What do patients say about their experiences of being listened to, involved in or enabled by their care interactions?

Thematic analysis of stories from Patient Opinion

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# 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:

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# Summary

This study aims to provide insight, from recent experiences of care, into:

* the kinds of health encounters and interactions in which people felt listened to and involved in their care; and the impacts this had on their health and future behaviours
* the kinds of health encounters and interactions in which these elements were lacking; and the impacts of this
* the implications of each of these for patients’ health and wellbeing and demands on services

## Key messages

Patients’ stories provided a rich source of insight into the aspects of health care encounters and interactions that contributed to their being actively involved in their own care.

Positive reported outcomes in terms of patient empowerment; productive engagement in their care; and enhanced health and wellbeing were associated with:

* Being listened to
* Being given time
* Being given *information* and *explanations,* communicated in ways that are accessible to patients
* *Two-way communication*: patients valued professionals’ expertise but wanted it to be recognised that they were knowledgeable too. Patients sometimes needed to be actively *enabled* to give the information they wished to impart
* Being treated ‘holistically’: as a *person* rather than *a set of problems*; as a *whole person* with bio-psycho-social needs; and as an *individual*, sometimes with idiosyncratic needs
* Recognition and promotion of patient self-determination: being presented with options where these existed and enabled to exercise choice where possible
* Shared decision-making
* Recognition that change involves ‘starting from where the patient is’ and incorporating an appropriate *pace* of change

The above features added up to a ‘partnership’ model of health care, which rested on respect for all patients and a recognition of patient knowledge, experience and resourcefulness that can be capitalised on to effect positive change leading to enhanced health and wellbeing. Where this was operating, positive reported outcomes included:

* Feeling valued/cared for
* Enhanced confidence (in services and/or in own recovery)
* Enhanced motivation
* Greater self-management
* Greater resilience
* Better health/quality of life

Negative reported outcomes in terms of patient empowerment; productive engagement in their care; and enhanced health and wellbeing were associated with:

* A demonstrable lack of respect shown to patients
* A lack of interest in patients’ questions
* Patients’ concerns ignored, dismissed or contradicted
* Being excluded from decision-making

These experiences illustrated not only a disregard for patients’ entitlement to a professional service but a failure to recognise the potential for patients to be active partners in their own care and/or a lack of understanding of how behavioural change is effectively achieved. Where this was the case, negative outcomes included:

* Distress
* Loss of trust/confidence
* Lack of compliance
* Inappropriate accessing of services
* Poorer health/quality of life

# Introduction

Sustainability of the NHS depends upon patients and communities playing a greater role in their health and care, as current management approaches are not working:

* Detrimental health behaviours cause 60% of deaths and the impact of long-term conditions (LTCs) on patients’ quality of life and NHS costs (around 70%) is escalating.
* Patients often do not act on professional advice e.g. comply with about half their prescribed medications[[1]](#footnote-1).
* Only about 50% of patients feel they are sufficiently involved in decisions about their care[[2]](#footnote-2).
* Clinician communication is a common cause of patient dissatisfaction.

This suggests that better outcomes will be achieved if patients can be enrolled as active agents in their care and enabled to undertake behavioural change; and raises questions about what ‘good practice’ in this area looks like. This small study uses stories posted on a public website by patients and carers to examine reported experiences of healthcare interactions, in terms of the degree to which people feel listened to, involved or enabled to make decisions or act, as a result. This work will help create the case for change and social movement and thereby contribute to the NIA work plan.

# Aims and method

The study aims to provide insight, from recent experiences of care, into:

* the kinds of health encounters and interactions in which people did feel listened to and involved in their care; and the impacts this had on them and their future behaviours
* the kinds of health encounters and interactions in which these elements were lacking; and the impacts of this
* the implications of each of these for patients’ health and well being

The study is based on a thematic analysis of 162 stories posted on Patient Opinion in the past two years. In order to identify relevant stories, a search was conducted, using terms such as “listened to”, involved”, “empowered”, “motivated”, “enabled”, “confident”, “important to me”, “person-centred”.

The largest categories of ‘types of service’ from which the stories were drawn were Adult Mental Health; General Medicine/General Hospital; GP (including Out of Hours services); and A&E. A full list of service types appears in the Appendix to the full report.

# Findings

## Enrolling patients

*Being listened to* was especially significant where patients felt at risk of being stigmatised (e.g. alcohol-related conditions); in ‘sensitive’ situations (such as bereavement or with conditions of an intimate nature); where they had had previous negative experiences; where chronic or complex conditions had led to lowered expectations of help/loss of hope; and where patients were aware that health professionals were working under pressure. Sometimes, being listened to in itself reportedly made a patient feel better.

Patients were often aware that staff were working under pressure and this made them especially appreciative of *being given time*, of consultations which were not ‘rushed’.

Being ill is synonymous with a loss of control over one’s body and to some extent one’s life, at least in the short-term. Wherever it is possible, *being given information and explanations*, both about one’s condition and about what is happening or is going to happen restores a level of control to a patient as a pre-requisite of being an active participant in their care as opposed to a passive recipient of it. Patients valued information and explanations and were especially appreciative of professionals who took the trouble to ensure that their communications were accessible; this sometimes involved finding a number of different ways to express things in order to ensure that the patient understood.

Patients valued professionals’ expertise but also wanted it to be recognised that they were knowledgeable too. For effective *two-way communication*, patients sometimes needed to be actively enabled to give the information they wished to impart – especially where they had ‘special needs’ or were themselves aware that they found it difficult to articulate what they wanted to say.

A desire to be treated holistically was expressed in terms of *being seen as a person* rather than a set of problems; as a whole person with social and psychological as well as purely medical needs, (which sometimes involved engaging with the patient’s family); and being seen as an individual, for whom a degree of ‘tailor-made’ as opposed to ‘off the shelf’ care might sometimes be needed.

The importance of patient *self-determination* was implicit in accounts of being presented with options, where these were available; and of professionals taking a neutral stance which enabled patient choice to be exercised. This is compatible with what we know about successful change being predicated on ‘ownership’ of decisions. Patients’ accounts of shared decision-making more generally were characterised as being atypical but highly valued.

“Yesterday we both agreed that I would be discharged from her care – please note ‘both agreed’.” [233433]

Finally, effectively engaging patients in positive change was associated first of all with ‘starting from where the patient is’ and secondly with taking things a step at a time at the patient’s own pace.

“As there was no pressure to do things or to succeed, it made me want to do things… It was a very gentle, steady and consistent process… having the support … has given me back the confidence in myself to carry on … Ideas were put forward and then I could pick them up when I was ready… There is responsibility without pressure.” [239996]

“At no time has (school nurse) ever judged me as a person she has always listened to what I have said and given me strategies and ways to cope… she will challenge me and ask me a little bit more but never ever says I am to blame… This has made me feel so much better in myself as a person. I am now looking forward and not back…” [239440]

“Today I received a letter from Dr Willocks at NHS Lanarkshire regarding my recent appointment with her to discuss my need for treatment in Lanarkshire for Early Menopause. A few weeks ago I got a similar letter from Dr Pererra at NHS Greater Glasgow. Both these letters have been circulated to all professionals involved in my care - and most importantly have also been sent to me. They communicate where we are currently at with regards to my care and treatment, and also future plans going forward. I have never before experienced this - actively being included in communications between health professionals regarding my care. I think it is excellent and really demonstrates that I am the person at the centre of my care package. I am involved as an equal partner in making decisions moving forward…” [221159]

The above features added up to enrolling patients in a ‘partnership’ model of health care.

“This is clearly a very busy but exceptionally well-run hospital with all professionals working together and the patient and family as equal partners”. [247643]

### Impact

The impacts of this approach were reported as patients and carers feeling valued, cared for and safe; as having increased confidence not only in services but in their own prospects for recovery; as having acquired the tools they needed to manage their health better; as having greater resilience to sustain progress; and in some cases as having begun a new and better life.

Illustrative examples are drawn from the full report:

“[I will miss] Dr Perera and his wonderful manner. A true gentleman who truly listens to his patients and has worked with me to optimise my health & well-being … My health & well-being has been the best it has been since my surgery 6 years ago. I feel ‘normal’.” [249866]

“I now feel I have the tools to improve my quality of life … The staff have empowered me to deal with different situations through their individual skills & techniques. I feel like a different person leaving here today.” [243398]

“She listened carefully to the problems I was having, understood my condition when I didn't completely understand myself and then helped me develop personalised skills to cope and progress in my day to day life”. [210635]

“I really appreciate the help and techniques he gave me to work with … The service met my needs in a holistic manner and addressed my issues more than I was expecting and has helped me to develop coping mechanisms”. [243406]

## Alienating patients

The negative experiences patients reported can be categorised under the following headings: a felt lack of respect; having one’s own concerns and priorities ignored, dismissed or contradicted; and a lack of involvement in decisions about one’s care.

Illustrative examples are drawn from the full report:

“One GP prescribed medication even though I said I would react to it… I then did react to it and had to go to the walk-in centre. The GP did apologise afterwards, but I hadn’t been listened to”. [233764]

“The whole conversation was frosty and it was made clear that I was inconveniencing them … I’d been up all night and was very worried about my son… I didn’t feel listened to at all… “[264028]

“Attended my GP for advice on PTSD treatment … was informed they knew nothing about it nor where to refer… Told me to research it for myself. Never thought to ask me about the intrusive thoughts or feelings. Never thought of consulting colleagues and getting back. No interest whatsoever.” [223242]

“My GP doesn’t seem to have any interest in what I have to say. When I asked how I would be able to get a certain piece of equipment to help me at home I was told you don’t need that, you’re fine, you’re healthy, which is certainly not the case!” [241644]

“I have had type 1 diabetes for 35 years. Same HbA1c since I can recall. Always good control. Same weight since I finished school, always active and lean build …because of that, I no longer let the NHS weigh me or test my HbA1c because it's always the same. I have no problems with my control, and it's not what I'm interested in measuring. My health care team are consistently openly frustrated and annoyed about this. One time a nurse would not let me see a doctor unless I let her take my blood … I've become better at ignoring all of their patronising and offensive behaviours and I write down what I need out of each appointment and stay focussed on getting that addressed. I've managed to do that, but each appointment is made so awful because the health care providers show no concern about what's important to me.”[208033]

“…a locum psychiatrist I had met only once for a routine appointment for 10 minute made the decision to discharge me … Purely based on case notes, no assessment, no discussion with other staff who knew me … I wasn't given a chance to air my point of view, concerns … His manner was rude. I was shocked and upset and confused. I have always been involved in decisions about my treatment, care and support.”[262603]

### Impact

The impact these experiences had on patients’ health and patients’ and carers’ relationships with health services were positioned along a spectrum from a negative impact on their feelings; through a loss of trust or confidence in health service providers; a lack of ‘compliance’; subsequent ‘inappropriate’ accessing of services; to a reported deterioration in health and quality of daily living.

