The NHS Constitution highlights the importance of good communication in order to build trust between healthcare providers and patients and their families. Despite this, poor communication is still one of the most common reasons for people to bring complaints about the NHS to the Ombudsman. Poor communication during care or treatment can be compounded by a health body’s failure to respond sensitively, thoroughly or properly to a patient’s complaint – resulting in an overall experience of the NHS that leaves a patient or their family feeling that they have not been listened to or that their individual needs have not been taken care of. Poor communication can undermine successful clinical treatment, turning a patient’s story of their experience with the NHS from one of success to one of frustration, anxiety and dissatisfaction.

Good communication involves asking for feedback, listening to patients, and understanding their concerns and the outcome they are looking for. It is about keeping patients and their families informed and giving them clear, prompt, accurate, complete and empathetic explanations for decisions. Issues of confidentiality, insensitive or inappropriate language, use of jargon and a failure to take account of patients’ own expertise in their condition feature frequently in complaints.

When the NHS fails, it is not always easy for patients to complain. We hear regularly of patients’ fears that complaining will affect the quality of their future treatment, or single them out in some way. Patients and their families need to be encouraged to speak up and give feedback, and be confident that their experience will be listened to. When they do complain, the NHS must properly and objectively investigate the complaint, acknowledge any failings and provide an appropriate remedy. Most often this is simply an apology, but it may also include an explanation, financial redress or wider policy or system changes to prevent the same thing happening again.

In last year’s Listening and Learning report, we told the stories of people who had a poor experience of NHS complaint handling. We repeatedly found incomplete responses, inadequate explanations, unnecessary delays, factual errors and no acknowledgement of mistakes. These all too familiar shortcomings remain amongst the main reasons which complainants give for their dissatisfaction with NHS complaint handling, as Figure 2 on page 29 shows. Opportunities are being missed to learn lessons which have the potential to improve services for others.

Over the next few pages we recount the experiences of people who suffered as a result of poor communication or who were left dissatisfied, frustrated and distressed with the way the NHS dealt with their complaint.
Ignored and excluded from their son’s care

Mr L was 21 years old and had severe learning disabilities. He had a polyp removed from his stomach at Luton and Dunstable Hospital NHS Foundation Trust (the Trust). He was discharged but was readmitted the next day and had a tumour removed from his colon. Despite some improvement, Mr L’s condition worsened. After further surgery, he died a few days later.

Mr L’s parents, Mr and Mrs W, were the experts in their son’s needs, but they felt excluded from his care. They said ‘even when we kept telling the nursing staff that we thought he was worse we were ignored’. Had the consultant talked to them about discharging Mr L, they could have explained ‘that he was still feeling sick and only wanted to go home because he did not like being in hospital’. They only learnt that their son was having more surgery when he was about to go into theatre, and were not told what the surgery involved. Unaware just how ill their son was, Mr and Mrs W were not with him when he died. This greatly saddened them. They told us that ‘if the doctors had listened to our concerns and noted all the symptoms we had told them of, we feel that his colon cancer would have been diagnosed … and this may have given him a chance of survival’.

The Trust should have taken Mr L’s learning disability into account while making decisions about his treatment, for example, by involving Mr and Mrs W or the learning disability liaison nurse. Our investigation found that the Trust did not. The consultant wrote to Mr L’s doctor saying that ‘[Mr L] was a very poor historian and I really could not tell what was going on. [He] was mentally sub-normal…’ He apologised to Mr and Mrs W for this extraordinarily inappropriate description which had understandably upset them.

The Trust took action to ensure greater involvement of families and carers in the care of patients with learning disabilities, and agreed to commission an external review of their care of such patients. They apologised to Mr and Mrs W and paid them £3,000 for the injustice caused.
Kept in the dark about their father’s illness

Mrs K’s 85 year old father had recently had cancer surgery at Gloucestershire Hospitals NHS Foundation Trust (the Trust). He fell the day after he was discharged, and was admitted to the Trust’s Cheltenham General Hospital. A Do Not Attempt Resuscitation (DNAR) order was made and then Mrs K’s father was moved to a different hospital for palliative care. He developed pneumonia and was moved back to Cheltenham General Hospital, where another DNAR order was made. He died a few days later.

Mrs K complained to the Trust about the level of consultation over the DNAR orders. She was also upset that doctors had told her that her father’s condition was not immediately life threatening, when the death certificate showed that he had terminal bladder cancer. Mrs K said ‘the deeper the investigation went the more discrepancies became apparent’. She was ‘concerned that other elderly people might encounter similar experiences’ and that she ‘would like to prevent more serious outcomes for those who do not have relatives to advocate on their behalves’.

