

# Patient experiences of urgent and emergency care in Yorkshire and The Humber

## An analysis of stories from Patient Opinion

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## Contents

About this report.....	3
Preface .....	4
Executive summary .....	5
Introduction .....	7
Waiting times.....	9
Treatment .....	13
Quality of consultation.....	14
Quality of interpersonal interactions.....	20
Physical environment.....	25
Food/drink .....	27
Service Organisation and Delivery .....	28
Patients as health care consumers .....	31
Positive and negative feedback .....	33
A different way of communicating .....	37
Conclusions .....	42
References .....	43
Appendix: About Patient Opinion .....	44

## About this report

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### Stories cited in this report

All of the patient stories cited in this report are available online at the Patient Opinion web site ([www.patientopinion.org.uk](http://www.patientopinion.org.uk)).

Each story cited is identified in the text with a number, such as [91644]. To read this story and any responses to it online, you would visit the following address:

[www.patientopinion.org.uk/opinions/91644](http://www.patientopinion.org.uk/opinions/91644)

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### Acknowledgement

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## Preface

This report examines a wide variety of patient experiences of urgent and emergency care services in one region of England, generating a range of insightful and important conclusions. Research of this kind is not unusual, and the key themes and findings of this analysis are in keeping with those reported by other academic researchers.

However, this report is very unusual in one important respect: it is based entirely on stories posted by patients and carers to a public website. Thus, the data on which this analysis is based is already in the public domain, and freely available. This substantially reduces the cost of research.

Although this report is based on just 156 stories, on the Patient Opinion web site over 115,000 stories are now available, accessible and searchable, covering a wide range of NHS services across much of the UK. Using this report as a model, the kind of analysis reported here could, relatively easily and cheaply, be replicated for other geographies, conditions, or kinds of service.

Of course, this data is not in any sense “representative”. A self-selected sample of people have posted their experiences, and in doing so had goals in mind other than research. Nonetheless, it is remarkable that the findings reported here are consistent with those from more rigorous (and expensive) studies.

These stories were originally posted by people not as “data” but as active contributions to improving local health care services. Their authors intended them as interventions and, long before this analysis was undertaken, these individual stories were having an impact on particular people and services in particular places. Many have responses from staff, and some will have contributed to changes to services, systems or even culture.

If you wish, you can read all the stories included in this analysis yourself, online, allowing you to come to your own conclusions about what matters most to patients. You can also see for yourself where the experiences shared by patients have been heard and acted on, and where they have not.

I hope you will find this report interesting and helpful in your own work, and perhaps you will be inspired either to share your own story online, or to conduct your own research – national or local – using the stories others have already told.

James Munro, chief executive, Patient Opinion

Sheffield

## Executive summary

The findings of this report are based on 156 stories about urgent and emergency care services in Yorkshire and The Humber, posted by patients and carers on the Patient Opinion web site. The key themes to emerge from this report are set out below.

### Waiting times

Unsurprisingly, patients appreciate short waiting times and resent longer ones. However, longer waits were more acceptable where patients were kept informed of their own progress, reassured they had not been forgotten, offered refreshment when appropriate, had information on the reason for waiting, and did not feel that their own wait was the result of inappropriate demand by others.

### Treatment

Medical interventions were not often mentioned by patients, apart from pain relief, perhaps because of the emergency nature of these stories. Patients lost confidence in their care if health professionals contradicted one another on treatment advice/decisions.

### Quality of consultation

Patients placed high value on a “professional” consultation: this term encompassed ideas of expertise, competence, experience, thoroughness, efficiency and explanation. In addition patients placed emphasis on the importance of two-way communication: feeling *listened to* as well as talked to. Consultations which lacked these features tended to result in frustration, dissatisfaction and a loss of confidence in the care provided.

### Quality of interpersonal interactions

Experiences of interpersonal interactions were by far the most frequent element of patient and carer stories. Patients reported their experiences of a wide range of individual staff, including receptionists, nurses, and doctors. They also remarked on where staff appeared to work effectively as a team, or failed to do so.

Patients valued what they saw as personal, human care for them as an individual. Professionals who introduced themselves by name were seen as exemplifying this kind of care, underlining the importance of the #hellomynameis campaign.

Conversely, where patients did not feel they were recognised or respected as individuals, they quickly lost trust in the professionals treating them, even to the extent of feeling unsafe and exiting the service.

### Physical environment

The environment of care is important to patients. In particular, in these stories the physical environment was mentioned specifically in relation to cleanliness or its absence. In addition, some care settings clearly led to failures of confidentiality or privacy, with some patients feeling they lacked privacy at moments when they most needed it.

## Service organisation and delivery

Patients are uniquely placed to comment, not just on the services of particular providers, but on how the system as a whole works. Indeed, patients and carers are the only people able to reliably report on whether the system does work as intended.

Many patients commented on how well their care was “joined up” across multiple services, and conversely, on how sometimes it was not. Where the system did not seem to be “joined up”, patients reported accessing multiple services to resolve their problem, recognising that this carried greater costs to both themselves and the NHS.

In addition, many patients valued the provision of treatment outside of A&E departments, in minor injury units or walk-in centres. These were often popular because they were seen to avoid long waits, although sometimes led to frustration if the service was unable to deal with the presenting condition.

## Patients as health care consumers

Patients posting their stories often gave explicit reasons for doing so. Positive stories were presented as expressions of thanks (and often as redressing what was seen as unfair media reporting) while negative stories were often intended to help improve care for others. As well as expressing gratitude for the specific episode of care, patients would often also say how much they valued the NHS as a whole.

## Positive and negative feedback

The stories analysed in this report present a wide range of experiences of urgent and emergency care. Some experiences are consistently positive, while others are mixed. Patients are often careful to report both what was good, alongside what could have been better.

In general, feedback tended to be the most positive for paramedics and ambulance staff, NHS Direct and 111, walk-in centres, minor injury units, and children’s A&E.

More negative experiences tended to be reported by particular (often vulnerable) groups, including people with drug/alcohol problems, frail older people (including those with dementia), people with mental health problems, and women suffering miscarriage.

## A different way of communicating

The patient experience reported here is unusual in that, in most cases, we are also able to see a response from relevant health service staff. Many responses were standardised, but often staff would post a personalised reply, and in some cases identify service changes to be made in response to feedback. Some of the stories led to a further dialogue, either online or in person, with evidence of issues being resolved.

The stories analysed here suggest that patients value the ability to give feedback safely, and with the expectation of a response. The issues they raise in their stories are consistent with the available research literature on experiences of emergency care, and highlight the importance of being treated as an individual, worthy of respect, dignity, privacy, understanding and clear information.

## Introduction

Taking account of the 'patient voice' has its origins in a number of developments, from social scientists' explorations of lay concepts of health and illness (Williams and Calnan, 2003), through discourses around the 'expert patient' (Donaldson, 2003) and models of joint decision-making (Wirtz et al, 2006), to notions of the 'project of the self/body' and the 'active citizen' with responsibility for their own health (Lupton, 2013), which have gained impetus in a context of rising demand on services, cuts in public spending and scarcity of resources – a context in which new services such as NHS Direct and the 111 service were created.

This report presents the findings of a thematic analysis of postings on the Patient Opinion web site ([www.patientopinion.org.uk](http://www.patientopinion.org.uk)) which illuminate what patients are saying about urgent and emergency care in Yorkshire and the Humber. The sample of postings analysed consisted of 156 different stories posted between 1 January 2012 and 24 November 2014.

This is not a 'representative' sample in any statistical sense and looks only at a particular 'slice in time'. For this reason it is worth noting that in 2014 the College of Emergency Medicine reported that "currently the challenges faced by urgent and emergency services overwhelm the capacity of the system"<sup>1</sup>.

Research on the patient voice specifically within emergency medicine is relatively limited but what studies there are reveal a high level of consistency in the factors identified as of significance to patients. Nairn et al's (2004) review covered both quantitative (predominantly American) and qualitative (typically from Sweden) studies, Despite the cultural differences, they were able to identify common themes which emerged across both kinds of study. These were: waiting times; communication and information; cultural aspects of care; pain; and the ED environment.

In Taylor and Benger's (2004) systematic review of patient satisfaction studies in emergency medicine, which covered both rank factors influencing overall satisfaction and intervention studies designed to improve patient satisfaction, the three most frequently identified factors were interpersonal skills/staff attitudes; provision of information/explanation; and waiting times. And Gordon et al, in their (2010) synthesis of qualitative research on the patient experience in the emergency department, identified: the emotional impact of experiencing an emergency situation; staff-patient interactions; waiting; the role of friends and family; and the physical environment

All of these are echoed in the sample analysed for this report, although they have been broken down here into more detailed categories under the following headings: Waiting times; Treatment, Quality of Consultation; Quality of interpersonal interactions; Physical environment; Food and Drink; Service Organisation and Delivery.

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<sup>1</sup> Acute and emergency care: prescribing the remedy  
<https://www.rcplondon.ac.uk/resources/acute-and-emergency-care-prescribing-remedy>

Additional sections cover patients' actions as 'health consumers'; some observations about the kinds of services and experiences that attract 'good press' and 'bad press' generally; and health service professionals' responses to postings and, where they appear, patients' responses to these – constituting the unique conversations facilitated by the site.