# Conclusions

The implications of these stories are that more positive outcomes in relation to both patient health and their accessing of services follow from a model of health care in which professionals actively engage patients (and sometimes their families) in their own care. Such ‘partnership’ working with ‘shared decision-making’ at its centre involves recognising, tapping into and/or enhancing a patients’ own skills, abilities and resourcefulness.

The consequences of this as described in these stories were universally positive. They ranged from positive feelings of being valued and cared for; through increased levels of confidence in services and in patients’ own potential for recovery, feeling ‘normal’, motivated and ‘empowered’; to greater self-management, leading in some cases to a whole new (healthier) life.

At the other end of the spectrum were a smaller number of stories of staff reportedly being disrespectful to patients; failing to recognise the legitimacy of patients’ knowledge, not providing space within a consultation for effective information-exchange; telling patients that they were not ill/not ill enough to warrant the attention they were seeking; an unresolved clash of priorities in relation to compliance with a regime; and a unilateral decision about discharge from care in contravention of the shared model of decision-making the patient was used to.

The consequences of a model of care in which patients are effectively excluded included distress, a loss of trust in health professionals; ‘inappropriate’ accessing of services; continuing ill-health; and poorer functioning.

While there may be wider contextual and ‘structural’ factors (to do with levels of demand on services, for example) to take into account when interpreting some of these negative stories, there are nevertheless communication skills and techniques available to health care professionals which are more likely to keep patients productively enrolled in their care than the experiences these patients reported.

# Appendix A: thematic analysis

## Context

Sustainability of the NHS depends upon patients and communities playing a greater role in their health and care, as current management approaches are not working:

* Detrimental health behaviours cause 60% of deaths and the impact of long-term conditions (LTCs) on patients’ quality of life and NHS costs (around 70%) is escalating.
* Patients often do not act on professional advice e.g. comply with about half their prescribed medications.
* Only about 50% of patients feel they are sufficiently involved in decisions about their care.
* Clinician communication is a common cause of patient dissatisfaction.

Health coaching is a method of patient education that guides and prompts a patient to be an active participant in their care and behaviour change. Increased patient awareness and responsibility is achieved through communication techniques that transform the clinician/patient relationship and develop patients’ intrinsic motivation for change.

Health Education East of England (HEEoE) has been at the forefront of introducing health coaching training into the NHS and its evaluation, and Dr Penny Newman appointed as national innovation accelerator (NIA) fellow to embed the approach into mainstream practice.

This small study will use stories posted on a public website by patients and carers to examine reported experiences of healthcare interactions, in terms of the degree to which people feel listened to, involved or enabled to make decisions or act, as a result. This work will help create the case for change and social movement and thereby contribute to the NIA work plan.

## Study objective

The objective of this study is to provide insight, from recent experiences of care, into a number of issues:

* Where and when people feel listened to, or not listened to, and how this affects them
* What experiences lead to people feeling involved, or not involved, in their care
* What experiences lead to people feeling motivated or enabled to take decisions or actions about their own or another’s health

## Study method

### Sample

The study is based on a thematic analysis of 162 stories posted on Patient Opinion in the past two years.

In order to identify relevant stories, a search was conducted, using terms such as “listened to”, involved”, “empowered”, “motivated”, “enabled”, “confident”, “important to me”, “person-centred”.

A thematic analysis of the resulting stories was undertaken in order to describe

* The experiences themselves
* The factors which seem to lead to such experiences
* The consequences of such experiences for patients and carers

Stories posted on the Patient Opinion website include information on type of service. The 162 stories analysed here were accounts of experiences of 32 different types of service. Almost a quarter (39) were from Adult Mental Health Services, followed by General Medicine/General Hospital (29); GP, including Out of Hours services (18); A&E (14); Trauma & Orthopaedics (13); Maternity Care (7); Memory Clinic (6); 111/NHS24 (6); Community/District Nursing (5); Children/Family/Motherhood Support Services (5); Surgery (5); and Physiotherapy (5). The remaining categories (Dental, School Nursing, Paediatrics, Emergency Ambulance, Gynaecology, Contraception & Sexual Health, Drugs & Alcohol Services, Health Visiting, Cardiology, Rheumatology, Older people’s health care, Gastroenterology, CAMH, Social Care, Dermatology, MIU, Oncology, ENT and an Independent Sector Bladder & Bowel service) each had between 1 and 4 stories (See Appendix B).

Just over half of the stories (84) were posted by patients themselves; of the rest, 40 were posted by a service staff member on behalf of a service user; 15 by a parent or guardian; 10 by a relative; four by a carer; three by a volunteer/advocate; three by a service user; and two by a friend.

## Analysis

All the stories were given a close initial reading, first of all to identify positive or negative experiences. Within those two categories, the contexts of the stories were then noted and different elements of what constituted ‘being listened to’, ‘involved’, ‘empowered’ etc. (or its opposite) were identified in order to offer descriptions of the phenomenon under examination; where it was included, the positive or negative impact of these experiences upon the authors’ own future motivation, decision-making and active involvement in their care, now and in the future, was also identified. This is the order in which the findings are offered below.

## Findings

The rest of the report is therefore structured as follows: analysis of negative experiences followed by their impact; analysis of positive experiences followed by their impact; summary/conclusions.

### Negative experiences

The vast majority (84 percent) of stories recounted positive experiences of being listened to, empowered or engaged in decision-making about the patient’s health care. Initially examining the 26 stories (16 percent) where this was clearly not the case highlighted some issues which offered a starting point for analysing the ‘positive’ stories.

Negative experiences can be categorised under the following headings: a felt lack of respect; having one’s own concerns and priorities ignored, dismissed or contradicted; and a lack of involvement in decisions about one’s care. Conceptually, they are obviously inter-connected, but will be treated here as distinct so as to reflect patients/carers’ lived experience as recounted by them.

#### Lack of respect

Some instances of this were implicit, for example in descriptions of failures in either the ‘system’ or the built environment. Examples of the former concern, firstly, the loss of valued personal effects and a very poor response to the relative’s unsuccessful attempts over a 5-month period to retrieve them, despite having kept and provided a receipt [235014], and secondly (below), a lack of respect or consideration towards patients’ families and the often considerable lengths they have to go to in making arrangements for a patient’s discharge from hospital, exacerbated by not being given any explanations for lengthy delays:

We arrived to take my mother in law home at 2pm visiting time, we had her husband who is 83 with us, we was told she could go home once the discharge letter had been done and her medication was ready … at 4-30 nothing was done and nothing was ready … my wife was with me who is a HCA and had a night shift to go to. The nurses etc was informed of this, at 7-30 pm we was still waiting. I had to arrange for my mother in laws grandson to come and pick her and her husband up on their way back from Blackpool as I had to leave to take my wife to work … My mother in law was allowed to leave and go home at last at 8-45pm … My 83 year old father in law was there since 2pm and not once was he or us given an explanation as to why it was taking so long ... [217677]

Examples involving the built environment include inadequate facilities not mitigated by the attitude of staff; and an environment that added to the confusion of a patient with mental health issues:

Apart from the building and the facilities which have not been brought up to date god only knows for how long, in my view the staff did nothing to make my .. very anxious stay, any more pleasant… the disabled facilities are as rudimentary as they can get away with and during my stay I was offered no help to shower in that less than easy to manoeuvre cubicle … when I asked for (who was in charge) they never came …I know a new building is going up and it will help … but I am not at all convinced that the mentality, the attitude of the staff towards the patients will change for the better just because the building is new. [254445]

The building layout was confusing due to a lack of signposting. I was unable to use the amenities i.e. cooker, TV, DVD Player as no instruction manuals were available. A better description of the centre would have helped…the centre itself added to my confused and exhausted state of mind [242045]

Some examples of a lack of respect were more explicit and involved accounts of staff talking disparagingly about patients in their hearing:

I am in pain and felt that they are talking behind my back, then one of the staff starts to give me mucky looks…I am then asked to sit by the security, after trying to explain that I didn’t like to hear myself being spoken of. I was then asked to enter a room with someone that seemed to be in charge but would not listen to a word…I break down into tears because of the pain I am in. The staff just kept speaking over me… my experience was despicable and appalling and staff seemed not willing to put patients’ needs first. [263299]

The night time staff was talking about me and joking behind my back not realising I was stood there and heard it. [252260]

Other stories described professionals being ‘frosty’, ‘cold’ or ‘unhelpful’. Patients interpreted this as a response to their perceived ‘inappropriate’ behaviour – either in relation to the way the system requires them to access care or in relation to not doing as they’d been told. In the first example, the mother of a sick infant has lost confidence in the NHS24 service due to the information given being contradicted by the pharmacist she was advised to see. She is aware of then accessing a service ‘inappropriately’ but feels her baby needs to actually be seen. She describes her reception on arriving at a Minor Injuries Unit (before an OOH doctor there finally sees her baby and diagnoses an ear infection):

The whole conversation was frosty and it was made clear that I was inconveniencing them … the nurse was very cold, unfriendly and didn’t show any understanding or provide any reassurance … I felt very uncomfortable and was on the verge of tears as I’d been up all night and was very worried about my son … I didn’t feel listened to at all… [264028]

In the second, a patient who has been given ‘devastating news’ about their condition and the treatment required is given a DVD plus contact details of a specialist nurse who will offer further information, advice and support. It takes her a while to make the phone call due to the time needed to ‘come to terms with’ the news. She describes the response:

The nurse gave me a lecture over the phone about commitment to this treatment. The nurse was less than impressed that I had not watched the DVD. I was met with negativity and a total lack of interest. I was told to phone back when I had at least watched the DVD! Person centred care? [261807]

#### Being ignored

##### Lack of interest

The ‘simplest’ category of ‘being ignored’ was being met with an apparent lack of interest in a patient’s needs and no attempt to signpost them to other sources of help:

Attended my GP for advice on PTSD treatment and referral. Was informed they knew nothing about it or where to refer … Told me to research it for myself. Never inquired about the intrusive thoughts or feelings. Never thought of consulting colleagues and getting back. No interest whatsoever.[223242]

##### Being ignored when trying to communicate important information

The first three examples in this category involve patients using their previous experience/knowledge to inform their current situation and asking for their need to be met in a way that had proved effective in the past. It is not possible to judge whether or not what they were asking for was appropriate in the current context; what is significant is that they felt that what they had to say was being dismissed:

I was operated by a wonderful team … I started throwing up from the evening of the day after … I was very weak and my lips were extremely dry but I was thirsty. The lovely Nurse took a urine sample which showed that I was presenting Ketones at this stage. I informed her that I had this condition (hyperemesis) with all 3 of my pregnancies and that I would need to be put on a drip in order to for me to recover.. …She then came back to me saying the doctor would not prescribe the drip and that I should try to drink water …She spoke to the doctor again who finally agreed to see me! I told him about the hyperemesis and that I should be on a drip but again he really wanted to dismiss what I had to say. I found his demeanour very arrogant and rude … What I want out of this is for doctor to have … some communication skills in order to listen to what a patient is trying to tell him. [205714]

Recently I went to East Surrey hospital for a flexi sigmoidoscopy and biopsies … waited 5 hrs before surgery. I was expected to be nil by mouth all this time? I have a ileostomy so I spend all day every day fighting dehydration so I told the surgeon and the pre op assessment nurse I need to be on a drip but it took 90 mins before they finally got one on me … I know my body and have been in this situation many times and every time it is very distressing … [229221]

This surgery used to be very good. You could see the same GP, maybe wait an extra day or two. Now I have seen 5 or 6 GPs since January, and most don’t know me … there is no continuity. One GP prescribed medication even though I said I would react to it, but they still prescribed it. I then did react to it and had to go to the walk-in centre. The GP did apologise afterwards, but I hadn’t been listened to. [233764]

The fourth example refers to a mother who was admitted to hospital with pneumonia. On arrival, the relative posting the story “could see she was not right” and asked a nurse if a doctor could take a look. The response was to be told “rudely” that s/he would have to wait. Over the ensuing two hours, the mother’s condition deteriorated until she lost speech. The relative told the doctor who then arrived that s/he thought the mother had had a stroke. Blood tests were immediately taken to assess oxygen levels, the results of which apparently confirmed this. [207862]

##### Patients’ assessment of their condition/ need/priorities dismissed or contradicted

These examples refer to patients (including but not exclusively mental health patients) being told they are not ill in the ways they claim to be or that their needs/requests are not legitimate or of sufficient priority:

Sudden excruciating pain shoot thru pelvis … paramedics did sats and did not accept pain was pelvic instead checking my abdomen and saying it's your lower quadrant. So what is the problem? They called my gp who did not take me seriously either … pelvis remains intolerably painful I can't function. [256763]

The worker continuously advises me I am not in crisis, and that I don't have mental health needs. I am desperately reaching out for help as I am no longer coping, and they are not listening to me or letting me speak. … I am at risk at this time of year. Why am I not being heard?? Why am I not being taken seriously?? [264289]

The CPN I saw at Aire Court is trying to say I'm not depressed because I find it hard to put things into words … I have a moderate learning difficulty and find it hard to put things into words. I hear voices and feel like Aire Court is not taking me seriously. [231464]

My GP doesn’t seem to have any interest in what I have to say and has very poor bedside manner. When I asked how I would be able to get a certain piece of equipment to help me at home I was told you don’t need that, you’re fine, you’re healthy, which is certainly not the case! [241644]

I have been a patient of the IBD service for five years after being diagnosed with ulcerative colitis … I've tried to call the helpline a number of times and seldom get a response. When they do get back to you, I've been told off because they don't think that my problem is urgent enough. I've spoken to my hospital Doctor about this, only to be told that they are very busy and that there are more needy patients waiting on calls. [223143]

The final example in this category, included here in its entirety, is a more extreme form of the lack of ‘compliance’ referred to earlier, but here there is a much more well worked out position being taken by a patient with diabetes in relation to his/her own priorities which, in the conflict it engenders, highlights the centrality of the notion of ‘control’ in the management of chronic conditions. Whose body is it? What does ‘choice’ mean? How is behavioural change effected? And what constitutes person-centred care/shared decision-making in such circumstances?

I have had type 1 diabetes for 35 years. Same HbA1c since I can recall. Always good control. Same weight since I finished school, always active and lean build. So, because of that, I no longer let the NHS weigh me or test my HbA1c because it's always the same. I have no problems with my control, and it's not what I'm interested in measuring. My health care team are consistently openly frustrated and annoyed about this. One time a nurse would not let me see a doctor unless I let her take my blood … I've become better at ignoring all of their patronising and offensive behaviours and I write down what I need out of each appointment and stay focussed on getting that addressed. I've managed to do that, but each appointment is made so awful because the health care providers show no concern about what's important to me. I said to my Dr that I need help to maintain good kidney function. He said he couldn't do anything for me because I refuse to do anything (he meant I don't give my blood or get weighed). I said to him that I do a lot: firstly, I'm here! Secondly, I reminded him the strict diet changes I've made to reduce protein in my diet, thirdly I reminded him that I've consistently taken the non-pharmaceutical treatments that were indicated to help kidney function, and finally I reminded him that although I won't consent to some blood tests I have done all the blood tests for kidney function and they've shown that the care I'm taking is working and my kidney function is improving. I was calm with him and said to him to please stay focussed on helping me sort my kidneys out but I left feeling defeated. I hate seeing people who are paid to do things to my diabetes. [208033]

The final sentence of this patient’s story is telling for what it reveals about experiences of ‘objectification’ (being seen as a ‘condition’ which has things ‘done to’ it) in a relationship which is experienced in instrumental (‘paid to’) rather than humanistic terms.

#### Lack of involvement in decision-making

Negative experiences of decision-making described not being involved in decisions to discharge from care. In both of the examples below, (one medical, one psychiatric), an unfamiliar medical professional makes what appears to be a peremptory decision without any consultation with the patient:

I had to be prescribed home oxygen about 10 years ago when I was also diagnosed with bronchiectasis. The British Thoracic Society Guidelines (updated in 2014) state that all patients with brittle asthma should remain under the care of a Consultant in Respiratory Medicine indefinitely, yet it November 2014, a new Consultant I'd never seen before discharged me. [229940]

At an emergency appointment due to a deterioration in my mental health a locum psychiatrist I had met only once for a routine appointment for 10 minute made the decision to discharge me from seeing a psychiatrist … He also said my diagnosis wasn't correct. In his opinion it was something else. Purely based on case notes, no assessment, no discussion with other staff who knew me … I wasn't given a chance to air my point of view, concerns, his explanation was vague. His manner was rude. I was shocked and upset and confused. I have always been involved in decisions about my treatment, care and support. To be told this is what's happening, end of. [262603]

### Impact

The impact these experiences had on patients’ health and patients’ and carers’ relationships with health services can be represented as being positioned along a spectrum from a negative impact on their feelings; through a loss of trust or confidence in health service providers; and an impact on the way services or treatment are accessed subsequently; to a reported deterioration in quality of daily living. Illustrative rather than exhaustive examples of each appear below.

#### Damaged feelings

A patient who had earlier reported positive experiences of being given support with mental health issues was now ‘saddened and distressed’ to be posting a story of feeling totally unsupported by the crisis team. As a result of “no longer being heard”, the patient is “upset and distressed”. S/he doesn’t understand why s/he isn’t being taken seriously and is left feeling “absolutely desperate”. [264289]

The patient with an ileostomy whose pleas to be properly rehydrated while in hospital were ignored has to have further surgery in the near future and reports: “I am now awaiting to go back in soon for major surgery… and this is now distressing me even more after this recent occurrence”. [229221]

An isolated patient with long-standing mental health issues who is suffering a bout of depression feels unsupported and a sense of hopelessness pervades the way s/he contemplates Christmas: “I don’t know what will happen to me five weeks to Christmas. It’s supposed to be family and friends gather at this time of year. To me every day is lonely and Christmas will be no different”. [261395]

A mental health patient who has been discharged from the care of a psychiatrist by a locum with ‘no discussion’ is left feeling “shocked and upset and confused”. [262603]

#### Loss of trust/confidence

A Dental access centre patient who was appalled by hearing themselves talked about by health care professionals, not listened to when s/he complained about this and finally accused of being aggressive, is encouraged to contact the Customer Care Team by the Communications an Engagement Team Leader responding to the story. The serious loss of trust is apparent in the patient’s unwillingness to do so: “I would take it further but I feel like it would get covered over and nothing done and I will be seen to be a ‘mad patient’, I am worried you will all stick together” [263200]

A stroke victim who was told by their GP that they did not need the equipment being requested reports: “I do not have any confidence in my GP… I am thinking of moving to a GP elsewhere” [241644]

#### Impact on behaviour in relation to accessing service/treatment

The mother who received initial advice by NHS24 (to consult a pharmacist about her sick 11-month old son) which did not meet his needs got referred, on a second call to the service, to an OOH doctor, where the child was treated successfully. When he fell ill again the following week, she took him straight to an MIU in order to be seen by an OOH doctor. She was aware that she was accessing this service ‘inappropriately’ and interpreted the ‘frosty’ reception she received from the nurse there in this light – but accounted for having done so as a direct consequence of her loss of trust in the NHS24 service:

Whilst I understand I didn’t follow the process, I think under the circumstances it was understandable… I’m guessing they were peeved at my insistence on seeing someone … I understand the pressure and challenges NHS staff are under but I’m not a neurotic time waster and expect to be treated with respect and understanding … I appreciate that unfortunately there’s a population of people who abuse the service. However, I don’t expect that to create cynicism for all patients. Every single patient should be treated in the right way and their issues and concerns listened to.” [264028]

A mental health patient feels like discontinuing in-patient treatment due to the physical environment not being conducive to recovery: “I wanted to quit and go home when I was still very unwell…I felt suicidal due to the serious shortcomings within the organisation” [242045]

#### Quality of Life

Other patients recount a negative impact on their quality of life, either due to continuing pain or to being less able to function on a day to day basis:

A patient who comes into conflict with paramedics about the location of her/his pain and feels ‘dismissed’ both by them and the GP reports “pelvis remains intolerably painful. I can’t function. [256763]

An elderly patient who remains in pain after a fall and who feels ‘left in limbo’ as far as diagnosis and appropriate treatment is concerned and consequently ‘let down by the NHS’ asks “Why do so many of the medical profession not listen to their patients?” before reporting: “Although I am 83, before the fall I was active, fit and upright: not any more. The quality of my life has been seriously affected and I am now unable to carry out many day to day activities. [259161]

### Professional response and resolution

To some extent the stories above reveal the high expectations patients have of the NHS and the negative impact not having these expectations met can have, whether this is to leave them shocked, distressed, disgusted etc; whether it damages trust and confidence in the NHS more broadly; whether it creates ‘inappropriate’ subsequent demand on services when such a lot of effort goes into signposting patients to the right place at the right time; or whether it actually impacts in an adverse way on their day to day functioning.

