unwanted intervention to prolong life when quality of life offers no happiness.”

“To be treated as a human being and an individual.”

“To be shown reports and records written about you.”

“Assurance that your worries will be taken seriously.”

“Right to be treated as the paying customer - you have paid in.”

“Those who paid national insurance contributions before the constitution were entitled to care free at the point of need. I believe we still have that right. It was on that understanding that money was taken from us. This right should be safeguarded in the Constitution. Anything less is fraudulent.”

We asked patients if they were aware that the NHS Constitution contains a list of responsibilities for patients to ensure resources are used responsibly. Of the 490 people who answered the question, 31% said that they were aware of this part of the NHS Constitution. When cross referenced against those who answered the first question positively ‘Do you know what the NHS Constitution is?’ then the percentage goes up to 61% indicating that 6 out of 10 of those who were aware of the NHS Constitution said they knew about responsibilities for patients.

Some patients have interpreted this ‘use of NHS resources’ as being responsible regarding attending medical appointments both as a patient and as a clinician and common themes emerged from the comments:
“Awareness of the cost of treatment would make people more motivated to NOT MISS appointments or misuse medications.”

“Most patients have to lose money by taking time off work. NHS staff should be fined for wasting patient’s time.”

“About missing appointments - sometimes it is because of being too ill to attend.”

“The rights not to have your appointment cancelled more than once.”

“The rights to be given a new appointment within 4 weeks and no longer.”

“If an operation is cancelled at short notice, for the patient to be offered another appointment within a reasonable time, say 2 weeks.”

When we asked if the NHS Constitution was a suitable name for the document, of the 466 who answered the question 34% said that they did, whilst 66% said ‘No’ or ‘not sure’.

Again when cross-referenced against those who answered the ‘Do you know what the NHS Constitution is?’ this 34% is increased to 42%, meaning that the more people understand the Constitution, the more they are comfortable with the name (though this still is not a majority of those individuals). However, approximately a quarter of the sample of those who answered the question suggested a new name, with over a third of those who made a suggestion or comment indicating that ‘Rights and/or Responsibilities’ would feature in the new title. The need for the title to mean something to the average person was also highlighted. Examples included:

Patient’s rights

Patient’s rights and responsibilities

NHS Code of Practice

NHS Charter: Rights and Responsibilities

We asked respondents which responsibilities they thought were the most important for the NHS Constitution to cover for patients and carers. Looking at the highest two scores (scored as 9 or 10) only, answers are ranked below:

1. You should treat NHS staff and other patients with respect (87%).
2. You should keep appointments or cancel within a reasonable time (84%).

3. You should register with a GP practice – the main point of access to care (83%).

4. You should provide accurate information about your health, condition and status (81%).

5. You should express any concerns about your treatment (77%).

6. You should follow the course of treatment which you have agreed (74%).

7. You should give feedback – both positive and negative – about the treatment and care you have received, including any adverse reactions you may have had (69%).

8. You should ensure that those closest to you are aware of your wishes about organ donation (64%).

9. You should participate in important public health programmes such as vaccination (57%).

Not surprisingly, treating NHS staff and patients with respect was the most important factor listed, closely followed by keeping appointments or cancelling within a reasonable time.

Responses to earlier questions show us that awareness of the NHS Constitution is not widespread. Awareness of what messages the Constitution contains is even less, so we asked respondents of this follow up survey how they thought awareness of the NHS Constitution could be improved. Just under half of those who answered the question made a comment or suggestion, some of which are outlined below. A majority (100 out of the 179 or 56% making a comment) mentioned GP or GP surgeries as a vehicle to improve awareness of the NHS Constitution.

“Publications clearly laid out at all NHS premises for example GP surgeries, hospitals etc…”

“Use notices in local surgeries offering copies to patients. Few patients know of its existence.”

“Keep it short, to the point and in plain language. Display it at all points of contact with the NHS”
“Consistent information and advice should be given to patients by all medical personnel”

“Legal responsibility for doctors surgeries/ A and E departments etc to display and list patient/doctor responsibilities in waiting areas and on websites.”

“Advertising campaign, posters in NHS services, leaflet with first appointment or on discharge letter.”