## Waiting times

Comments on waiting times included references to how long the patient or relative had to wait for an initial response; and how long they waited to be seen, assessed, diagnosed or discharged. Instances of the former were usually positive, expressing appreciation for a speedy response from NHS Direct, OOH service, paramedics and ambulances etc:

“...rang NHS Direct, got through straight away...” [86371]

“We telephoned the Out of Hours GP triage service who answered the phoned very quickly...” [66741]

“A first responder and ambulance arrived quickly...” [63035]

“We had to call 999. We cannot thank enough the people who delivered care to our mum so quickly” [75850]

“I called 999 and a paramedic was there within 5 minutes followed by an ambulance 5 minutes later” [107403]

Accounts of how long patients waited to be attended to at the point of service delivery were more mixed. Often, when they were happy with the brevity of the wait, comments were as short and factual as the descriptions of waits for first responses above:

“Upon arrival I was seen within ten minutes of the time stated by the doctor which was brilliant” [66510, OOH centre]

If a service provider took the initiative themselves to alleviate unnecessary waiting, this was seen as even more impressive:

“There was a young boy sat next to us and the person on the x-ray reception came over and said that she noticed they had been there some time and asked him and his dad what they were waiting for. She then helped get them sorted, I thought this was really impressive”. [86371]

Speedy progress from arrival through to discharge; or to treatment and being settled on a ward, also merited a more detailed account:

“Speedy service through A&E. Fell off bike and taken (to A&E) by friend. Arrived approx. 7.45pm, registered, waited about 20 mins, triaged by nurse, given Entonox, taken by George for X-ray, back to A&E, seen by Dr assessed, monitored by nurse and further pain relief and sling applied. Back home within 2 hours including 30 mins travelling.” [91644]

“My dad was rushed to the coronary care unit this weekend after having a heart attack at home. I want to say what an excellent NHS team we have right from the paramedic who was on the scene first, then the ambulance men and the team of

nurses and doctors on the coronary care unit. Within three hours of it all beginning, my dad was in coronary care unit stented and back with us on the ward. I can't thank you all enough for your swift actions that resulted in you saving my dad's life". [83307]

The opposite experience - of what were felt to be unacceptably long waits between different stages – were also recounted at greater length:

"...last night at around 6: 30pm I arrived at A&E with my almost 4 year old daughter. After around 45 minutes we were taken into a booth, which was satisfactory. Her stats were taken & we were told she would need a nebuliser (which I suspected). We were also told that the children's ward was full, so we would probably have to be transferred to Sheffield. Fair enough. This was before 8pm. We saw an on duty doctor who put my daughter on oxygen. We then had to wait until 2: 30am before seeing another doctor, & we were transferred to (another) hospital at a little after 4am. This was a ridiculous length of time, we had waited over 6 hours to be transferred. I was not even offered a drink until well after 2am. My daughter & I were exhausted. It was after 6am before I was given a bed. Worst experience at (...) hospital ever. Not happy". [79692]

It wasn't as straightforward, however, as speedy progress being seen as good and longer waits being seen as bad; the unwelcome experience of having to spend a long time overall or between different stages of assessment, treatment and final 'destination' was exacerbated by several factors: being left completely unattended for an extended period (for example, being left on a trolley for hours without being assessed, 64434, 144142); not knowing what was happening/what to expect/how long things might take [70780, below]; and attributing the length of waiting time to levels of demand contributed to by others who were seen to be there unnecessarily (102175, 193950, 84944, below):

"Once he arrived in A+E, he had to wait 30 minutes to be seen by a nurse, who said he needed to have an ECG. 45 minutes later, I went to ask what was happening ... he said they didn't realise he was waiting for an ECG and someone would come. 10 minutes later no-one had come ... All of this time the ECG machine stood stationary next to the doctor's station. By this time we had been in the hospital for 90 minutes and been waiting for the ECG for one hour ... After over an hour later, someone came to take Dad's bloods and do the ECG, 2 and a half hours after being told he needed it. He was moved shortly after to the Clinical Decisions Unit where he waited for the doctor to come and discharge him, over an hour and a half later". [70780]

"The wait time was 2 hours. It was irritating to see that some patients clearly did not have either accident or emergency that required their attendance at A&E. They should have gone to a GP. This makes waiting worse. One couple walked in - said "I'm not waiting 2 hours" and left. The nurse was really nice - given pain relief straight away, prioritised, but this made no difference to queue in A&E X-ray. The fracture was confirmed. Then had an hour wait left in the plaster room for a nurse to do plaster." [102175]

"I went to a&e ... at 10: 30 pm with a bleed at 24 weeks pregnant, after an hour I saw a triage nurse (after seeing 4 drunk people go straight In to see doctors who had clearly been fighting and were not severely injured) The nurse took a urine sample which never got tested, and said I had to wait for a doctor, 3 hours later a doctor called us in and we then had to wait in another room for over half an hour to tell us they couldn't do anything". [193950]

"Unfortunately, some parents overreact over a really minor injury and surely these can be taken and treated by a nurse at the Triage stage to free up the doctor to treat the 'serious' injuries". [84944]

While posts didn't state explicitly the kinds of things that ameliorated the frustrations of waiting, there were implicit indications within stories. Firstly, people's evaluations of waiting depended to some extent on the administrative arrangements for being seen:

"You expect long waits in A&E departments etc., but when you have a dedicated outpatient appointment time, you do expect the department to stick to it or even be 20 minutes late, not 1½ hours".[172465]

The expectations patients bring, therefore, clearly influence how they experience waiting. If A&E was obviously busy, not to have to wait a long time led patients to a positive evaluation regardless of actual waiting time:

"I must say that given the numbers of people in A and E at the time I was there (5. 45 until 8. 30pm on a Saturday), I am impressed that I was not kept waiting for much longer than I was! Well Done!" [88895]

The relative below appeared to have been pleasantly surprised by her mother being spared the distress of a long wait, but one gets the impression that even if they had had a longer wait, this would have been made more tolerable by the attentiveness they received, the demonstrations of care and being kept informed of when they *would* be seen:

"...my mum is in her 80s ... had a fall last night and had to be taken to the (hospital) strapped down to a board with a hard collar on and blocks to keep her head still in an ambulance ... At first I dreaded yet another long wait in a cubicle not knowing what was going to happen, but I was pleasantly surprised. We were greeted by a lovely nurse who introduced herself as 'Shakira' (sorry if that is misspelled) she was friendly and jolly and explained to both mum and I what would happen she made sure mum was comfortable, offered her pain relief and explained exactly what would happen. After a number of tests we were moved to another room to wait for a Dr. Again I dreaded a wait with my terrified mum being strapped down, but again I was surprised. Another nurse 'Jess' came in, she held my mother's hand, reassured her and asked us both if we would like a drink. She then informed us we were next to be seen, but if we needed anything while we waited to not hesitate to ask as it was no trouble... Even though the A&E department was busy from the onset we were greeted with friendly approachable staff who frankly made the whole experience a lot less frightening for both my mum and I! I felt I had to write this as I was so impressed. [193728]

The inference that being treated pleasantly, being given explanations and even an apology makes waiting easier is confirmed by the following patients:

“I understand they were busy with another patient but there were no apologies, no explanations, just a ‘wait there till I call you’. If they had just smiled and said I’m really sorry I’m dealing with another patient it would have been a different experience ...” [160334]

“They apologised for the minor waits I had between the various stages of treatment I had, eg x-rays, reassessment etc.” [103944]

Perhaps the fullest description of how ‘human contact’ factors can lead a patient to be appreciative of the care they received during a whole day spent in A&E at a ‘crazy busy’ time is contained in the following story. And although there were evidently added risks here for a patient whose condition ‘can deteriorate quickly’, the account offers a model of good practice for any and all patients:

“I had to go to A&E to get some tests and treatment for a flare up of a long term condition that I have. A&E was mobbed and the hospital was full - partly the result of an acute increase in patients due to the Halloween weekend. Despite the pressure, every member of staff I saw was not just courteous, they were actually kind. I must have dealt with about 12 staff, and everybody introduced themselves, everybody listened to me, everybody seemed genuinely caring. As soon as I was triaged I was taken to a cubicle because my condition can deteriorate quickly. From there it was quite a long wait to get all of the treatment I needed, but that was because I was stable and there were so many patients to be seen (so I have no complaint about this at all). I felt that had I started to get worse at any time then staff would have responded quickly ... the bed management team were helping out the nurses. Despite the obvious pressure the atmosphere was very pleasant - all staff were smiley and said hello, even though they were busy. I had a really good chat with one of the bed managers - Darren - about care pathways and how important it is that patients speak up for what they feel is right for them. All his colleagues were excellent too, and in particular Rose, a nurse who treated me in A&E ... was lovely. The Doctor (Med Reg) who saw me (Dr Martin) was fantastic. She was really reassuring and positive about how well I had managed before coming to hospital and sorted out my treatment quickly so that I was able to go home. She answered all of my questions patiently and I felt like I was in good hands. We were never short of a cup of tea, and everybody from the triage nurse to the AP who admitted me to the porter I met was approachable. It's never nice being in hospital, especially when you're there all day, but the actual experience couldn't have been any better in terms of human contact. Thank you all, for such good work on a crazy-busy weekend.” [191880]

## Treatment

References to the actual *treatment* patients received (sometimes referred to as ‘medical-technical’ as opposed to biopsychosocial aspects of care, Kihlgren et al, 2204) are fewer than one might expect. Where it *is* mentioned, the nature of the treatment may not be specified but the patient may simply report that it was ‘good’ or that they were pleased with it. Where they *are* more specific, patients are: ‘setting the scene’ for the rest of the story to come (“I had a total hip replacement ...”, “My ankle was dislocated and broken in three places...requiring it to be put back into place and an operation”); or describing investigations, tests and procedures (“...sent for treatment, sent for x-ray... attended to my wound”); or referring to diagnosis and prescribing (“They decided I needed a pacemaker fitted”, “I was given antibiotics”, “He prescribed me with some anti-virals”, “... after a diagnosis of croup, our son was given steroids”).