Our investigation highlighted the importance of good communication with patients and their families. We found that Mrs K’s father should have been informed about the severity and finality of his condition and asked if he wanted his family kept updated. Instead, his family were generally kept in the dark about his illness and his deteriorating condition. The level of communication with doctors about his condition did not meet the family’s needs, and the family were given limited information about the DNAR orders, which upset them greatly. Mrs K said ‘not consulting my father or I was both disempowering and insensitive’.

Following our recommendations, the Trust drew up plans to provide communication training for medical and nursing staff. The Trust also paid £1,000 to Mrs K and her family, which they donated to a hospice.
Expert patient’s requests for medication ignored

Mrs V had an operation at the Croydon Health Services NHS Trust (the Trust – formerly Mayday Healthcare NHS Trust). After a previous operation there, she developed blood clots because the Trust had not properly managed her anticoagulant medication. This time, she was worried about not receiving the right medication, so the Trust agreed that she could go home on the day of the operation and manage her own medication.

However, the discharge letter explaining this did not reach Mrs V’s ward and she was kept in hospital overnight. Staff did not deal with her anxious requests for her anticoagulant medication. As Mrs V’s husband said, ‘my wife fully understands her need for correct daily medication … She “knows” her own body well’. He felt ‘petrified’, ‘helpless’ and fearful that his wife’s life was in danger.

Just days after Mrs V was discharged she returned limping and in pain. She was readmitted to hospital and found to have blood clots. Mrs V had to use crutches for several weeks, and relied on her husband to do everything for her.

When we investigated, Mr and Mrs V said they were pleased that finally ‘someone was actually listening to us’. We found breakdowns in communication about Mrs V’s discharge and her medication, and a succession of failures in her care. All of this increased her risk of developing blood clots. The Trust failed to acknowledge that Mrs V had been readmitted to hospital and that the lack of her medication might have contributed to this.

Eventually the Trust apologised to Mr and Mrs V for their poor care and treatment and for their complaint handling. They also drew up plans to prevent the same mistakes happening again, including introducing guidelines for prescribing anticoagulant medication. The Trust also paid Mrs V £5,000 for the injustice caused.
Failure to understand a life threatening condition

Mr T was left paralysed in all four limbs after he damaged his spine. He also has an uncommon and life threatening condition called autonomic dysreflexia: a sudden and exaggerated response to stimuli. An episode is a medical emergency and early treatment of the symptoms is crucial.

Mr T was visiting a garden centre with his wife and nurse when he noticed the symptoms of an autonomic dysreflexia episode. He was taken to a hospital run by North Bristol NHS Trust, accompanied by a paramedic from Great Western Ambulance Service NHS Trust. According to Mr T, the paramedic appeared unaware of the importance of early treatment, and the triage nurse in A&E was also unfamiliar with his condition. Mr T described ‘two hours of unmitigated hell and anxiousness’ as he waited longer than he should have to see a doctor.

Mr T complained to us that both Trusts failed to understand and deal with his condition appropriately. He said he did not want individual members of staff ‘hauling over the coals’ as all he wanted was to raise awareness of autonomic dysreflexia. Although a rare condition, people with a spinal cord injury worry that it is not known about.

We swiftly resolved the complaint and there was no need for a formal investigation. Both Trusts met Mr T to discuss how to raise awareness of autonomic dysreflexia. Mr T later told us that someone he knew with a spinal injury had recently been taken to hospital, and had been impressed and surprised to be asked if she was susceptible to autonomic dysreflexia. In Mr T’s own words: ‘evidently the educative information about AD [autonomic dysreflexia] given to their staff by the two Trusts has had the desired effect’. This was exactly the outcome he wanted.
Left feeling that ‘complaining gets you nowhere’

Mrs Q takes medication daily for a kidney disease and always carries the medication in her bag. While Mrs Q was an inpatient in Guy’s and St Thomas’ NHS Foundation Trust (the Trust), a pharmacy technician asked her if she had brought her own medication with her. Mrs Q said ‘yes’, and the technician told her she was not supposed to have any drugs with her. Mrs Q said she had not realised this and handed over all her medication.

The next day, the same technician asked Mrs Q where her medication was. She replied that she did not know, having had no access to the drug cabinet by her bed. The technician then insisted that Mrs Q empty out her bag, in front of other patients and nurses. This embarrassed and upset Mrs Q.