“Needs to be included in all training and induction courses for all NHS staff at all levels.”

“Leaflet to be given out with prescriptions or information on the back of prescriptions.”

“Somehow patients need to understand they have responsibilities as well as an automatic right to NHS care.”
In a 2010 Department of Health survey, it was found that just 22% of patients were aware of the NHS Constitution\textsuperscript{xxvii}. In the document’s early days, the lack of awareness was understandable. Two years on, after various amendments and attempts at increasing publicity, the Patients Association’s 2012 survey disappointingly revealed just a 2% increase in awareness. A further two years later, the latest survey shows a dramatic increase, with 60.45% of respondents claiming to know about the document.

The general trend indicates a positive change in levels of awareness of the NHS Constitution over the past four years. However, this change isn’t happening at the pace required for the NHS Constitution to be truly effective. It has been two years since the Health and Social Care Act 2012 outlined a legally enforced duty on healthcare providers, Commissioners and Regulators to promote awareness of the NHS Constitution in their work. In that time we have seen little improvement in awareness and understanding as a direct result of patient/doctor interactions. Whether there is a conscious lack of regard for the statute, or simply NHS staff’s lack of awareness of their legal obligation, it is crucial for future patient experience that this changes. In particular, face to face interaction between patients and their healthcare providers during primary care is what bridges the gap between the NHS and the public. It is vital that every opportunity is taken to promote awareness of the NHS Constitution at this level if it is ever to be effective.

The NHS Constitution is intended to be a roadmap for patients and the public, laying out what they have the right to expect from their health services, and the pledges the NHS has made to them. There is no way it can effectively fulfil this purpose if patients are not aware of its existence when using NHS services. It is vital that more is done to ensure that patients are made aware of the NHS Constitution before seeking treatment or advice, and moreover that healthcare professionals understand exactly what is expected of them when providing care. If NHS staff and healthcare providers are better able to meet patient expectations, patient satisfaction will naturally improve. Equally, as per the respondents’ suggestions, there is a vital need to educate the younger generation of patients about their rights through effective and appropriate channels such as social media campaigns.

“The problem is that it is too easy to see where the NHS is not living up to the promises of the Constitution; punitive political attitudes and media coverage make people cynical. It is possible that a focus on the Constitution and evidence of how the NHS is fulfilling, or attempting to fulfill, its promises might help to turn that around.”
Beyond general awareness, the following main issues have arisen in the findings:

- Whilst awareness of the NHS Constitution may be slowly increasing there appears to be in many cases an absence of in-depth understanding of the NHS Constitution and how to use it effectively. Although more people are now aware of the NHS Constitution, many of the respondents explain that they merely know of its existence but lack any credible knowledge of its content or legal standing.

- The priorities for the patients surveyed are to be treated with dignity and respect and to have information about, and be involved in decisions regarding their own care. The overwhelming desire for patients to be treated with dignity and respect shone out. It was recognised that this need was greater than having patient choice or even maximum waiting times. Having a safe environment, being involved in decision-making and being given information about their treatment were also seen as very important priorities. This is logical; if someone keeps us informed of what is happening and tells us why we are waiting, it is so much easier for us to understand and accept than if we are just kept waiting, and do not know why or how long we will need to keep waiting.

- Allowing patients to acknowledge their own responsibility for their healthcare and relationship with provider services was a key theme that respondents thought the NHS Constitution should cover. Patient responsibilities were highlighted in this report with the most important ones (for patients) being treating NHS staff and other patients with respect, and the importance for patients to keep appointments or cancel within a reasonable time.

- The survey indicated that interest in the NHS Constitution increases when the NHS Constitution becomes relevant to an individual’s situation. For example, if an individual is embarking on a period of hospital care then s/he may be more inclined to find out about the NHS Constitution before embarking on the episode of care.