In a context of urgent and emergency care, it is perhaps not surprising that a number of stories refer to *pain relief* as part of their treatment. Typically, it is only to say that this was administered - but implicit in these references, when account is taken of the context of the overall story in which the reference is made, is that it was felt to be needed and was given in a timely way - so that the comment can be read as a positive one. Occasionally, a story contains a reference to pain relief *not* being administered when a relative felt that it was needed:

“I witnessed nurses using computers ... to access websites – discussing amongst each other about soft-furnishings!!! All this whilst my daughter is in agony waiting for pain relief!” [84980]

Also on a less positive note, patients lost confidence in those caring for them if health professionals contradicted each other regarding appropriate treatment:

“Over the weekend my aspirin was stopped by one doctor and started by another (after pressure from stroke nurse). Presumably because they did not know what type of stroke I had had!” [76070]

“On discharge the nurses disagreed with the doctors on my condition and gave me morphine as I was in agony” [144142]

“A doctor who saw me said I was to have an enema and sent home. The nurse insisted that neither of these should happen as I was in too much pain” [82035]

## Quality of consultation

What did inspire confidence in patients was when a medical consultation was experienced as 'professional'. This was a very popular choice of term to indicate the quality of consultation or encounter:

"Simply speaking, a wonderful service (Walk-In Centre) with friendly professional staff" [105200, Walk-In Centre]

"James and Gemma ... as well as being professional were very pleasant" [19, Podiatry clinic]

"The District nurses were very professional in how they treated me" [101759, District nursing and out of hours]

"The district nurse and her students... were very professional and pleasant" [108220, District Nursing and Out of hours]

"I can't fault the professionalism of the staff" [111136, A&E]

"Jill Roberts and her team are the most caring and professional bunch of people I have EVER met" [99404, A&E]

"From the moment we came into A&E we were dealt with professionally..." [198077, A&E]

"The lady doctor in A&E should be congratulated on her professionalism and ability to achieve things we have never seen before" [144141, A&E]

Where lacking, however, it was used to indicate how *unimpressed* a patient was with a medical encounter:

"We waited to see the doctor, who straightaway came across as very unprofessional" [66775, A&E]

But what did patients *mean* when they described an encounter or an individual as 'professional'? It was the juxtaposition of certain attributes or elements alongside the term that made it clear what patients saw as professionalism in medical and health care. The examples below illustrate the elements cited by patients which, particularly when combined, they saw as constituting professional practice:

### Knowledge/expertise, competence, experience

"The GP was incredibly knowledgeable [66741, GP service out-of-hours]

"This was the easiest smear test I have ever experienced... I felt that this was due to the nurse's experience" [138695, Walk-in Centre]

"I was cared for by specialist trauma nurse who's knowledge and handling of the situation was second to none" [126418, Trauma and orthopaedics]

"... there is nothing she does not know about the heart..." [191680, Cardiology]

"... (they) told me things I didn't know..." [61593, Heart failure support services]

"Staff very competent..." [120462, Ambulance]

"I found staff knowledgeable, competent..." [127698, A&E]

For some, a professional's knowledge was evidenced by the *advice* they gave during or after treatment:

"I was using a Stanley knife and managed to cut through my knuckle...the nurse manager quickly attended my wound, she was lovely, explaining to me that I must not bend my finger". (91506, A&E)

Written advice was also cited:

"My 5-year old daughter needed to come to A&E with breathing difficulties ... the leaflet on croup for further advice was perfect and easy to understand". (198077, A&E)

## Thoroughness

Being *thorough* was also cited approvingly:

"She did really thorough checks" (133162, Walk-in Centre)

"The staff were very thorough in doing x-rays and blood tests as well as the procedure itself to make sure nothing else was going on" (179862, A&E)

"They took a very good history and descriptions of symptoms from me" (71461, GP out of hours service)

"I didn't feel rushed and she assessed me thoroughly (103944, A&E)

## Efficiency

Efficiency was another element of professionalism:

"Seen very quickly by a very efficient nurse." (114961, Walk In Centre)

"The nurse was great and efficient as she could be, given how busy it was" (142237, A&E)

"... the surgeon who was very friendly and efficient..." (79692, Trauma and orthopaedics)

"After the break was confirmed the staff pulled out the stops to get me through the plaster room and on to physio just in time for closing, so that I could get

some lessons about using my crutches. This was all very efficient..." (178636, A&E)

"From the moment we came into A&E we were dealt with professionally, efficiently and thoughtfully" (198077A&E)

"We spoke to several different members of staff, doctors and nurses...they too were professional, caring and efficient" (132616, A&E)

## Explanations

Being given information, explanations, being kept in the loop etc. was also a valued component of professionalism:

"When he brought (my inner soles) to me he explained fully how to use them as well as an explanation sheet. What excellent service I received..." (114420, Podiatry)

"I was given a good explanation of the shoulder pain" (138053, Walk-In Centre)

"The nursing and doctors kept giving us information and keeping us in the loop" (134346, A&E)

"The staff on the Ambulance ... constantly ensured mum knew exactly what was happening" [193728, A&E]

"I was given very clear information about the procedure and after care" (101759, District nursing and out of hours)

"The medic was kind – explained what had broken" (102175, A&E)

A measure of the weight patients attached to being kept informed as part of professional care can be found in accounts of where this was *not* the case - whether this was a question of trying to manage a 90-year old relative with dementia who had sustained a large gash on her head, as in the first extract below; being left to find one's way around the hospital, not understanding the implications of X-ray results and not having procedures explained, as in the second; or not being helped to understand what to expect when experiencing a painful and distressing miscarriage, as in the third:

"We waited for approx. an hour between each 'intervention'. She got very tired & fed up & wanted to leave several times ... We had little sense of the plan or when we might be finished..." (134306, A&E)

"The consultant finally told us to go to the X-ray dept., not bothering to explain where this was ... the doctor then came over and said that my son had a "suspicious area" on the X-ray and that he would need a cast on. The doctor then walked off and I had to run to find out WHEN exactly he would need this cast on ...The day after, we then had to take my son to the fracture clinic, where...nurses...did not explain any of the procedure and just expected us to automatically know what was going on" (66775, A&E and Fracture Clinic)

“I was given very little information throughout about what to expect when I was sent home each time; I had no idea that I would experience contractions, how much bleeding to expect or what would happen when the foetus came out” (139988, A&E)

## Two-way communication

While the value of *two-way* communication, where patients give information to professionals and are listened to as well as the other way around, has been well-documented in the academic literature (e.g Lee and Garvin, 2003), there were only a few references to it in these stories. As in the earlier example of a patient referring to a ‘good history-taking’, another patient refers to being listened to:

“They listened as I was concerned about losing 2 stone in weight, loss of appetite...becoming frail and unable to do my housework” (88664, Cardiology)

And a third describes what appears to be an example of joint decision-making:

“I then met a female registrar called Anna, who listened attentively to my tale of woe and gave me a thorough and respectful examination. She had also seen the ECG results. She decided I should have bloods taken, informed me it would take about 35 minutes for the results to return, and indeed that proved to be the case. Anna then discussed these results with me and we concluded, with the ECG results also being good, that I could return home” (81551, A&E)

Patients were frustrated, however, by not being given an opportunity to give what they saw as relevant information (“I never got time to tell her about my Diabetes and was never asked”, 165089); and an extended story posted by another patient reveals the complexities of good health professional- patient communication in the context of urgent and emergency care. Even in the case of what is sometimes referred to as an ‘expert’ patient, (as in the case of this patient who usually managed their Addison’s Disease and insulin-dependent diabetes effectively themselves), it is still seen as essentially an asymmetrical relationship in which the onus is on the professional to facilitate effective communication. The extract below, taken from this patient’s story, which should perhaps be read in full, shows that, after having informed the staff of their conditions, the patient found it difficult to draw attention to the implications of these in the light of the injury sustained:

“I had taken my own emergency steroid injection as soon as the injury happened, and the ambulance had given me IV fluids which helped. But at A&E they seemed not to realise that I could be unstable medically as a result of a broken ankle. No extra blood sugar readings were taken – of course I carried on monitoring myself, but the shock in Addison’s can cause hypoglycaemia, which can be tricky to notice if you have a distracting injury...it’s not the nurse’s fault that she hasn’t been trained in Addison’s, but it’s one of those things where even a medical student would say “Adrenal crisis ... uh oh!” Especially in the presence of diabetes. I should have asked to see a Dr, but I should also have been asked if I needed to see one, given the number of serious medical conditions I have ... Clearly there’s responsibility on both sides in these situations, so I hold my hands up to not being ‘demanding enough” (178636, A&E)

Usually it was the *presence* of these attributes:

- Knowledge/expertise, competence, experience
- Thoroughness
- Efficiency
- Information/Explanation-giving
- Two-way communication

which, when appearing in various combinations, merited a description of a *professional* consultation/encounter. Sometimes, however, it was their *absence* which was the subject of a story and in one instance [73319], the carer who posted the story records potentially disastrous consequences:

“The doctor in A&E did not seem to know what Quinsy was or what to do about it” [93933, A&E]

“I kept telling staff that I had Lupus but I felt no notice was taken of this and majority of staff seemed to have no knowledge of the significance of my illness” [71225, A&E]

“One of the clinical staff asked us to stay a night so they could trace my daughter’s oxygen sats but yet forgot to record it, causing us all to have to stay a further night” [144141, A&E]

“The doctor discharged her telling her there was nothing wrong with her. She gets home and is called by the hospital and is told she needs to come in for an emergency platelet transfusion/transplant or she would die of internal bleeding. The reason: the Doctor who discharged her read the wrong file” [73319, A&E2].