Nevertheless, such is the goodwill towards the NHS, as reflected in the majority of stories posted on Patient Opinion, together with the facility the site provides for professionals to respond to patients’ experiences, that we can also see evidence that negative experiences can be ‘repaired’ and ‘conflicts’ resolved. Such was the case with the patient with a chronic respiratory condition (above) who reported being peremptorily discharged by a consultant they had never seen before. After the story was responded to by the hospital’s ‘Online Communications Officer’, the patient posted again:

Following my posting, I received a reply from the Patient Experience Team. Today, I had a further appointment with this Respiratory Consultant, and there have been misunderstandings both on my part and his … I’m pleased to tell you that these problems have now been resolved to my satisfaction and that I will continue to be seen by him or one of the clinical team every six months. So … my concerns have been addressed. [229940]

The implications of these stories for what constitutes good practice in terms of patient-centred health care is that it should include:

* demonstrating respect for the patient, whether this involves the provision of a physical environment conducive to health; taking proper care of their personal belongings; recognising that they and their families have lives and demands on their time which have to be accommodated when striving to meet the demands placed upon them by the rhythms and requirements of the ‘system’; or being professional enough to reserve any private thoughts or judgements about them rather than share these with colleagues within patients’ hearing.
* actively showing an interest in patients
* recognising patients’ concerns as legitimate to them
* attending to patients’ attempts to impart information (even when they may not be very verbally articulate or confident)
* actively consulting patients about/including them in decisions that affect them and their care

The notion of ‘patient-centred care’ and its place in effective health care delivery is discussed briefly below before presenting patients’ descriptions and positive experiences of it.

### Positive experiences

In describing accounts of ‘being listened to’, being ‘involved’ in their care etc. that patients have posted on the Patient Opinion site, and in analysing them and the factors at play in contributing to patient ‘empowerment’ and other positive health outcomes, two conceptual tools have been drawn upon. These are ‘crisis intervention theory’ and within that, the notion of ‘person-centred care’. Neither is new but each is worth briefly outlining here in order to clarify the approach taken to analysis and to make sense of the ‘findings’ presented below.

Crisis intervention theory is based on the conceptualisation of a crisis as a disruption in a ‘normal’ or usual state of being; adaptation to a crisis can lead to a dysfunctional state of affairs but also offer an opportunity for further ‘growth’ or ‘healing’. Caplan (1964, 1974) suggests that a crisis is provoked when a person faces a problem for which s/he appears not to have an immediate solution and that is, for a period of time, insurmountable via methods of problem solving usually drawn upon. A period of upset or tension follows in which attempts are made at a solution. Eventually some kind of adaptation or equilibrium is achieved which may leave the person in a better or worse state than before the crisis. The essential factor in defining an event as a ‘crisis’ in this sense is an imbalance between the perceived difficulty/significance of the threatening situation and the resources immediately available to deal with it. The crisis refers to the person’s emotional reaction to the threat rather than the threat itself.

Rapoport (1967, 1970) built on Caplan’s theory by defining a crisis as a threat, a loss or a challenge. She identified three interrelated factors producing a state of crisis: a hazardous event; a threat to life goals; and the inability to respond with adequate coping mechanisms. She also classified crises into three different types: developmental crises which are biopsychosocial in nature; crises of role transition (e.g. redundancy, retirement, acquired disability); and accidental crises, or ‘hazardous events’. We can therefore see the (physical or mental) illness that presents to medical and health professional as an event (a threat, a loss, a challenge – or all three) which has provoked a crisis for the patient due to her/his inability to respond to it with adequate (in their own terms) coping mechanisms.

A crisis in this sense also constitutes an opportunity which practitioners in the caring professions can capitalise upon through some kind of therapeutic ‘crisis intervention’ (for an outline of different models of crisis intervention and their characteristics, see Poal, 1990). Central to any effective intervention is recognising the importance of the individual’s perception of what constitutes a crisis. What is experienced as ‘real’ to the individual is ‘real’ in its effects. This is behind one of the main tenets of crisis intervention – that of ‘person-centredness’ - with the associated idea, in relation to desired change for example, of ‘starting from where the person is’.

As described by the British Association for the Person-Centred approach (http://www.bapca.org.uk/about/what-is-it.html) the notion of ‘person-centredness’ developed from the work of the psychologist Dr. Carl Rogers. He advanced an approach to psychotherapy and counselling that, at the time (1940s – 1960s), was considered radical.

Originally conceived as ‘non-directive’, therapeutic interventions using this approach moved away from the idea that the therapist was the expert and towards a theory that trusted the innate tendency (known as the actualising tendency) of human beings to find fulfilment of their personal potentials (supported, in social work theory/practice, by enhancing ‘client self-determination’). The requisite environment for the effectiveness of such an approach is one where a person feels free from threat, both physically and psychologically. This environment can be achieved within a relationship with a person who is deeply understanding (empathic), accepting (having unconditional positive regard and being non-judgmental) and genuine (congruent).

Although initially developed as an approach to psychotherapy (eventually becoming known as client/person-centred therapy/counselling), Rogers and his colleagues came to believe that their ideas could be transferred to other areas where people were in relationship, for example teaching, management, childcare, patient care, conflict resolution. In relation to health, it involves placing people at the forefront of their health and care. It ensures people retain control, helps them make informed decisions and supports a partnership between individuals, families and services.

We will see elements of all of the above (and the other elements identified by their absence in the ‘negative’ stories) in the stories which follow of patients’ positive experiences.

#### The significance of context: sensitive situations, previous service experience and chronic conditions

A number of contextual factors identifiable in these accounts serve to highlight situations in which patients particularly valued being ‘attended to’:

##### Sensitive situations

‘Sensitive’ situations in which patients may be especially fearful of a health care encounter (and appreciative when it is a positive one) included presenting with potentially stigmatising illnesses (e.g. alcohol-related conditions), as in the first example); ‘intimate’ and life-changing experiences which impact on one’s identity, (as in the second); and bereavement (as in the third and fourth:

Admitted with suspected organ failure. Supported by the hospital alcohol nurse. I felt listened to, at ease and did not feel embarrassed. [223789]

I had a bilateral Mastectomy … the nurses were ALL lovely and attentive... I was a very shy girl with regards to showing off certain parts of my body but these Nurses, Consultants and Doctors made this side of treatment easy to cope with ... The NHS and its staff are all amazing! [207490]

My mum was admitted to the intensive care unit … I can't recommend the nurses and consultants on the unit highly enough. They were the true epitome of the 6cs through an incredibly tough emotional time, talking us through what was going on every step of the way. Sadly mum didn't make it but the care they showed myself and my family made an incredibly emotional time easier to bear. [250454]

My mother was admitted to ward 10 Stoke Mandeville hospital in late July and passed away in early August. During that time in this ward and the subsequent move to ward 5, her care was of the most exceptional standard. It was a privilege to observe. I spent 7 hours a day with her and witnessed from domestic to sister and everyone between, holistic care personal care and a very high degree of efficiency and attention to detail. My mother was treated with respect and great dignity and if I had to lose her, it was in a way that gave her last days on earth love compassion and comfort … The NHS is knocked all the time by various agencies, but it is only when witnessing it first hand on a daily basis for over two weeks can you really feel qualified to comment. [254484]

##### Following previous ‘failures’

Patients who had had earlier negative experiences of health-care services or encounters were also fearful of this being repeated and so were especially appreciative of experiencing ‘patient-centred care’ in which their needs were recognised and met:

My daughter … had many health complications … it has been the support of Suzi Kilroy and Annalese (health visitors) that has helped me get through a difficult 4-5 weeks …empathetic, excellent communication and quick to respond when I needed support and help. Excellent support given to my daughter and to myself where some health professionals have failed to recognise that support and help was needed. Thanks to both Suzi, Annaliesa and the student health visitor who gave me that comforting touch when needed! A fantastic team of health visitors! [244768]

We took our 2yr old son (to the Lincoln OOH service) … after being dissatisfied with the outcome from Newark MIU and out of hours service. Ian Haresign the Nurse Practitioner in the Lincoln out of hours team was the first person to truly listen to us and take the time to explain everything clearly. Thanks to him my son is now on the Paediatric ward having IV antibiotics for suspected mastoiditis. Thank you so much Ian for your outstanding professionalism and compassion, you are a credit to the service [222719]

##### Long history of symptoms/chronic conditions

Where patients have chronic conditions and/or a long history of treatment that has failed to ‘cure’ or ameliorate their symptoms, they may have low expectations of the efficacy of the attention they are still seeking and therefore be especially appreciative of receiving care which ‘puts them at the centre’. The first example refers to a dental patient who believes that genetics and an earlier experience of head trauma had led not only to many missing adult teeth consequent on calcium loss but also to serious mental health problems. Earlier implants, bridges and veneers had “helped immensely with my social phobia, self-esteem and confidence” while the treatment which formed the basis of the story posted on this occasion gave the patient “such a huge psychological boost”, by enabling the use of a guard which had been abandoned due to its inadequate fit:

Then what was very remarkable was that I had two occlusal guards one of which was a hard guard made by Croydon Dental Hospital to stop me grinding at night, many years ago. I had never used this as it caused a great deal of pain. When I had told Croydon this they had said take two aspirin and force it on. Dr Nasseripour told me this would have broken my veneers so instead of it being wasted she took a drill and saved the NHS about £50 to £100 in 3 minutes by adjusting it so it would fit. Thank you all so very much for your superb care, compassion and technical ability [234366]

The second example refers to a patient who has a 3 year history of an ongoing skin complaint that, despite “struggling on” through weekly consultations and various treatments, was “beginning to have a major impact on my day to day life”. A turning point comes with a specific GP at a new practice and a hospital referral but the prescribed anti-histamine has little impact and a recurrence of the condition brings the patient to her/his “wits’ end”. S/he wonders whether another medication to accompany the current one might help. S/he is delighted to get an appointment with the same GP and some joint decision-making ensues. This, together with the ‘keen interest’ shown by the GP sees the patient leaving the consultation feeling hopeful:

Again I explained the situation and again the truly marvellous lady that she is made a call to the Dermatology dept and as luck would have it she spoke with my consultant. A plan of action was agreed between Dr Murray and the consultant and a prescription for another drug was issued once advice had been sought. Again Dr Murray took a keen interest in me and my skin complaint which meant an awful lot. I left the practice feeling positive that both the medications would work. [264631]

##### Awareness of pressures on service

Being made to feel that you are still deserving of care as an individual in a context of pressures seen to be beyond the control of staff is also particularly appreciated and commented upon in some patients’ stories - as in first example below, where weekly visits to a busy maternity clinic by a woman experiencing “a rather eventful pregnancy” allow her to observe the dedication and patience of reception, maternity and nursing staff dealing “respectfully” even with “angry pregnant ladies” who are “exceptionally rude” to them. What may be ‘doing their job’ as far as the staff are concerned is experienced in this pressurised context as a level of personal care which is highly valued by the patient:

Keep up your awesome work, and thank you for helping me personally so far, to you it might just be doing your job, but it means a lot, especially when what should be a happy and joyous event is very scary. [202910]

The second example refers to a new born baby who required attention four times in the first four weeks of life. The mother is aware that there are babies on the ward with much more serious illnesses than her baby and appreciates the time, individual care and attention that they both received despite the demands this placed on staff:

Even though the ward had to deal with some serious illness with the babies, they still treated us with the same care, understanding and empathy no matter what was wrong with our daughter. [244769]

The final example is from a patient with mental health issues who appreciates the time and support given on a very busy unit:

I was admitted for 2 weeks and I can honestly say without them or CAS (crisis assessment service) I hate to think what would have happened. I want to really say thank you to Lucy and Michaela for their time and constant support at a very difficult time even though the whole team did a fantastic job, even when they were run off their feet. [213720]

#### Descriptions of what constitutes ‘person-centred care’

##### Being given time

It is self-evident that genuine listening takes time; and in descriptions of what, for patients, constituted ‘patient-centred care’, being given time was a significant component, whether it is the time to simply listen or the time needed to soothe and calm a patient. The first example refers to a call to 111, the next two to patients with mental health issues and the fourth, to a consultation with a psychologist:

Sometimes it's not just the illness why someone calls, often even feeling that someone listens makes patient feel better. Especially as GP often is forced in time and to not accept a long talk. [248131]

Vida gave me a lot of attention, and helped me to look at things clearly. Her calm and patient nature soothed me. The other was Waheed who treated me with respect and helped me to have confidence in my own recovery. This was invaluable and I took advantage of it as much as I could. [233754]

Those who have dealt with me have been very much appreciated for the support and time which they have provided during this period of being unwell. As someone who finds it hard to reach out for help, the team where possible have been understanding and tried to make communicating at this difficult time easier … A special thanks must go to Danny whose approach has allowed me to feel at ease and never rushed whilst being distressed and particularly unwell. His approach to his job makes communicating in difficult circumstances easier. [240284]

She really put me at ease and let me know at the start of the meeting that we had plenty of time to go over all of my issues. [229431]

Enabling pain management also takes time; the following examples all illustrate patients’ appreciation of being given time to address painful physical conditions:

I have been here before but never received the care I was given by Ian on this visit. He was knowledgeable about pain and how it affects you. He also listened to what was said so that meant questions I asked were answered so that I understood why I was having the pain and how to deal with it. He had time to complete the consultation without rushing it. I felt cared for. [259535]

Suffering from severe neck pain and with the meds for my GP having no effect my husband took me to Blackburn A&E. They were very busy and as soon as I was seen by the triage nurse she recognised my pain and made it her immediate priority… The staff nurse Ian Sturdy couldn't be more suited to his job. He showed compassion, patience, and humour. He made time to listen and talk to the patients in distress and nothing was too much trouble. What a wonderful ward [240457]

She was extremely supportive and helpful, information at fingertips, ideas to help my condition (arthritis), leaflets to support what she had said ( very useful as sometimes in a situation like this, things are forgotten), took time to go over suggestions at end of visit. Really impressed, as previous encounters with OT have been less than productive. [255631]

The final example refers to a ‘generous amount’ of time being given to assess, advise and reassure the patient:

We were astounded by the care, compassion and attention we received, particularly, that from the Consultant who spent a generous amount of time assessing, advising and reassuring my relative. He felt supported, listened to, cared for and safe. [251240]

##### Being given information and explanations

As obvious as it sounds, giving patients information about and explanations of what is likely to happen to them is integral to including them in (as opposed to excluding them from) their own health care and is therefore a vital component of person-centredness. The fact that patients comment on being given information and explanations in this context might suggest that it doesn’t always happen – and that they clearly value it when it does:

Attended the Memory Assessment Service at the Mansfield Community Hospital Seeing the same person throughout really helped as you didn't have to keep saying the same thing over and over and being given the information pack at the diagnosis was good as we could take it home and talk about it all as a family A real person-centred approach … [223410]

The Doctors in A&E were very patient and explained everything very well. I was admitted to Swinley Ward overnight and told by the consultant the following day that my pain was probably caused by a hiatus hernia and gall stones. [215685]

I went for a second opinion regarding shoulder pain I still had after 2 previous operations elsewhere. … Mr Bale and his team gave me a thorough explanation of everything and I felt as though I had been listened to for the first time in over 2 years! The relief I felt to be informed that I still had a problem with my shoulder and it could be fixed was immense as I had got to the point of thinking I was making up the pain I still felt. [233681]

I was referred to Mr Vathanan … for investigation of a uterine polyp … Mr Vathanan talked through the situation and the likely procedures and I also felt listened to. …I was referred to Heatherwood for a full hysteroscopy and resection of polyps as a day patient. Again, all the staff were excellent in explaining what to expect during and after the procedure, despite being clearly very busy, and I felt confident I was in safe hands. The consultant was Mr Furtado who came to speak to me before the op and again, I felt reassured by him and had my questions answered. The associated complications that could arise were fully explained by him before I signed the consent form. [260981]

##### ‘Holistic’ care

‘Holistic’ care may be seen as ‘person-centred’ in that it refers to treating not just ‘symptoms’ or seeing ‘a problem’ rather than a person, but to addressing ‘the whole person’. This means taking into account their broader psychological and social circumstances – and sometimes ‘treating’ the whole family. The first example refers to a consultation with a psychologist; the second shows how ‘reading between the lines’ and paying attention to social psychological as well as physical factors is seen to represent holistic care:

…what made the appointment a success in my view was that Dr Williamson actually listened to me and gave me the chance to fully explain my issues, both my personal issues such as anxiety, gender and sexuality issues, as well as my previous negative experiences with her colleagues. I actually felt my opinion was being valued and taken seriously and that I was seen as a person, not a problem. [229431]

I saw my GP, Dr Queenan, on a number of occasions last year because, since the breakdown of my long-term relationship, I had been having my period every fortnight. After our initial discussion, Dr Queenan agreed that I should have some blood tests and an ultrasound scan to check there was nothing amiss physiologically or chemically. However, he also ascertained that it was a very stressful time for me and that maybe I would benefit from some extra counselling… Dr Queenan really listened to my concerns and read between the lines to diagnose my needs. I feel he continues to view my issues in a holistic way in order to offer the best treatment. [207146]

The third example refers to ‘really understanding’ a family’s needs in order to offer services which contributed to greater family harmony; while the fourth illustrates supporting a mother by engaging also with her sons and partner:

Attended 1-2-3 Magic and Big Bag of Emotions. The service offered by Rachael and the team was excellent. Their approach to us as a family and their ability to listen and really understand our needs meant they were able to recommend the right help and support. The courses attended by myself and my son have helped beyond belief and have contributed to a much more harmonious family home! [238219]

I have 2 sons and both of them needs support in different ways. One of my sons broke his foot and he would not use the stairs outside our flat … with the reassurance and support that (school nurse) gave him, he did it and carried on to show her how well he could do. He then asked my partner can we go to the shops and he went down the stairs and walked to the shop. Bev was so patient with my son and this is a positive quality she has. For my other son she supported me through help with his bed wetting. She gave me a number of different techniques to try and she completed a referral to Enuresis service. Within 3 months he was dry at night and I no longer need to go and see the consultant. Bev has also supported me with a few other family issues and given me so much positive advice and support … If there was an award I could give to Bev it would be for being caring and putting people before herself. [229878]

The fifth example, featuring the same school nurse as above, also includes a number of other elements discussed earlier, such as information-sharing, unconditional acceptance and being non-judgmental, which all lead to the patient feeling better ‘as a person’:

Bev completed a referral to CAMHS and came into school and showed me what she had put into the referral. There was nothing that said everything that had happened was my fault this meant a lot to me has everyone else was saying I was asking for it and knew what I was doing. At no time has Bev ever judged me has a person she has always listened to what I have said and given me strategies and ways to cope… she will challenge me and ask me a little bit more but never ever says I am to blame… she was so positive with me she told me I looked really well and that she was so happy to see me smile. This has made me feel so much better in myself has a person I am now looking forward and not back… [239440]