- The need for greater awareness and promotion of the NHS Constitution was highlighted. Promotion through GP surgeries and primary care networks was a popular suggestion as a vehicle for promotion. In addition, the need for a more user-friendly document and name change is required along with targeting of the younger audience to allow the NHS Constitution to be more accessible. A ‘catchy’ name may assist with promoting the NHS Constitution and a vast number of respondents to the survey independently thought of titles like NHS: Rights and Responsibilities which are easily remembered and have more direct meaning.
If individuals are proactive, and/or members of disease specific groups, community groups or the Patients Association, then many have and will continue to find out about the NHS Constitution through these networks and their own personal research. Many participants of this survey said they did not find out about the NHS Constitution through interaction with the NHS but through independent research and the Patients Association.

As always, any survey gives individuals the opportunity to give their opinion on any issue and the NHS is a highly regarded organisation in many people’s minds. Some comments reiterate this message.

*The NHS saved my life. Thank you big time.*
The Patients Association’s Mission Statement

The Patients Association is a healthcare charity which for almost 50 years has advocated for better access to accurate and independent information for patients and the public; equal access to high quality health care for patients; and the right for patients to be involved in all aspects of decision making regarding their health care. By listening to patients, we are able to campaign to improve services. We will work with all healthcare providers to improve services. Very often patients think they are alone with the problem or complaint they have. When patients talk to us we are able to track problems arising in more than one place and realize there is a nationwide issue that needs change.
APPENDIX A: FEBRUARY – JUNE SURVEY QUESTIONS

Public Awareness of the NHS Constitution survey questions (undertaken from February to June 2014 on SurveyMonkey.com)

1. Are you completing this questionnaire for yourself?
   - Yes
   - No - I am completing this questionnaire on behalf of someone else

2. Have you ever heard of the NHS Constitution?
   - Yes
   - No

3. Have you used any NHS services in the last 2 years? (E.g. GP, Hospital, Community services, NHS dentist, Pharmacist etc.)
   - Yes
   - No

4. Which NHS services have you used in the last 2 years? (Please tick all that apply)
   - I was staying in hospital as an in-patient
   - I was attending an appointment in an outpatients department in hospital
   - I was visiting my GP, Nurse and/or other services at my local practice
   - I was using the services of community practitioners in my home, such as district nurses, matrons, podiatrists, occupational therapy or other community services
   - I was visiting an NHS Dentist
   - I was visiting/seeking advice from a Pharmacist
   - I was using another service – please explain

5. Had you heard of the NHS Constitution before you used these services?
   - Yes
   - No

6. What information have you had, or seen, about the NHS Constitution in the last 2 years? (Please tick all that apply)
   - None
   - A healthcare professional spoke to me about it
• I picked up or saw a leaflet about it
• I saw a poster about it
• Other (please state)

7. Which NHS services were you using when you heard about the NHS Constitution?

• I was staying in hospital as an in-patient
• I was attending an appointment in an outpatients department in hospital
• I was visiting my GP, Nurse and/or other services at my local practice
• I was using the services of community practitioners in my home, such as district nurses, matrons, podiatrists, occupational therapy or other community services
• I was visiting an NHS Dentist
• I was visiting/seeking advice from a Pharmacist
• I was using another service – please explain

8. How often have you accessed the services of an NHS healthcare professional over the last 2 years? (You can be approximate)

• Never
• Once or twice
• 3-6 times
• 6 – 12 times
• 12 – 24 times
• More than 24 times

9. Have you made use of the NHS Constitution in any way in the last 2 years?

• I had never heard of it before taking this survey
• No
• Yes - in what way did you do this? Please describe below

10. Which of the following phrases best describes what you think of the NHS Constitution?

• I had never heard of it before taking this survey
• Pretty meaningless
• A helpful statement of principles
• A great way of giving power to patients and carers
• Other (please state)

11. What do you think the NHS Constitution contains? (Please tick all the options that you think are included)

• A list of legal rights for patients
• A description of how the NHS works
• A guide to NHS complaints
• Responsibilities for NHS staff
- Responsibilities for patients
- A guide to NHS departments
- Don’t know
- Other (please state)

12. How likely are you to read the NHS Constitution and try to understand it if you are NOT already using or expecting to use NHS services?

- Already read it
- Not at all likely
- Very likely
- Don’t know
- Not applicable

13. How likely are you to read the NHS Constitution and try to understand it if you ARE already using or expecting to use NHS services?