Although in a small minority, instances of care that could be seen as the reverse of professional also included patients who felt they had been neglected, for example by being left on a trolley; out of reach of a buzzer; without the help needed to wash or dress; or without necessary sanitary products [177875, 144142, 77907, 125948]; and patients who felt that procedures simply did not reach what they regarded as standards of good practice (e.g. in relation to the hygienic taking of blood, 71458).

In contrast to these experiences and more numerous were descriptions which *surpassed* ‘professional’ - being described variously as ‘over and above’ what might be expected, going beyond the call of duty, care that was ‘second to none’ or ‘impressive’. An illustrative example is one in which a ‘very young doctor’ persuades a frightened patient who may have had a bleed on the brain to undergo further investigations:

“I wanted to discharge myself against medical advice. A very young doctor talked to me several times, explaining that he respected my wishes but there were dangers of a sudden bleed at home, when 999 might not be fast enough. I was still adamant. Finally he came back and quietly said he would not sleep if I went home. Good for him! I stayed, and even agreed to a lumbar puncture, something

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<sup>2</sup> This was responded to by the Patient Experience and Engagement Lead – see Section 10 below.

which I had sworn I would never do. In the end, all went well, all was well, and I went home in the morning, a grateful and happy customer” [100375]

## Quality of interpersonal interactions

Although related to a specific *medical* intervention, perhaps what the last patient in Section 3 was also expressing gratitude for was the level of *care* shown to her by the young doctor and she finishes her story by referring to other aspects of care. She concludes:

“Every single member of staff was delightful and the care superb – right down to the bed socks for my cold feet and the choice of pjs or a nightie. Congratulations to you all.” [100375]

The nature of care/ing is demonstrated and experienced through the quality of interpersonal interactions between health professionals and patients. In line with the studies cited earlier, which referred to ‘interpersonal skills/staff attitudes’ (Taylor and Bengler); the ‘cultural’ (as opposed to the ‘medical-technical’) aspects of care, in which a more holistic approach is taken (Nairn et al, 2004); and the patients’ psychosocial and emotional needs (Gordon et al, 2010), experiences of interpersonal interactions were by far the most frequently occurring elements of stories. And patients were usually specific in identifying which category of personnel they were referring to when citing such interactions.

### Receptionists

GP and hospital receptionists create crucial ‘first impressions’ and those who were ‘friendly’, ‘welcoming’ and ‘helpful’ were remarked upon appreciatively. In contrast, they were criticised if they were seen to be ‘rude’, ‘abrupt’, ‘arrogant’ – or ignoring patients:

“Reception – 3 staff, 2 chatting, only 1 booking” [114961]

“The receptionist was talking to a colleague so we waited to be called over ... we must have waited nearly 10 minutes ... I understand they were busy with another patient but there were no apologies, no explanations, just a ‘wait there till I call you’. If they had just smiled and said I’m really sorry I’m dealing with another patient it would have been a different experience ... people who report to A&E are generally worried and in pain ... And a reassuring smile could go a long way ... it’s such a shame that the first impression let the whole experience down” [160334]

What the second extract reveals here is an understanding that there will be times when one has to wait but an expectation of common courtesy that appeared to be lacking. Where this is the case, there is a risk that it sets the tone for the experience of the visit as a whole.

### Nurses

Nurses came in for widespread praise and there was a consistency in the way their approach was described, with the same words cropping up again and again: welcoming, approachable, kind, friendly, pleasant, helpful, understanding, lovely, caring, reassuring, respectful, polite and calm. In a setting which is often fraught with competing demands, a nurse who holds the hand of an elderly patient is noted by the patient’s daughter and seen by her as a model of caring [193728]. The same

is true where nursing staff are seen to be 'caring and supportive' not only towards patients but towards each other, as in the extended story worth reading in full, in which the patient comments: "It's the little things that make it bearable when you're ill" [134306, A&E/Acute Medical Unit]

Nurses who failed to demonstrate such care, on the other hand, received disapprobation:

"The attitude of the nurse allocated to me was unsympathetic, dismissive of the severity of my symptoms and lacking in diligence" [60443]

And where nursing staff were seen as uncaring towards an elderly and vulnerable patient as well as inconsiderate to his family, relatives report being 'astounded' at what was seen to amount to 'cruelty'. Extended stories that may be worth reading in full [61770 and 73124] reveal, respectively, a care team that the relative felt "needed to be seen to be believed" and a patient who felt 'frightened', 'scared', 'unsafe', 'upset' and 'uncared for'.

## Doctors

Where doctors were experienced as caring, they were described as: 'interested', 'compassionate', 'gentle', 'kind', 'respectful', '(child)friendly', 'fab', 'excellent' and 'reassuring'. In fact, reassurance was often cited as a valued element of care received from both nurses and doctors. In an extended story the full version of which is worth looking at, a doctor who could take the anxiety out of the situation for a patient who had come alone and was "deathly scared of hospitals and illnesses" exemplified this. An extract reads:

"At this point I was crying and emotional, but one of the senior doctors made me laugh and feel safe and told me I was going to be fine" [73145]

These examples were in marked contrast to descriptions of other doctors as 'rude', 'ignorant', 'arrogant', 'threatening', 'patronising', 'uncaring', making 'derogatory' comments or treating the patient in an 'undignified' or disrespectful way.

## Teams

Where a patient needs care from a *succession* of health care professionals, and this is experienced as of consistently high quality throughout, it was particularly valued:

"I was admitted under a trauma call... The fire crew and paramedics on the scene were superb and got me through to resus very quickly. I was cared for by a specialist trauma nurse whose knowledge and handling of the situation was second to none. I ...underwent two successful operations which were carried out incredibly well. The care on the ward was absolutely second to none. The nursing staff and health care assistants were on hand day and night and absolutely lovely and friendly. I ...feel indebted to everyone on the ward for all their hard work. The physio team were also very attentive and great to me. A special thank you to the consultant and all the staff that cared for me" [126418]

"The whole atmosphere was of kindness and exceptional care... this has been the very best experience of NHS care that I have witnessed. Thank you to the excellent support staff, managers, nurses and doctors..." [134346]

“From the ambulance and paramedics to nurses, doctors and support staff, I have always been treated with dignity and respect [107687]

“His care throughout from the paramedics who attended to him at home, the staff in casualty...Mr Parry and his surgical team, all the staff in ICU and last but by no means least the staff of ward 3 was absolutely superb. The care and support my sister and I also received during this time was outstanding. [73192]

### A humanistic approach

Exemplifying what might be described as a ‘humanistic’ approach, a number of stories referring to all categories of health professional either use the names of the health professionals who tended them or comment on the fact that the professionals introduced themselves by name. This practice, as well as expressions of warmth and comfort, were experienced favourably as exemplifying genuine *human contact* and *personal care* for an *individual* who was seen as more than a *body* to be prodded and processed:

“I would like to suggest that the second person I met should be the role model for a good patient/team member relationship. He greeted me with a ‘good morning’ and introduced himself. This made all the difference. The previous visit I was called by name and never greeted or told the podiatrists name. It doesn't take much to make the patient feel as if you actually care or are interested in their problem. So thanks to James for treating me like a person.” [141994]

“I recall feeling reassured that all the staff seemed to use their first names on introduction, which makes the whole situation less intimidating” [81551]

“It's never nice being in hospital, especially when you're there all day, but the actual experience couldn't have been any better in terms of human contact”. [191880]

“A fantastic environment with high quality care and attention to the small details which can make end of life care comfortable and personal. The clinical care and the hospitality and support services were excellent, provided in a warm and caring way by everyone and extremely supportive of the family and friends visiting Mum. My Mum's condition meant that she was very frightened living alone - she was very much reassured by all the care she received in the last month of life and felt safe and secure - we couldn't have asked for more”. [173063]

“The staff were wonderful at making me feel calm, at home and treated me as an individual, not just prodding and testing me to get me out of there quick as possible”. [73145]

These extracts, with references to ‘it never being nice to be in hospital’ and to feeling safe and secure remind us that the experience of being ill, injured or in distress, especially when urgent or emergency care is needed, is one of vulnerability and is often accompanied by stress, anxiety and fear. This is made even more explicit in a number of stories:

“Diagnosis was so quick and treatment delivered with such care and compassion at a time of great stress for us as a family. We are eternally grateful.” [75850]

“I felt very secure in their hands” [164074]

“I felt safe and like my care would be good” [103944]

“I dreaded a wait with my terrified mum strapped down...” [19372]

“To be in such distress is the most frightening experience one can endure” [106732]

In contrast to the above accounts where patients/relatives were made to feel safe and secure at a time of great vulnerability, were stories where patients were apparently *left* feeling frightened:

“Although my husband's home telephone number was on his admittance forms, they discharged him in a confused state early in the morning, in thin PJs, slippers and with a wash bag. Because they knew he had an appointment mid-afternoon that day to have an endoscopy in the same hospital, they left him in the waiting room for that procedure. Since then, the hospital staff I have spoken to have put all blame for being left there onto him for not knowing his own phone number ... Encephalopathy causes him not to know where he is or who his family are.” [81663]