#####  ‘Individualised’ care

Another theme constitutive of patient-centredness identifiable in patients’ stories is that of ‘individualised’ care. This sometimes means taking additional needs into account. One patient implies such individualisation when he speaks of a doctor who has “an obvious passion for doing what is right for every patient” [235071], while the next six patients (respectively, the mother of a young child; a patient who says they have ‘specific additional needs’; a patient receiving support from a City Crisis team; a mother who calls a dental service team her ‘saviours’ for enabling her son to access the treatment he needs; the mother of a daughter with a needle phobia; and a new mother of a premature baby with tongue tie) all refer to ‘individual’ or ‘tailor-made’ care, advice or treatment:

…the nurse, Geri, was very understanding and was absolutely brilliant with my wee girl. She undertook a thorough examination and was very reassuring … Geri’s clinical and communications skills were of the highest standard – person-centred care at its best. [236791]

Couldn't have wished for more respect and individual treatment. Staff showed empathy and listened to me [232886]

The support is person centred and tailored around me. [257426]

The team are amazing and I am so happy that he feels able to have this much needed treatment now to prolong his dental health ... I cannot thank the team enough for listening to him, working at his speed, not getting cross at all this little ways and questions and being my saviours [244414]

My daughter needed bloods taken. She has a terrible needle phobia … First time out of paediatrics and the nurses got her spray to numb the area before taking blood … They also promised to stock the local anaesthetic spray in future. They went the extra mile [214081]

You have the ability to listen and observe moms and babies and give tailor made advice, making moms feel confident and empowered to continue feeding their babies themselves. I have met other breast-feeding ‘guru’s’ who have been a little condescending and patronizing but you manage to get the balance of encouragement and advice just right. You manage to make each mom feel that they are important and that you have time for them despite the fact you are in incredibly high demand. [222868]

It is also notable that, in the last case above, there are once more references to being accorded respect and given time at periods of high demand. The next example demonstrates an appreciation of what the patient calls a ‘human and personal’ approach in that the doctor tailors his recommendation not to the medical indications but to his understanding, gleaned from listening, of the patient’s own current needs:

I was very nervous about my appointment as at 55 I was apprehensive at the thought of needing a replacement hip so early. Dr Elmeligy sat and talked to me about why I was there and then took me to see my X-ray. He was very kind, took the time to listen to me and explain the results. He spoke in a clear manner and in language I understood, no jargon. I felt comfortable and had every confidence in him. The most significant thing he said was that my X-ray suggested an immediate replacement but that they do not operate on X-rays but people and after speaking to me he felt it unnecessary, showing a human and personal approach. [237672]

Finally, some patients refer to being made to feel that they are the only ones being cared for:

Nothing is too much trouble, I am made to feel that I am the only person on the ward. They made me feel safe. [209253]

They make you feel like you are the only one they are caring for while you are there. [207490]

##### Starting where the patient is

Connected to the idea of ‘individualised’ care, but also compatible with what is known about professionals working in partnership with patients to effect change, is the need to ‘start where the patient is’. This is illustrated in the stories below. The first two show doctor/nurses taking the trouble to use language that the patient will understand:

He spoke in a clear manner and in language I understood, no jargon. [237672]

I have been supported at every stage by the breast care nurses, mostly Susan. They make sure that I understand everything that is said to me and if needed they will explain it in a different way so that I understand. [249478]

The third story concerns being supported by the ‘Social Inclusion and Wellbeing Service’ (SIWS) following a breakdown at work. The patient is reluctant to leave the house or mix with people and so is accompanied to a first meeting of a Women’s Group by a support worker:

They listened so well and seemed to know things about me that I didn’t know myself, and just understood me. Because they were not a doctor, or a family member, they were a lot easier to talk to. As I have problems answering the phone, they found other ways to communicate with me, by text or email. Nothing phased my support worker, so I was confident to tell her more. I am now more able to open up when I am at the Women’s Group. I was supported to keep appointments on the occasions when family were unable to attend with me. As there was no pressure to do things or to succeed, it made me want to do things … It was a very gentle, steady and consistent process, better than any medication. Having the support of the SIWS, especially on bad days, has given me back the confidence in myself to carry on. J and S were there not to judge, just to listen and come up with ideas … Ideas were put forward, and then I could pick them up when I was ready. … There is responsibility without pressure. … I have not been left alone in the world of Doctors and hospitals [239996]

And a patient at ‘Turning Point’ describes being encouraged to progress at their own pace:

People here make you feel safe and cared for, encouraged to improve without being pushed or rushed. Nurturing is the word I would use to describe Turning Point. [243404]

##### ‘Partnership working’/Shared decision-making

Partnership working and the shared decision-making integral to it is perhaps the ultimate in patient-centredness in that it rests not only on professional medical expertise but on a recognition of the patient’s own resources - and it seeks thereby to ‘empower’ the patient by capitalising upon these resources. It also presupposes some continuity and consistency of contact between the various people involved in the patient’s care (different professionals, patient, family members, carers etc.). The following two examples show evidence of good and not-so-good practice in this respect. The first story is posted by the parent of a son who has had mental health issues for the past 12 years, a period during which he has been sectioned and relapsed on numerous occasions. It reveals a lack (until recently) of effective communication with his parents, leaving them without information that would have helped them to support him back to health. Finally, a professional with dedicated responsibility for ‘collaborative care coordination’ enters the picture. The second story reads as a model of good practice in this respect:

Every time there was a relapse we were left to pick up the pieces with no help from the NHS trust (Nottingham). Although we knew of the crisis team, only two months ago did we learn that the team was proactive and could be called on before matters reached a crisis point …The latest relapse was caused by his wishing to again try to manage without meds - perhaps not an unreasonable request after two years - but the NICE guidelines say that this should be carefully monitored: it wasn't - he went for two months without supervision - by which time it was too late. This time, however, we have been much better informed and included in proceedings. The crucial link was Debbie - responsible for collaborative care coordination at Highbury Hospital. She has been able to draw us much more into the process and has set up meetings with the doctor. Also we have been introduced to a programme called 'Time to Talk' which has given us a means of voicing our concerns while our son is in hospital - an arena we have not previously had. Things are moving forward slowly - the diverse agencies seem to be coordinating a little better - but there is still some way to go! [249967]

Today I received a letter from Dr Clare Willocks at NHS Lanarkshire regarding my recent appointment with her to discuss my need for treatment in Lanarkshire for Early Menopause. A few weeks ago I got a similar letter from Dr Pererra at NHS Greater Glasgow. Both these letters have been circulated to all professionals involved in my care - and most importantly have also been sent to me. They communicate where we are currently at with regards to my care and treatment, and also future plans going forward. I have never before experienced this - actively being included in communications between health professionals regarding my care. I think it is excellent and really demonstrates that I am the person at the centre of my care package. I am involved as an equal partner in making decisions moving forward … So thank you Dr Pererra, Dr Willocks, Dr Gemmill for the excellent person centred care that I am receiving, and thank you Patient Opinion for helping me to not only access the right treatment - but hopefully helping other women access better care and treatment. [221159]

Other stories speak for themselves in describing and valuing partnership working:

My 84 year old mum was admitted to Raigmore Hospital as an emergency and was in hospital for a week before getting home … This is clearly a very busy but exceptionally well run hospital with all professionals working together and the patient and family as equal partners. Visibility of senior managers was very good. Now we are back home and the follow up care has already kicked in. [247643]

I was treated at St. John's hospital and referred to the physiotherapy department by the orthopaedic surgeon … Grace (who) has taken me through 4-5 months of intensive physiotherapy. She has walked with me through my journey of rehabilitation with great kindness support and with a real person centred approach to her care. When I became down she kept me going with her smile and encouragement and real determination that I could maximise my rehabilitation. Yesterday we both agreed that I would be discharged from her care - please note 'both agreed'. [233433]

The nurse, Izzie, listened to my concerns and took them seriously, she assessed my father thoroughly in a professional and extremely respectful sensitive way- the only one to treat him like an adult rather than a naughty child. She very quickly put a sensible and realistic treatment plan in place, ensured that it was implemented and kept me informed throughout the process. I felt that she really valued and embraced partnership working with patients and carers. My father is now recovering and thankfully cannot remember the worst of his experience. I am not convinced that he would have recovered if it had not been for Izzie. [264630]

##### Core Values

Although the values underpinning person-centred care have either been referred to or have appeared implicitly in the foregoing stories, they perhaps more commonly appear in social care and community-based contexts. And yet there is no reason why they should be exclusive to these settings or should not also underpin the delivery of primary and secondary medical care. Below are stories which act as reminders of these values by illustrating acceptance; being non-judgmental; and patient/client self-determination.

When my daughter was born she required some additional care for jaundice, reflux and other allergies….they helped with breastfeeding, bathing and gave excellent emotional and physical support to myself (mum) making time and effort to sit with me and discuss options. As a new mum some options were difficult, the nurse remained neutral and professional at all times [244769]

J and S (Social Inclusion and Wellbeing Support service workers) were there not to judge, just to listen and come up with ideas. [239996]

My Wife gave birth in the Midwife led unit 3 weeks ago and I feel it is important that their hard work and caring attitude should be noted. The staff were excellent all day and night, at an incredibly busy time. They ensured that my wife was comfortable throughout and that she followed the birth plan she desired. [254930]

I was struggling for a number of weeks and had a fair bit of contact with CAS (crisis assessment service) at my home and on the phone in particular Laurence. The way in which I was dealt with by everyone I spoke to was friendly, listened and didn't judge what I was going through. [213720]

I have recently had sex reassignment surgery (I am a transsexual man) and had been catheterised for a week. I am a disabled man who is bed-ridden and has extremely limited mobility. I had many, many problems with the catheter, and both the district nursing team and the rapid response team were beyond amazing. They were all incredibly kind, open-minded, gentle and patient. [243265]

I was admitted to Whitchurch following a stay in the crisis house after an overdose I went voluntarily to Whitchurch as I knew I was no longer safe to myself in the open house. I found all staff (bar 1) to be helpful, non-judgemental and willing to listen and support I honestly had a negative view of going into the hospital but wanted potential service users to know it’s not as bad as it may seem and I really think it has helped on my road to recovery. [252707]

### Impact

Having described patients’ experiences of being listened to, included in decision-making and put at the centre of their care; outlined the contexts in which such experiences did or did not take place; and analysed what the components are of patient-centred care that patients valued and benefitted from, we turn now to identifying what these benefits are – what is the impact upon patients and their health of such experiences?