- Already read it
- Not at all likely
- Very likely
- Don’t know
- Not applicable

14. Which of the following issues do you think are the most important issues for the NHS Constitution to cover for patients and carers? (Please tick all that apply)

- Rights to maximum waiting times for your treatment
- Rights to choose treatment by an independent private provider if waiting times exceed guidelines set out in Handbook to NHS Constitution
- Rights to be offered the most appropriate treatment or medication as recommended by National Institute of Clinical Excellence (NICE)
- Rights to be treated with dignity and respect
- Rights to choose where you will be treated
- Rights to choose who will treat you
- Rights to be involved in decisions about your treatment
- Rights to be given information about your treatment
- Rights not to be treated in mixed sex accommodation
- Rights to be treated in safe environment and in a safe way
- Rights to complain and have that complaint dealt with properly
- Responsibility for patients and carers not to miss appointments without good reason / notice
- Responsibility to give feedback – both positive and negative - about your experience and the treatment and care you have received
- All of the above
- None of the above

15. How could awareness of the NHS constitution be improved?
16. Anything else to add?

17. Would you be willing to be contacted by the Patients Association to discuss your responses to the questions in more detail?

- Yes
- No

18. Please provide us with your contact details

- Email address
- Telephone
- Preferred method of contact
- Preferred time
Follow-up survey Public Awareness of the NHS Constitution questions (undertaken over August 2014 on SurveyMonkey.com)

1. Do you know what the NHS Constitution is?
   - Yes
   - No

2. If yes, what do you understand is included in the NHS Constitution?
   - A document establishing and setting out patients' rights and responsibilities within the NHS
   - A document summarising the services offered by the NHS
   - Other (please give details below)

3. On a scale of one to ten, with ten being the most positive, what would you like to see most in the NHS Constitution?
   - Rights to maximum waiting times for your treatment
   - Rights to choose treatment
   - Rights to be offered the most appropriate treatment as recommended by the National Institute of Clinical Excellence (NICE)
   - Rights to be treated with dignity and respect
   - Rights to be involved in decisions about your treatment
   - Rights to be given information about your treatment
   - Rights to be treated in a safe environment and in a safe way
   - Rights to complain and have that complaint dealt with properly
   - Responsibility for patients and carers not to miss appointments without good reason/notice
   - Responsibility to give feedback - both positive and negative - about your experience and the treatment and care you have received
   - Other (please specify)

4. Were you aware that the NHS Constitution contains a list of responsibilities for patients to ensure resources are used responsibly?
   - Yes
   - Not sure
   - No

5. Is the 'NHS Constitution' a suitable name for the document itself?
   - Yes
   - Not sure
6. On a scale of one to ten, with ten being the most positive, which of the following responsibilities do you think are most important for the NHS Constitution to cover for patients and carers?

- You should register with a GP practice - the main point of access to NHS care
- You should treat NHS staff and other patients with respect
- You should provide accurate information about your health, condition and status
- You should keep appointments, or cancel within a reasonable time
- You should follow the course of treatment which you have agreed
- You should participate in important public health programmes such as a vaccination
- You should ensure that those closest to you are aware of your wishes about organ donation
- You should give feedback - both positive and negative - about the treatment and care you have received, including any adverse reactions you may have had
- You should express any concerns about your treatment
- None of the above
- Other (please state)

7. How could awareness of the NHS Constitution be improved?

- I don't know
- Patients Association
- I don't think it needs to be improved
- I have some suggestions:

Other Information:
We would be grateful if you could complete the details below outlining your background information. This information will be kept confidential and is purely for information and background purposes only. If you would prefer not to comment, please leave blank.

8. Gender:
- Male
- Female

9. Age:
- Under 18
- 18-29
- 30-64
- 65-74
• 75-84
• 85+

10. Do you consider yourself to have a disability?
• Yes
• No

11. Ethnic background
• White British
• White Irish
• Any other White background
• Indian
• Pakistani
• Bangladeshi
• Any other Asian Background
• Mixed White and Black Caribbean
• Mixed White and Black African
• Mixed White and Asian
• Any other Mixed background
• Caribbean
• African
• Any other Black background
• Chinese
• Any other ethnic background
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