“Communication was very poor, some staff I met were surly and dismissive, and many elderly ladies on the ward seemed frightened to ask staff for basic nursing care as they felt this would lead to their buzzers being taken away.” [71225]

There was an acknowledgement that, on the one hand, anxiety might lead to an ‘overreaction’ (although reassurance of appropriate care-seeking were given in the first case below); and on the other, some indications that feelings of isolation and fear, if not ameliorated, can become magnified, as in the second extract from a much longer story:

“When he really started struggling for breath we called an ambulance, feeling a mixture of panic for our son and concern that we were being typical overreacting new parents!” [132616]

“I was cold, scared and did not feel safe ... asked for my cannula to be removed as I felt so upset and uncared for, as well as unsafe, that I would take my chances at home and die in bed rather than feel that isolated and scared there...if I perish this will serve as a demonstration of the total and utter lack of empathy and understanding of a frightened man who has been close to death before ... and who has always enjoyed the wonderful service and care of the nhs in the past” [73124]

There were acknowledgments from patients of lapses in care being attributable to insufficient staff being available to meet demand, as in the first extract below; as well as a suggestion of how this was being managed, as in the second extract. And finally, a plea not to forget ‘basic patient care’:

“Was saddened to see the elderly and frail not helped more with their meals but due to lack of staff this was not available”. [88664]

“There was no eye contact from staff. I think so that you didn’t ask them anything as they were passing ... They didn’t ask how patients, families were feeling even though some looked extremely scared ... Have patience for people, care for people. They don’t just want you to make them feel physically well. They want to feel at ease. Please remember that when you come across someone in extreme pain, someone who is scared or alone, someone who doesn’t understand what’s happening to them ... surely that is better than forgetting basic patient care? [178635]

## Physical environment

Observations in stories about the physical environment suggest that it is a significant aspect of care for patients. Indeed, renovating a traditional waiting area in a neurology clinic by making small changes to the general layout, colour scheme, furniture, floor covering, curtains, and providing informational material and information display has been shown to result in more positive environmental appraisals, improved mood, altered physiological state, and greater reported satisfaction among waiting patients (Leather et al, 2003). A number of patients commented approvingly on the 'ergonomics' of the building or waiting area, the implication being that a pleasant environment may make *waiting* more tolerable psychologically:

"The building was very clean and well designed, it was a very pleasant place"  
[66741]

"The environment was clean and pleasant to wait in" [120851]

"The place was clean and bright" [86371]

"The seating is hard and the lighting is very bright. The environment is very clean and modern" [111136]

Other references - to *wards* (or a room where treatment was being administered) – are, in the context of the whole story, demonstrating an awareness by patients of the relationship between hygiene and *physical health*:

"The ward was spotless and was being cleaned constantly" [134346]

"The ward was clean and peaceful" [63035]

"The ward I ended up on was perfectly cleaned" [92261]

"It was a v clean, light, airy bay" [88664]

"The part of the hospital I visited was run down and dirty" [115404]

"The room was filthy and disorganised" [102175, plaster room]

Other comments about the environment in which they were being cared for related to a *combination* of physical and human factors. One study of an emergency department at a university hospital showed the prevalence of physicians and other clinical personnel who committed breaches of confidentiality and privacy (Mlinek and Pierce, 1997), and a number of the stories analysed here revealed just how sensitive patients are to this issue and how they are affected by poor practice in relation to both confidentiality and privacy:

"I ask for a bedpan. Staff are attentive & prompt. A nurse comes, begloved, and afterwards lets me wipe myself clean. No gloves for me, of course. Or wipes.

'600ml!' it's announced to the whole ward. 'That lady in the corner's just done 600ml!' I am mortified." [77907]

"...discussing one poor patient's medical records and history in full ear shot of the ward, saying some unpleasant things about this lady". [191873]

"We also had to listen to staff behind the curtains discussing (in what I felt was a very rude, insensitive and wholly unprofessional manner) my daughter and other patients. If this is how they talk about you when you are within 3 feet-not to mention hearing distance-I dread to think of the alternative!" [84980]

"I was inconsolable as I knew I was losing our baby and yet me and my partner were left with no privacy of a cubicle or room ...just left in the corridor. Eventually we were moved to a curtained area but one which the public could look into ...I gave birth to our baby into the bowl... Eventually a nurse came and took the bowl from my partner without saying anything ... She came back a while later and told us that I needed to see a doctor...we were just left with no privacy. We were moved from curtained cubicle to what I can only describe as a waiting room and eventually, after hours of being at (hospital), we were moved back to curtained cubicle (but one which belonged to another patient who was having an x-ray). [125948]

## Food/drink

There were not many comments about food and drink, but where they did appear, they were both good and bad. For example, in relation to drinking, some patients or relatives expressed appreciation at being offered a hot drink, while others commented on water being left out of their reach. In relation to food, too, experiences were mixed:

“...the food was excellent and had a good choice...” [134346, Cardiology]

“The food was much better than I’d anticipated. The best meal I had was Cottage pie. Totally yummy! The porridge at breakfast was also yummy.” [69737, A&E, on ward, post-operation]

“The food’s disgusting” [7790, Admissions ward]

## Service Organisation and Delivery

Stories whose main narrative is about how patients experienced the way services are organised and delivered can be divided into three broad areas: experiences of services to which patients were signposted as a way of relieving pressure on Emergency Departments (such as Walk-in Centres and Minor Injury Units); those relating to continuity of care throughout a patient journey; and those relating to patients' experiences of 'the system' not working well in terms of cancellations. Many elements of these stories are consistent with the findings on coordination between services and continuity across services found by O'Cathain et al (2008).

### 'Extra'-ED services

Those whose needs there were met by these services expressed appreciation of them as invaluable additions to NHS care:

"A couple of days after moving I still couldn't locate my medication ("safely" packed in box). Spoke to a local GP practice who recommended we attend the Walk-In Centre ...a fantastic Nurse Practitioner ... not only did she allay my concerns about attending an A&E area for such a minor issue by telling me the service does not impact A&E, she also made the effort to contact my previous GP's surgery to confirm the dosage of the medication I was missing. Simply speaking a wonderful service..." [105200]

"I contacted the A&E reception and after speaking to the admission staff we attended the walk in centre to be immediately seen, monitored and condition diagnosed with a prescription for antibiotics by an outstanding nurse in the children's department. I was thoroughly impressed needless to say with this invaluable service". [110224]

"Very grateful this service (MIU) is available. Would definitely use and recommend this service, sure beats waiting in ... A&E for hours. Thank you". [68929]

"I attended MIU to check on a cut finger ... My main worry was causing any further damage or ignoring anything that required treatment so the visit was more about reassurance. With NHS Direct only taking emergency calls at the time and it not being serious enough to visit A&E, the MIU was ideal ... This service certainly fits the gap between something which can't wait for a doctor's appointment but equally isn't bad enough for a hospital visit". [60880]

"This service meant that I didn't have to spend hours waiting to be seen and I was soon on my way again. I would recommend this service to anyone with minor injuries. [86232, MIU]

Where patients' needs were *not* met in what they felt was an effective way, however, there was evidence of an amplification in the accessing of services:

“My daughter attended your A&E department ... The bottles he gave her did not have her name on, or the dose or frequency of the dose, which I believe is not good practice. I brought her home (as she is a student...) and have been to see our own GP (3 days later). She informs me that the antibiotic that my daughter was given was not the correct type ... so we have now started on another 10 day dose. [93933]

“We arrived at 16.30 on a Sunday with a 9 year old girl with a large piece of glass in the top of her foot. We were turned away from (specific MIU) as glass was involved and so wasn't a Minor Injury.....This was removed on arrival, dressed and then we waited for an X Ray to see if any glass was left in. This done, we waited another 2 hours for the wound to be dressed. The doctor sprayed the foot with a numbing lotion and told the nurse to put 2 stitches in and bandage it. She put on 2 steristrips and a plaster.....by now it was 20.30 and we didn't want to wait again for the doctor to be free for him to tell another nurse to do the job as instructed and so left. It was dressed properly at ... (another) Minor Injuries and the nurse there said it should have been glued, stitched and bandaged. By now it was too late to stitch and there is now a risk of infection. [84944, Children's A&E]

Other extended stories in which patients describe not being able to access what they felt was the right service to meet their needs in a timely way (being subject to a 'postcode lottery' in the first case; and in the second, an escalation in accessing services after an OOH GP attempted to diagnosis a 'very old and very frail' lady over the telephone), can be found at 72683 and 58891 respectively.