#### Feeling valued

What is immediately evident from patient stories is a psychological or emotional impact – they feel valued and cared for:

Angela, the community nurse has been a great support regarding how to get referred to the ENT for my son. She listened carefully to my concerns and acted really quickly in getting Julie to support me through the process. Her support is very appreciated and I felt valued- that my voice was being heard. [251685]

I felt as a Volunteer that the Trust in general hold our views in high regard… [247300]

I had an appointment at Victoria Infirmary in Northwich to see the endocrinologist. I am delighted to say that the Consultant really listened and empathised with what I was saying, instead of rushing me. I felt really valued as a patient and that the Consultant was really trying their best for me. [206805]

He … listened to what was said so that meant questions I asked were answered so that I understood why I was having the pain and how to deal with it. He had time to complete the consultation without rushing it. I felt cared for. [259535]

#### Confidence (in service/own recovery)

Just as the negative experiences outlined earlier destroyed patients’ trust in services, positive experiences of being listened to etc. created confidence. The stories below show that impact in this respect can include both confidence in service delivery and any future diagnosis and treatment that may be required and confidence in oneself and the prospects of recovery:

The work that Mr Howe and Professor Palmer did helped immensely with my social phobia, self-esteem and confidence which had all been 'hit’ by the TBI. [234366]

I was admitted to Queen Mary's in Roehampton in January 2014 and stayed for 2 months. I was having a manic episode - the first in 11 years … Vida gave me a lot of attention, and helped me to look at things clearly. Her calm and patient nature soothed me. The other was Waheed who treated me with respect and helped me to have confidence in my own recovery [233754]

My Mum has attended the Mansfield Memory Assessment Service and during this time she has had Gold Service and has met people who listened to her and they have given my Mum a lot of confidence. [223404]

Attended the Memory Assessment Service with my wife. We were treated well, given the time to ask questions and felt listened to. I can't think of anything to improve the service it was very good and the best thing was that my wife will now get diagnosed properly [216399]

I saw a young male GP for an appointment who was very attentive … I felt I could back to him again & always get the help I need. [215917]

(At a physiotherapy service :) Was reassured by patient caring assessment of my condition - listening and analysing together with viewing x-ray helpful and boosted confidence for any future treatment I may need … [232855]

#### ‘Normalising’

Related to the kinds of contexts referred to earlier which are ‘sensitive’ in one respect or another (e.g. where patients feel at risk of being stigmatised, where ‘specific’ or ‘additional’ needs are present, where patients fear being seen as time-wasters, or where their symptoms have made them feel very unlike themselves), receiving ‘patient-centred’ care clearly enabled some patients to feel ‘normal’. The impact here, then, is of a ‘normalising’, ‘validating’ or ‘legitimising’ nature:

Staff within A&E were very professional and caring, respecting my specific additional needs and making me feel like a 'normal' patient. Couldn't have wished for more respect and individual treatment. Staff showed empathy and listened to me. [232886]

I went to bed early last night and woke up from sleep with extreme confusion. I didn't recognise my husband's face or where I was. This kind of episode had happened before to me, but not for as long as this… By the time a paramedic arrived I was much more "with it" and felt like I was wasting his time a little but he assured me that I wasn't, thoroughly checked me over and took his time talking to me. I have had a few experiences with paramedics in the past who have been unsympathetic at best, but I could tell that this man really cared about my condition … I was amazed by his friendliness and compassion and I didn't feel like just another call out, I felt like I really mattered as a patient. He didn't play down my condition, or make me feel like I was being silly. [228311]

Two years ago I posted about fighting to get the right treatment to help me manage my early menopause. A lot has happened in the last 2 years - and finally I have been given access to the right treatment option for me. I am certain that this would not have happened if it had not been for Patient Opinion and the ability to communicate directly with the people who needed to hear my voice. I now understand that my GP and even Consultant were equally as frustrated as me at the lack of care available for women such as myself. My medical team Dr Gemmill and Dr Perera have been truly wonderful in supporting me on this journey. I received a telephone call on Friday from a lovely member of the pharmacy team at Wishaw general to advise me that they now have my medication available in Lanarkshire and that my care will be transferred to Dr Willocks at Hairmyers. This is excellent news - I will however miss Dr Perera and his wonderful manner. A true gentleman who truly listens to his patients and has worked with me to optimise my health & well-being … My health & well-being has been the best it has been since my surgery 6 years ago. I feel "normal". [249866]

As a child and now adult with learning disabilities and physical disabilities I have worn a splint on my leg and each time a new splint was made a new pattern followed. But as I reached adulthood and moved to adult services for orthopaedic services I took one look at the so plain boring white plastic splints and … so I have made it my goal every time I get a new splint I ask for butterflies on my day splint and a space theme on my night splint … It should be like getting a pair of shoes you should be shown a pattern or colour catalogue to make a choice. Life should be fun and healthy. Not dull and full of stress. Most of the time when I have asked the member of staff, they have been nice, open and honest about my choice and not been nasty… I am getting measured for a new day and night splint soon I hope it goes well and that my needs are met and listened to. [234566]

#### Empowerment/self-management

In the following stories, the impact is more ‘agentic’ – patients feel ‘empowered’ to achieve something – whether that is achieving the kind of giving birth they had chosen, finding the right route to the help needed, motivating a child or enabling patients to actively manage their own health in some tangible way. In some cases, there is a positive impact on family relationships and functioning too

##### Empowered

My husband and I recently had a wonderful birth experience with the home birthing team of the Royal Surrey Hospital and one of the senior midwives, Sally Stainer who runs a Hypnobirthing course at the hospital….As a first time mother I was understandably apprehensive about having a baby but having attended the Hypnobirthing course run by Sally Stainer at the RSH I felt hugely empowered and excited about the prospect of having our child in the comforts of our own home… Using the Hypnobirthing methods I had my baby at home with the use of a birthing pool and cannot express enough how positive the whole experience was… we were supported by the RSH homebirthing team … all three of whom were amazing and made the birth the most wonderful, calm and empowering experience … All three also provided my husband with the support and encouragement he needed to truly participate in the experience [240677]

I was lucky enough to have the same midwife for the entire labour and delivery. At all times I was listened to and felt safe and empowered … helped to feel 'normal' and have nothing but praise for the whole unit. [249676]

After the birth of my second child I was feeling quite low in my mood, isolated and confused about day to day life. It was suggested I attend ‘Making the most of Motherhood’ course. I wasn't sure what to expect but I was pleasantly surprised. It was a valuable course where I met other mothers in similar situations. I learnt how to manage my mood and be a bit more optimistic. It put everything into perspective and I feel has given me a better relationship with my children and partner. [268539]

I have been experiencing some very personal problems lately and when I was let down by my GP … I have turned to the 111 service. Although I was not sure they would be able to help me with my symptoms (a lump in my private parts) I have had a lot of reassurance and advice from all of the advisors I have spoken to in the past two days. They all tried to find locations I could attend to get checked out and explained everything to me - I was even put through to a clinician who was absolutely amazing and took all the time to help me. Me being a student nurse myself, I am very pleased to see the effort all the health advisors put in to enable and empower a patient. [264919]

In relation to the breast feeding support you have given to my son and I, I’m not sure we would still be doing it and so successfully without your help …You have the ability to listen and observe moms and babies and give tailor made advice, making moms feel confident and empowered to continue feeding their babies themselves. [222868]

##### Motivating

Really friendly and encouraging to children! Listens and motivates well to make the experience good. [244410]

##### Greater self-management

I came to Crisis Point feeling hopeless. I now feel I have the tools to improve my quality of life … The staff have empowered me to deal with different situations through their individual skills & techniques. I feel like a different person leaving here today. [243398]

Helped me through anxiety issues I've had for some time. Helped me to identify the problems and deal with them... [209454]

Lizzie (Inclusion Matters) was really helpful and understanding. She listened carefully to the problems I was having, understood my condition when I didn't completely understand myself and then helped me develop personalised skills to cope and progress in my day to day life. [210635]

(Inclusion Matters) Service has been useful and beneficial to me. Made me feel calmer in approaching the problems/issues I have. Judy has listened and helped me see things clearer. I do feel more able to approach the ongoing problems with less irrational and spur of the moment behaviour. [210637]

Months of anxiety, sleeplessness, fear of failure – I was so wound up. I had physical symptoms and was referred to A&E – to rule out the possibility of strokes … my GP referred me to Inclusion Matters. My confidence was low, I felt stupid and useless … I started CBT therapy. Working life is still pretty awful but CBT started to help me find solutions and challenge my own thinking and seek alternative views. I have a little tool-chest of techniques now. [220361]

(Rightsteps) made me understand better how I feel and always looked on the black side of life and worried too much about everything and everybody else except myself. Changing things now. Mark was fantastic, he gave me the space and the security to expose and work through my issues. I really appreciate the help and techniques he gave me to work with … The service met my needs in a holistic manner and addressed my issues more than I was expecting and has helped me to develop coping mechanisms [243406]

#### Resilience

Borrowed from social work/care, the term ‘resilience’ is defined as ‘the ability to withstand or recover from difficult conditions’. The concept has been expanded upon, professionalised and augmented into a theoretical framework widely referred to as the ‘resilience construct’ (Luthar et al. 2000, Ungar 2004). This framework seeks to explain why many individuals, irrespective of the presence of a variety of psychosocial (and health/illness-related) risk indicators in their lives, are able to adopt resourceful strategies which have the effect of attenuating negative (health), social and cognitive experiences (McMurray et al, 2008).

By their own accounts, the self-management ‘techniques’ acquired by some of the patients above are likely to lead to greater resilience in the future. In other cases, patients recount what might be described as enhanced ‘resilience’ in so far as a desired state of affairs becomes established or is continuing beyond initial early stages of a recovery or a regime). Patients talk of ‘coping’ (when they wouldn’t have done so without the care received) or of having become ‘stronger’ or of not giving up:

When my daughter was born she required some additional care for jaundice, reflux and other allergies … they helped with breastfeeding, bathing and gave excellent emotional and physical support to myself (mum) … We don't know how we wouldn't have coped without the help of all staff on the ward … [244769]

Amazed at what a difference Crisis Point has made for me. …they’ve changed my life and my family’s … thank you all for helping me and making me a stronger person. [243399]

I called the service as I was having difficulty breastfeeding my 1 year old since his teeth had come through. I thought our feeding journey was going to have to come to an end … I am still feeding now my son is 16 months with no plans to stop soon. [258322]

#### New (quality of) life

Especially when patients’ positive experiences of being listened to, included, enabled, or put at the centre of their care as described above, follow long-term conditions or occur in a context of having complex needs, the beneficial impact consequent on this care is expressed as giving them a whole new life. Again, this can be on a spectrum from facing the future with greater hope, through looking forward rather than back to earlier traumatic events, to ‘turning one’s life around’ in terms of greater social inclusion in relation to employment, housing, marriage and parenting:

I have been treated like family and my concerns are always listened to. The (orthopaedic) staff are great. God love 'em cos I do, for sure. They give me hope. [206520]

Bev (school nurse) has also supported me with a few other family issues and given me so much positive advice and support. I am just about to start a new life in a new home in a new area and this is all down to the support, advice and encouragement from Bev. [229878]

The school nurse started to work with myself following an incident that happened to myself which is very sensitive. This has made me feel so much better in myself has a person I am now looking forward and not back. [239440]

I first came to Sure Start shortly after having my first baby girl … was ready to leave with the feelings that I never wanted to go back … then a member of staff came behind me as I was leaving to see if I was ok, clearly noticing I wasn’t … She was a support worker … the worker came in for a coffee and a chat … She sat back and listened … I was probably more petrified on my second (child) as I felt I couldn’t cope with the first … I still saw my family support worker and decided to give Sure Start another go … My family support worker was leaving so she introduced me to a new family support worker. She was just as kind and supportive. I got offered a lot of support and guidance by her. I was having doubts at the time about keeping my youngest. I loved her so much, but at that time I didn’t think I did, or could cope … The girls attended crèche and I felt happy and confident to leave them. I made more friends and my confidence was growing. I was feeling happier within myself. Things were getting thrown at me too but I felt I could cope with the help I was receiving … With support from the support worker, I did a CV and handed them out. I eventually got a job. Now I am a working single mum and couldn’t be happier. [208248]

I suffered intense emotional abuse from my husband towards the end of a lengthy marriage. This affected my mental health and the health of my children, despite being young adults. I was referred to Right Steps at a very low time in my life, having little fight left, very low self-esteem and no confidence whatsoever … reluctantly embarked on a course of CBT. Wow, what can I say, it turned my life around. It’s not a quick fix and probably doesn’t make much impact straight away, but it teaches you how to deal with all the crap that life throws at you. Since then I have picked myself up, brushed myself down, gained enough self-esteem to finally divorce, eventually met someone else and re-married. I know that sounds like a fairy tale ending, but believe me it was a bumpy ride. However, my point is that sometimes taking a step back, re-evaluating your life and gaining the strength through counselling … [254462]

#### Changes made by professionals

Finally, the changes services make in response to the stories posted in Patient Opinion are themselves an example of listening to patients, valuing their experiences and putting them at the centre of their care. A nice example, posted by a staff member on behalf of service users, comes from a forensic mental health service:

Patients were asked for their opinions on how we could improve their experience of the service. The following suggestions were made during a September community meeting: 1. We would like a pet rabbit to look after this would be therapeutic. 2. We would like to review the ward manifesto to better suit the current patient group and promote respect for one another. 3. Please also consider creating a sensory room for the ward.

1. The appropriate equipment has been purchased for the rabbit, so now it is just waiting for a risk assessment and a policy to be written up. Once this has been done we will set up the rabbit with the local vet prior to it coming onto Seacole.

2. The current manifesto no longer suits the needs on Seacole. So during Community Meeting the ladies evaluated with a new manifesto devised to suit those who are currently on the ward. This is now displayed in the communal area.

3. We now have a sensory room that is up and running thank you to the ladies who helped set it up by painting walls etc. It has been a great addition to the ward. [250830]

## Conclusions

The stories which recount negative experiences (of not being listened to, involved, enabled etc.) were associated with a number of factors, the first of which was an unprofessional attitude on the part of staff that took the form of being disrespectful to patients. This included talking about them disparagingly in their own hearing and being cold, ‘frosty’ and unhelpful. In such cases, the risk is not only that trust in a service may be damaged but that ‘inappropriate’ subsequent demand on services is created.

Secondly, there were issues to do with the exchange of information. Professional medical expertise rests on epidemiological knowledge while lay expertise rests on a deep and intimate familiarity with the singular; as one patient observed ‘I know my own body’. Stories about not being listened to in relation to information-giving emphasised the failure of some clinicians to recognise that patients might be able to tell them something important. In some cases, the patient admitted to not being very articulate, and in such circumstances there are no doubt specific skills that need to be acquired and deployed by professionals to enable patients to participate in their care in this way; a necessary precursor to this, however, is an attitude that recognises the legitimacy of patients’ knowledge. Where patients recounted negative experiences in respect of information-giving, adverse outcomes ensued, including unnecessary distress and ‘allergic’ reactions. These are relatively ‘mild’ incidents compared to what can happen in such circumstances.

It is hard to know how to interpret accounts which describe patients being told that they are not ill or not in need. There may be a clue in one such example, in which a patient is effectively told that they are not ill enough to warrant the attention they were seeking. Such accounts can be set in a context of rising demand on services and the informal ‘rationing’ which inevitably occurs. Nevertheless, there are more effective ways of communicating an inability to meet the patient’s expressed needs – or of being unable to meet them immediately. In the case of a refusal on the part of professional to respond to a (diabetic) patient’s request unless and until he complied with their requests (for blood); and that of the patient who had failed to watch a recommended DVD because she was struggling with the prescribed treatment it featured, we can see even more clearly instances of competing assessments of priorities. ‘Non-compliant’ patients may sometimes be seen as truculent, un-cooperative and difficult to manage by the professionals trying to help them but the conflict which arose in these cases goes against all that the evidence tells us about effective methods of enrolling patients in regimes of behavioural change (including ‘starting from where the patient is’).

Examples of being excluded from decisions about one’s care (in these instances, being discharged from long-term out-patient care with no explanation/consultation) had something in common – a new/locum clinician who did not have an ongoing relationship with the patient. In one such case, posting the story on the Patient Opinion website resulted in ‘misunderstandings’ on both sides being resolved to the patient’s satisfaction. More broadly, however, a context where continuity of care is increasingly unavailable only serves to emphasise the need for shared decision-making between clinicians, patients and the teams who have known them over a more sustained period.

Situations in which patients particularly appreciated being listened to, involved and ‘enabled’ (‘sensitive’ topics such as those to do with intimate areas of the body, or end of life care; potentially stigmatising conditions; negative prior service encounters; and chronic and sometimes intractable conditions) hint at some of the values that underpin what is referred to as ‘person-centred’ or ‘patient-centred’ care – values that are spelled out more explicitly in other stories. They are: acceptance; being non-judgmental; and patient/client self-determination. If we include patients’ recognition of the pressures that medical and health professionals are subject to at work which permeates so many of the patients’ stories, we might add ‘mutual respect’ to the list.

It is in the context of this recognition that patients’ genuinely expressed appreciation of the factors which contribute to their positive experiences of patient-centred care can be set; elements such as being given time, being given information and explanations, not only being seen as a person as opposed to a problem but as a ‘whole’ person in all their bio-psycho-social dimensions. Where ‘good practice’ follows from this, patients describe ‘individualised’ or ‘tailor-made’ care. Further, they are enrolled as participants in their care, who have their own resources (including, but not restricted to, their knowledge of their own bodies referred to earlier) to bring. ‘Partnership’ working and ‘shared decision-making’ are examples of recognising, enhancing and/or tapping into patients’ own skills, abilities and resourcefulness and the consequences of this as described in these stories were universally positive. They stretched from positive feelings of being valued and cared for; through increased levels of confidence in services and in patients’ own potential for recovery, feeling ‘normal’, motivated and ‘empowered’; to greater self-management, leading in some cases to a whole new (healthy) life.

It is obviously a function of the sample analysed here that many of the stories of empowerment, enhanced self-management and in some cases a trajectory which took a patient from (for example) being depressed, anxious and unable to leave the house, to being a healthy, functioning, socially engaged, fulfilled and happy person were drawn from mental health service users and community-based practitioners. This should not be seen to limit the applicability of the ‘findings’ to the wider population of patients and clinicians. What is good practice for mental health patients is good practice for all.

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## Appendix: sample by service type

1. Adult Mental Health Services 40

2. General Medicine/General Hospital 29

3. GP (including OOH) 18

4. A&E 14

5. Trauma & Orthopaedics 13

6. Maternity care 7

7. Memory Clinic 6

8. 111/NHS24 6

9. Community/District Nursing 5

10. Children/Family/Motherhood Support Services 5

11. Surgery 5

12. Physiotherapy 4

13. Dental 3

14. School Nursing 3

15. Paediatrics 3

16. Emergency Ambulance 3

17. Gynaecology 3

18. Contraception & Sexual Health 2

19. Drugs & Alcohol Services 2

20. Health Visiting 2

21. Cardiology 2

22. Rheumatology 2

23. Older people’s health care 2

24. Gastroenterology 2

25. Podiatry 1

26. CAMH 1

27. Social Care 1

28. Dermatology 1

29. Minor Injuries Unit 1

30. Oncology 1

31. ENT 1

32. Bladder & Bowel (Independent Sector) 1

# Appendix B: 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).

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, or call 0114 281 6256.

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<https://www.nice.org.uk/guidance/CG76/chapter/introduction> [↑](#footnote-ref-1)
2. Coulter A, What patients want from their clinician, Talking Differently, HEEoE Health Coaching Conference, November 2014 [↑](#footnote-ref-2)