### Continuity of care

A number of stories demonstrated what patients clearly felt represented models of good practice in continuity of care throughout their journey. Three stories illustrate this:

“After feeling ill we contacted NHS Direct. They were very helpful and a first responder and ambulance arrived quickly ... I was taken to the A&E department and was well cared for until I was admitted to the coronary care unit ...Since coming home I have had excellent care, advice and support from the heart failure nurse, and hope to join some of the activities suggested. I was diagnosed with a heart attack and heart failure and I'm sure the excellent care I received has helped me on the road to recovery. Thank you.” [63035]

“My experience started at ... Medical Centre when I was examined by medical staff and doctors who referred me on to ... Community Hospital musculoskeletal clinic, who sent me for an x-ray. After the x-ray I was referred to ... Royal Infirmary for a check-up. I was seen by Mr Brew who decided to do a complete knee replacement. After a check-up by a physio I was sent to ward 28 and found the ward very busy but extremely dedicated and overworked staff, from nurses to doctors. Even at busy times I found they cared well for all patients with a cheerful smile, which I found kept me calm and relaxed. Mr Brew and his team did my knee replacement at the end of a hard day, but still made me very welcome and their professional manner helped me to relax and have a smile as I look around and thought I had been abducted by aliens...back on the ward I was

looked after with dedication from the physio department and was soon on my feet and leaving ... I was passed on to the district nurse and her students who were very professional and pleasant and changed my dressing. [108220]

“The Dr who took charge of my care made every possible effort to ensure that longer-term community support was put in place to help me to avoid acute admissions in future - so they didn't just patch me up and ship me out, they enrolled me into the services I'll need ongoing help from too”. [134306]

## Systemic issues

In contrast to the above were accounts of ways in which patients felt the system had let them down, usually due to cancellations of planned operations. The three extracts below from what were typically extended stories on this issue, illustrate how patients/relatives felt about the situation:

“I have no complaints about the people who treated/looked after me - all very good. But the system was poor! If a scan had been available while in A&E I may have been able to be treated to prevent the second stroke and proper medication could have been started straight away. In addition I was discharged very rapidly...without a proper discussion with a stroke doctor. (I assume to free up a bed). Other tests had to be done as an outpatient.” [76070]

“Following an emergency admission my mother-in-law was referred in early October for a gallbladder removal operation. Within a few weeks she had a pre-op assessment, which made the family think that she would have her procedure sometime soon ... Earlier this week the hospital contacted her offering a cancellation slot for this week. As this was sooner than the 4-6 weeks post infection period this offer could not be accepted. Today she has been contacted for yet another pre-op assessment appointment... has been advised that the list is full and that she shouldn't have been told that an appointment would be given within 4-6 weeks after discharge. She is now back to square one, with no idea of how much longer she will have to wait ... and extremely worried that if she doesn't have her op soon the cycle of emergency admission will start all over again. Surely there is a more efficient way of running such a service?” [82467]

“I attended the A&E department and was given an x-ray ... In my opinion, the bone/hip was so badly damaged owing to neglect. The consultant promised he would help to put matters right but excuse after excuse, I'm still waiting. I've just been told my op at the end of this month has been cancelled owing to high blood pressure. I'm in so much pain and discomfort and need 24 care ... 6 cancellations is not on.” [82676]

A further example of a patient with a kidney transplant being prepared for theatre, including having fasted all day and gone without fluids for 16 hours, before being told that they were not in fact on the list for that day, can be found at 86497. Waiting at home for another phone call inviting them for surgery, and looking for some reassurance that the experience will be investigated, the patient comments that “The high tech front that (the hospital) puts up with the impressive waiting area is just that...a front”.

## Patients as health care consumers

### Patients as good citizens

Patients' stories offer accounts of their subjective experiences. We do not have evidence through which to determine whether they are 'truthful' or 'accurate' in an objective sense. Health professionals recognise, however, that what is real for the patient has real consequences for their health. In any case, as well as identifying the *content* of the themes they cover, we can pay attention to the rhetorical 'work' that other aspects of these stories do: how do patients present themselves and why? In addition to their accounts of *events*, patients also tell readers *why* they are posting their stories. They are explicit about feeding back positive experiences as an expression of gratitude; feeding back less positive experiences in order to improve services for others; and expressing how much they appreciate such high quality care being available free on the NHS:

"We could not have been treated anywhere any better. Thank you to all the staff..." [93080]

"I have stayed in hotels that have struggled to get the level of hospitality and kindness shown to date! There are so many people to thank, I can't name them, but they ALL deserve a huge medal. My wife is still there now and will be a while longer, but please pass on our gratitude to Jill and her team as soon as you can, please." [99404]

"If anyone is worried about having a smear test or putting it off, then I would encourage you to go to this health centre. You will be in safe hands!" [138695]

"I felt sorry for anyone attending A&E and would like to highlight this so that steps can be taken to improve customer service to all those attending..." [95117]

"Normally I would not write a review on here but I feel this is the only way my experience may find a voice and may help someone else" [191873]

"I am writing this because I do not want anyone else to have to go through this" [82035]

"If this is the normal standard of 'customer care' I would be discouraged to use this service (OOH) again & instead visit the A&E dept. instead – a behaviour which the NHS is working hard to reduce..." [71461]

"We left feeling very well looked after, and extremely grateful that the NHS exists - I dread to think what we'd have done and how much we'd have had to pay were it not for the NHS." [132616]

"I feel the only people in the wrong are the politicians who run down the NHS and don't pay the staff a decent living wage." [108220]

### Patients 'performing entitlement'

Patients also (directly or indirectly) give information about themselves which is aimed at enabling the reader to judge the merit of their story – and their own merit as 'deserving' patients. This notion of 'deservingness' appears in the way people 'perform' the patient role in 'real life' medical settings, when negotiating their entitlement to treatment/care in a context in which there is a risk of being labelled as a 'time-waster' (Goode et al, 2004). There were examples in these stories of patients recognising that in times of increasing demand for emergency care, patients will be prioritised. If this level of demand is combined with the 'staff shortages' they also observed on occasions, we might expect patients to perform their own 'deservingness' in accessing urgent care. And we can indeed see this dynamic at play not only in their medical encounters but in the stories they told about these encounters:

"I felt that I didn't want to waste valuable NHS resources..." [86232]

"I fell and hurt a rib just under a week ago - I expected it to be painful for a good month, and know that simple rib fractures are just managed with painkillers and rest (and making sure to keep coughing) - so I didn't bother the hospital with it. However ... I went to ... A&E this morning in case it was something more serious developing. They ... confirmed that there's nothing too serious to worry about - but reassured me that I was right to come in". [127153]

"I always try to be understanding and polite and don't feel am more important than anyone else" [73124]

## Positive and negative feedback

Are there any observable patterns in quality of care described in these stories? Most express gratitude for care received but they cannot simply be divided into 'good' stories and 'bad' stories. Some patients have a consistently positive 'journey' through a series of health care encounters; some stories focus on negative aspects of the patient's care; other patients have a mixed experience and they seem keen to fairly represent this more complex picture. Nevertheless, analysing a sample of this size does allow some broad generalisations to be made. There are some professionals and services who get a 'good press' overall; they are: paramedics and ambulance staff; NHS Direct and 111; Walk-in Centres; Minor Injury Units; Podiatry; and, on the whole, Children's A&E (with notable exceptions in the form of unsympathetic doctors in fracture clinics: 66775 and 172465).

Although few in number, some negative experiences described by patients who might be considered exceptionally vulnerable are particularly striking. These include: those presenting with alcohol/drug related conditions; frail elderly people, including with Alzheimer's; those with mental health issues; and two cases of women undergoing miscarriage.

A long story [60136] posted by the husband of a woman with Alzheimer's catalogues his unhappiness with the care she received during a stay in hospital; a patient reports observing other patients who were elderly and frail not being helped with their meals (see reference to 88664 in Section 10 for further details); and the relative of a 90-year old with dementia reports a lack of awareness of the difficulties of managing the patient while waiting to be seen (134306, referred to earlier in Section 3).

A student nurse whose housemates took her to A&E because they were suspicious that she had been a victim of drink spiking describes being spoken to by a doctor "in a very patronising manner". She recounts that the doctor then 'pretended' to take her pulse, told her she was fine and "claimed that drink spiking is a myth and it's only used as an excuse for girls who've gotten too drunk". And while disclosing the anxiety she felt from the outset about how she might be viewed, she goes on to make the point that "no person who could potentially have been a victim of sexual assault would feel comfortable disclosing this to the staff who "attended" me". [189477]

A patient who reports having Asperger's and who self-harms feels that the Crisis team is of no help because they simply "call an ambulance so that I spend 4 hrs alone with my thoughts and free to continue hurting myself". The crisis team also calls the police, which results in the patient "getting blamed for being the one who puts myself in hospital by ringing the crisis team even though they actually ring the emergency services and now thanks to them I'm probably at risk of getting sectioned". [84534] (It is worth reading the lengthy and sensitive response to this story from the Clinical Operations Manager of the Crisis Assessment Service. For more on responses to stories, see Section 10).

Another long story [82035] from a patient with mental health issues (an eating disorder and laxative dependency) describes highly unsympathetic treatment from a series of health professionals. The patient recounts being told by Adult Mental Health Services that "they didn't know anything about

eating disorders. They said that they didn't know how CMHT could help and that if I was Bipolar or Schizophrenic it would be "simply a case of changing your meds". They could offer me help if I needed "help with your shopping or something like that". Which I don't." After a GP emergency admission on a later date, the patient describes an interaction with a doctor: "I asked if they could please get me some MH support somehow. I wrote down what he said next, as they depressed me so much. He told me that I don't understand how difficult it is for one part of the NHS to speak to another part, and that even if he did contact the MH team I needed to understand that, whilst my mental health problems are obviously of great importance to me, they are not a priority for the mental health team: they have more important cases to deal with." (See the final entry in Section 10 for details of the responses to this story and an outcome with which the patient expresses satisfaction).

Finally, three stories from women suffering threatened and actual miscarriages raise questions about the right initial destinations for patients needing maternity care but also paint a picture of insensitivity that leads to pleas for more dignity, sympathy and privacy. The first patient [193950] went to A&E with a bleed at 24 weeks. After a wait of an hour (during which she observed men who were drunk but not seriously injured "go straight in to see doctors", a nurse took a urine sample "which never got tested" and after a wait of another 3 hours, she saw a doctor who told her that they couldn't do anything and that she needed to see an obstetrician at a second hospital. She reports receiving care there which was "a million times better".

After an initial assessment at a General Infirmary A&E in relation to the onset of a miscarriage, the second patient was booked in for a scan the following day at a Teaching Hospital and went home to rest. When cramps and more severe bleeding continued at home, she was taken to her nearest hospital. She lost her baby there in circumstances that exacerbated her distress:

"I was left in a corridor with a lady having a fit next to me and a prisoner handcuffed to his chair at the other side of me. As I was bleeding really heavily, I was placed in a wheelchair by the ambulance staff but no nurse or hospital staff came to see me. I was inconsolable as I knew I was losing our baby and yet me and my partner were left with no privacy of a cubicle or room. ...At no time was I offered any sanitary products or anything for the pain. A nurse came to see us and I was asked to do a urine sample and was given a bowl to provide the sample in ... I was asked to use the unisex toilet just off of the corridor. The only way I can describe this is I gave birth to our baby into the bowl. This was very distressing for both me and my partner and something which I will never forget. To make matters worse we were left for some time with the bowl containing our baby. Eventually a nurse came and took the bowl from my partner without saying anything ... We saw a doctor. She handed me a cocodamol and a paracetamol and told me to go home and that she could book me in for a scan for 3 days' time. As I had a scan booked ... for the following day I told her not to book me in. The care I received (the next day at the scheduled hospital) was fantastic. They were very caring and professional at the most difficult time in my life. They confirmed that I had had a complete miscarriage. We still don't know to this day what (local hospital) have done with our baby and that for me is the hardest

thing. I just hope they learn and treat people who are going through this with the dignity, sympathy and privacy that they deserve." [125948]

A response to this story was posted by the Patient Experience Team at the Teaching Hospitals NHS Trust, expressing condolences and thanking her for her kind comments; and by the Regional Hospitals NHS Trust Patient Liaison Manager, also expressing condolences and asking her to contact them or the Assistant Chief Nurse in order to speak with her about her 'poor experience'. The patient did in fact post a reply, but this was specifically addressed to the "Patient Experience Team Teaching Hospitals NHS" where she had received more sympathetic treatment, which read:

"Thank you for passing on my comments with regards to my care at (the first two hospitals), this is really appreciated. Many thanks."

The third story has some similarities with the second: heavy bleeding which took the patient to A&E; an initial wait (of an hour and a half) to be seen; being left in a corridor, which she found "incredibly traumatic" (She was still bleeding fairly heavily and "crying uncontrollably as I felt that the wait could be harming any chance of my baby being saved"); finally being seen by a doctor whom the patient found "completely unsympathetic"; a scan being suggested for a later date; and a pattern of returning home and back to A&E again to finally have the miscarriage confirmed. This patient too felt that the inadequate level of care she received only compounded the traumatic nature of the experience:

"He... stated that it was likely that I was having a miscarriage but couldn't have a scan until Monday as my miscarriage was not an emergency (although to me it certainly was) and they were no available staff to perform an ultrasound. He said I should go home and return on Monday. This left me completely devastated as the thought of having to wait two days to find out if my baby was alive - coupled with the idea of having to deal with it at home - was appalling....By Sunday evening at around 9pm I had been experiencing painful contractions for around 6-7hours; by the time I arrived back in A&E I was losing a huge amount of blood and could no longer stand. I was admitted and stayed in hospital until around 3am when the full miscarriage was confirmed and the pain had alleviated. I returned at 9am for a final ultrasound to check that the miscarriage was complete; this time I waited for over an hour in a waiting area full of couples looking at their scan pictures. Again, I was very emotional - it wasn't until a nurse spotted how upset me and my partner were that I was taken in for the scan, where it was explained (very apologetically) that the reception staff had misplaced my notes so the nurses were not aware I was waiting. Overall, I obviously found the entire experience extremely traumatic and looking back I feel that the care I received only compounded this."

She understands that little could have been done to prevent the miscarriage, but expected not only more sympathetic treatment but more information about what to expect:

"I had no idea that I would experience contractions, how much bleeding to expect or what would happen when the fetus came out".

She concludes that:

“The way that miscarriages are dealt with - the speed of care, information provided and support - all needs to be drastically improved from my experience.”  
[139988]

The response this patient receives does express sympathy and invites her (with contact details) to contact the A&E Matron so that her experience can be investigated and improvements made. Quite apart from the distress that the patient felt had been exacerbated by the way she was treated, her story also highlights differences in professional and lay definitions of what constitutes a (medical) emergency and raises issues of how the implications of these different definitions might be more effectively communicated to patients, especially in times of heightened distress.

## A different way of communicating

### Responding to patient stories

The vast majority of stories received a response; where patients referred to receiving care from a succession of health professionals (paramedics, ambulance, A&E staff, ward staff, physios etc), it was not unusual to receive more than one response. Many responses used a standard form of wording, which occasionally included 'management-speak' mantras:

"At... we have values, one of which is Work Together, Win Together..." [114420]

"... works to ensure patients are seen by the right person, with the right skills, at the right time" [101759]

Standard responses are used either to express appreciation that the patient or relative took the time to post a positive story together with a promise to pass on patients' thanks and gratitude to the relevant people where they could be identified; or to express regret that the patient felt they had had a less than satisfactory experience. Depending on the extent of the perceived failure on the part of services to deliver quality care, responses might also urge the patient to contact PALS so that their experiences can be further investigated. Again, a standard format of wording is usually used in these cases. In two cases, the response to a negative experience is also accompanied by a note saying "We are preparing to make a change" [141994; 73319];

In contrast to 'template' responses, there is evidence elsewhere of efforts to personalise messages, by using the patient/relative's pseudonym within the text, by 'reflecting back' elements of the story in their response or, as below, by adding good wishes for further recovery - all coming across as warm and genuine in their recognition of the kind of feedback that they assure patients "will mean a lot" to the recipients:

"I hope your shoulder is feeling better..." [138053]

"It sounds like you had a very frightening experience indeed... I do hope your recovery is going well and I wish you a comfortable and peaceful Christmas and New Year..." [126418]

"With all our best wished for your continued recovery" [113145]

"Your comments have been passed on to James, I'm sure it will mean a lot to him" [181683]

In some cases of largely negative stories, it is clear that the service has taken steps to look into the patient/relative's dissatisfaction, as in the case below (which appeared in Section 1 on waiting times):

"...at around 6: 30pm I arrived at A&E with my almost 4 year old daughter. After around 45 minutes we were taken into a booth, which was satisfactory ... We were also told that the children's ward was full, so we would probably have to be

transferred to Sheffield. Fair enough. This was before 8pm. We saw an on duty doctor who put my daughter on oxygen. We then had to wait until 2: 30am before seeing another doctor, & we were transferred to Bassetlaw hospital at a little after 4am. This was a ridiculous length of time, we had waited over 6 hours to be transferred. I was not even offered a drink until well after 2am. My daughter & I were exhausted. It was after 6am before I was given a bed. Worst experience ... ever. Not happy. [79692]

The Associate Director of Communications and Marketing for the first hospital responds thus:

“We are really sorry for the length of time you and your daughter had to wait. Services across South Yorkshire were very busy on the evening you came in and we always need to work with other hospitals at times when it is so busy, for the safety of our patients. However, we would like to talk to you in more detail about your experience, so we can learn lessons and ensure our patients are better communicated with”.

She then goes on to ask the relative to contact PALS. This is a response which a) acknowledges the patient’s displeasure, b) apologises, c) gives an explanation specific to the patient’s particular experience, and d) offers follow up to enable the hospital to learn and improve. The Director of Communications at another hospital also offers a lengthy explanation to a patient who is sitting in an A&E waiting room looking at an L-E-D information display which they read as indicating that all patients will be dealt with in 4 hours [92637]. There is no way of knowing how satisfied the patient was with the response they got to their story, but it highlights two things: the difficulties patients are presented with in interpreting ‘national targets’; and the time and effort that was put into helping this patient to do so.

A final example of a personal, detailed and sensitive response which gives full recognition to the patients concerns comes from a Patient Involvement Manager who picks up on two issues within a story describing a predominantly positive experience. The patient “Was saddened to see the elderly and frail not helped more with their meals but due to lack of staff this was not available”. They add “As usual my medication was messed up due to staff not ordering from the pharmacy (e.g. warfarin) which sent my INR results haywire” [88664]. The respondent thanks the patient for their kind comments about a number of services cited approvingly in the story before adding:

“I am however most concerned to hear of your observations of elderly and frail patients who to eat their meals. We have a system in place in all wards to ensure that those patients who require assistance with eating meals are provided with this help regardless of the number of staff on duty or the number of patients requiring assistance and I apologise that it appears that this system failed on this ward. Senior nurses, governors and our commissioners undertake unannounced visits to ward areas at mealtimes every month and Matrons undertake more frequent spot checks to ensure that patients are provided with assistance; however your comments provide us with vital additional information of the times when we are not undertaking these observations of practice, which I am very grateful to receive. I am also concerned that your medication seems to be an on-going problem when you are admitted to hospital and that we are not able to

obtain your warfarin medication in a timely way which results in your INR not being controlled, for which I am very sorry. I would be very grateful if you would take a little more of your time to contact our Patient Services department at ... to allow us to identify the ward and team you refer to. This will allow us to take appropriate steps to ensure that the concerns you have highlighted to us are remedied. Thank you once again for taking the time to highlight both the positive and negative aspects of care.”

### Facilitating dialogue

Beyond such comprehensive responses are examples of the site actually facilitating dialogue between patients/relatives and service providers. While not all of these exchanges provide evidence of resolution for the patient, they do demonstrate genuine efforts to address patients' concerns. In one instance, a patient's partner tells a brief story about the patient's post-operative experience of a prolonged open wound and 'one problem after another', culminating in a visit to A&E and from there to another hospital. The story ends: "told you should have rung your consultants secretary to make an appointment would have saved you wasting time (WHOS) anyway the swelling in your stomach may be something may not your bloods are fine so come back on Monday for a scan (if they remember) but in the meantime if you cough hold your stomach hahahahah fed up" [118656]. The Patient Liaison Manager responds: "We are concerned to note these comments and would be pleased to arrange for the matter to be investigated if the patient/partner would like to contact us directly with the appropriate details". Further short posts follow. The relative replies: "Thank you very much for your response. I will pass the information to him and he will be in touch. Regards" and the exchanges conclude with "Thank you. We will await contact".

A lengthier story recounting a catalogue of what the patient experienced as poor care [77907], is responded to by the Patient Involvement Manager expressing concern and asking the patient to contact Patient Services. This solicits a response from the patient, which highlights the dangers of any hint of the kind of 'management speak' referred to earlier:

"Well thanks for acknowledging that there are some issues that need to be addressed. It's a pity that some of them are the same as were raised by me in August 2011. And I do have reservations about the effectiveness of your Patient Services. Your filthy over-bed tables and the poor hand hygiene OF PATIENTS were detailed, among other issues, in a formal complaint also in 2011. (...) Hospital is full of aspirational posters about its Core Values and 'As Nurses we will ' etc. etc. The Trust might do well to spend less time talking the talk and do more walking the walk".

The Manager responds to this once more in a very thorough way:

"I'm sorry that you don't wish to contact us directly. Our Patient Services department co-ordinate the investigation of complaints and the responsibility of remediating any evidence that standards have not been upheld lies with the relevant team where the lapse occurred. In the absence of further detail (dates help us to identify specific staff involved), we have ensured that your feedback has been shared with the Matrons for A&E and (ward) who have been required to do further spot audits regarding access to buzzers, pain relief, provision of

wipes post use of bedpans (as well as pre every meal time) and to remind all their staff regarding the need for aural privacy. That you experienced breaches in such essential care is unacceptable and we apologise unreservedly for this. With regards to the cleaning of the bedside tables you are correct that the need to consider the edges/lip has been highlighted before (though not in relation to (ward in question) and this matter has been addressed with our Domestic Services Manager. We do conduct monthly unannounced inspections of our wards with regard to essential aspects of care and will continue to praise, challenge and remediate as necessary to ensure all our patients received a consistently high standard of care.”

A further example of an extended dialogue between this manager and a relative can be found at 82467. The relative is not totally satisfied with the initial response she receives. Her reply to it makes it clear that she thinks there is a systemic problem; and again highlights the dangers of what is seen as a ‘standard response’ (although to be fair, the initial response was more personalised than some, even if it did end with the standard request to contact Patient Services):

“Thank you for taking the time to respond to my story, it’s great to know that you are accessing patient views from this site. I do think you missed the point of the story though. This was not an attempt to bump my mother-in-law up the waiting list or to solely resolve her issue, but to highlight to you what patients in general are experiencing. I would have preferred a response outlining how the hospital intends to improve its communication processes in general, rather than a standard response given by so many hospitals of 'please contact us to discuss this one example of a less than satisfactory service'.” [82467]

This solicits a much more lengthy response from the Manager in which she outlines organisational communication processes, the Patient Experience Strategy, Corporate Induction packages and bespoke workshops for staff. There is no way of knowing whether this provides the ‘assurances’ intended but it difficult to imagine anything further the Manager could offer. Unequivocally positive dialogues include an exchange between a patient whose visit to hospital was evidently alcohol-related and those who treated her [107728]. The post reads: “Thanx for Your Kind responses, 8 days later Feeling Great & NO Feelings for alcohol whatsoever. Sobriety Is The New HI, with a little Lucozade!! Thanx Again Jam32 XX; )))”. The first response to this simply says “Fantastic, grateful for the update! Keep it up!” while the second, from a Customer Engagement Manager, echoes this: “Lovely to have an update, and as Linda says keep it up.” Another positive outcome arises from a dialogue about a discharge letter. The patient writes:

“The only disappointment I have is with my discharge letter. It does contain everything it needs to, but also contains some sensitive information which wasn't written with much thought or consideration, and I'm not sure needed to be included. I'm hopeful that this is a simple clerical error by the doctor who summarised the notes for the letter and will be corrected without too much fuss. [134306]

In addition to an appreciative response from the Patient Experience Team to the otherwise positive elements of the patient’s story, she also responded separately to the issue of the discharge letter:

“We passed your comments to the Matron for Acute Medicine and she would like to correct your discharge letter but in order to do this would need to obtain some patient details from you. If you would like to contact the Patient Advice and Liaison Service (PALS), they can put you in touch with the Matron. You can contact them on ...”

The final response from the patient indicates her satisfaction with the resolution of the problem:

“Thank you! The Jr Doctor who wrote the discharge letter actually corrected it for me within a week or so of me contacting the ward about it. So - we're all resolved (very impressed by how fast they did it), but thank you so much for offering to sort it out.”

The lengthiest dialogue resulted from a story posted by a patient with mental health issues. This story [82035], which merits being read in full, began: “Not a good experience and one that has left me feeling there is no help out there.” The patient’s last posting reads:

“I would like to respond to the above firstly by thanking (Associate Medical Director), and Tobias ... for their quick and comprehensive responses. It is reassuring to feel that I am being listened to and that my issues are being dealt with. I was especially pleased that Guy Brookes came to chat to me face-to-face and treated my concerns in a professional, yet humane, manner (even having a tissue at hand when I started to get upset!). The confidence I feel, from these interactions, is beyond my initial expectations and a refreshing change from my prior experience of trying to resolve my concerns. I had previously built up an unhealthy level of cynicism about the processes by which service users/patients can feedback to service providers, and viewed the upper echelons of the NHS as quite distinct and removed from those who use the services. I am glad to say that this is no longer my opinion. One of the great things about Patient Opinion is that it provides the necessary route for voicing opinion but without having to make an official complaint. As someone who is proud that we have an NHS and likes to defend it, I am always hesitant to criticise. Patient Opinion is done in a way that doesn't feel like making an official complaint but still with an expectation of outcome.”

The final post in this dialogue was from the Director of Patient Opinion Scotland, and reads:

“We're so glad to see you feel something positive has come from sharing your story on Patient Opinion. Your latest reply supports the things we say about Patient Opinion being a refreshing alternative to a very often negative complaints process. However, it sounds so much better coming from you! Thank you so much for taking the time to put how you feel into words. You've encouraged us no end! Hope you feel encouraged too and more confident about the future.”

## Conclusions

Patient Opinion is indeed a different way of enabling patients to tell their stories and of offering health professionals the opportunity to respond. The stories analysed here reveal that patients value this facility and use it to express their gratitude for high quality 'professional' care, to draw attention to perceived shortcomings and to outline the kinds of improvements that they feel would benefit them and others in the future.

The themes they cover in the stories they tell echo those identified in the relatively modest literature on patients' experience of emergency departments: in terms of medical treatment they are looking for knowledge, expertise, competence, thoroughness, efficiency and an appropriate exchange of information; in terms of care, they are looking above all to be treated in a humanistic way as a person deserving of respect, dignity, understanding, attention and recognition; from services, they are looking for co-ordinated care and a system that works. Often, according to these stories, they get all of this. Sometimes, they don't.

In contrast to the academic literature, however, the accounts posted here bring an immediacy and an 'authentic' voice to the telling of patients' stories that reveal more than is contained in the themes themselves. They tell us about patients as reflective consumers who are fully aware of the constraints health professionals are under in urgent and emergency care settings, and they reveal how patients try to negotiate this environment to present themselves not as time-wasters but as deserving of attention at a highly vulnerable time for them.

Proponents of 'narrative medicine' (Charon, 2006) recognise how powerful stories are and the ones analysed here represent a rich source of feedback to be mined by service providers wishing to deliver the high quality care patients expect.

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## Appendix: About Patient Opinion

Patient Opinion is a not-for-profit social enterprise based in Sheffield. Since 2005, Patient Opinion has pioneered new forms of online, public feedback for health and social care services across the UK.

Patient Opinion's award-winning web site ([www.patientopinion.org.uk](http://www.patientopinion.org.uk)) enables patients, carers and service users to give feedback to the services they use in ways which are safe, simple and effective. To date, over 115,000 stories of care are available on Patient Opinion. About half of these were contributed via NHS Choices ([nhs.uk](http://nhs.uk)).

Patient Opinion is currently used at some level by 90% of NHS trusts in England and Wales, and all public-facing health boards in Scotland. A similar service is provided by affiliated teams in Ireland and Australia.

The service is also used by the national care regulators CQC and the Care Inspectorate, and a range of commissioners and patient organisations. Three universities are now using Patient Opinion to bring the experiences of patients and carers into professional education.

Approximately 65% of stories in England, and almost 100% of stories in Scotland, receive a response from the relevant health care provider(s), and around 10% of stories raising a concern lead to an identifiable change.

### Further information

A wide range of resources, information, video and animation is available at the Patient Opinion web site: [www.patientopinion.org.uk](http://www.patientopinion.org.uk)

To contact Patient Opinion directly, please email [info@patientopinion.org.uk](mailto:info@patientopinion.org.uk), or call 0114 281 6256.