Mrs Q complained that the technician had been disrespectful to her, as she had ‘belittled me and made me look like a thief’. She wanted the technician to apologise and felt the Trust had not handled her complaint well. She told us she had no idea what the Trust had done following her complaint and if they had disciplined the technician. This meant she had no reassurance that the member of staff involved would not cause similar problems in the future. She was left feeling that ‘complaining gets you nowhere’.

Following our intervention the Trust sent Mrs Q a more detailed response to her complaint and apologised for the technician’s behaviour. They also told her that they had taken disciplinary action against the technician. Mrs Q was very satisfied with this outcome.
A flawed investigation into an alleged assault

Ms J has a borderline personality disorder, which means she sometimes has little physical or mental awareness. During a therapy session at Avon and Wiltshire Mental Health Partnership NHS Trust (the Trust), Ms J became distressed. She went into a nearby room and lay down on the floor under her coat. Later, a clinician called in two security guards to remove her and one of them allegedly kicked Ms J.

Ms J complained to the Trust that she had been assaulted, saying that after the incident her ‘levels of distress were massive’ and she had thought of harming herself.

The Trust took nearly a year to respond formally to Ms J’s complaint. Our investigation uncovered serious flaws in the Trust’s two investigations into the incident. Neither was independent or thorough. The Trust did not take statements from all the key witnesses, nor seek advice about the wisdom of calling in security guards given Ms J’s condition. The Trust’s formal response to Ms J lacked authority because it was not signed by the chief executive or nominated deputy, as required by the Trust’s own policy, and made no mention of any potential learning for the Trust. The Trust’s response did not give proper respect to Ms J’s account of events. She felt bewildered and frustrated: ‘It was bad enough being kicked by the security guard. It has now all been made even worse by a very unsatisfactory complaints process’.

In line with our recommendations, the Trust apologised to Ms J for the considerable distress and inconvenience they had caused her, and paid her compensation of £250. They also agreed that their executive board would consider our investigation report, and that they would commission an independent review into their complaint handling function.
Mr C’s sister died during palliative chemotherapy at East and North Hertfordshire NHS Trust (the Trust). Mr C described the impact of her death on his family as ‘immense’ and said his surviving sister had ‘not only lost her sister but also her closest friend and soul mate’.

Dissatisfied with the Trust’s response to his complaint, Mr C came to us because he wanted to know exactly what had happened during his sister’s final hours.

Our investigation did not uphold Mr C’s complaint about the Trust’s care of his sister. However, we found very poor complaint handling. The Trust did not review the clinical notes promptly and clarify events while key people’s memories were still fresh. Some written statements taken by the Trust were undated and unsigned, other sources of information they gave to Mr C were unclear, and still further information did not tally with the clinical records. There were no records to back up some of the Trust’s statements.

The Trust used unhelpful medical jargon at a local resolution meeting with Mr C and did not clear up points that Mr C had not understood. The Trust did not apologise to Mr C for their poor record keeping. They also did not refer to professional standards and guidance when investigating his concerns, or when committing themselves to improving the monitoring of observations and record keeping.

Describing to the Trust how their answers to his concerns had affected him and his family, he said, ‘We feel that your avoidance by giving minimal answers has prolonged our suffering’. Mr C was put through two years of distress as he struggled to make sense of what happened to his sister at the end of her life.

The Trust apologised to Mr C and used his case study in training sessions for staff in how to investigate and respond to complaints.

A two year wait for answers
Unfair removal from GP patient lists

Often a patient’s experience of the NHS begins with their GP. It is common for the relationship between a patient and their GP to be long established and to extend across an entire family. In the last year, we received an increased number of complaints about GPs, some of which suggest that GPs are failing to manage relationships with patients properly, resulting in breakdown in communication and patients being removed from GP patient lists without fair warning or proper explanation.

Last year, the number of complaints about people being removed from their GP’s list of registered patients accounted for 21 per cent of all complaints about GPs investigated, a rise of 6 per cent over 2009-10. We accepted 13 complaints for investigation about removal from GP patient lists and completed 10, all of which were upheld.

There is clear guidance for GPs about removing patients from their lists. NHS contracts require GPs to give patients a warning before they remove them, except where this would pose a risk to health or safety or where it would be unreasonable or impractical to do so. The British Medical Association’s guidance stipulates that patients should not be removed solely because they have made a complaint. It also says that, if the behaviour of one family member has led to his or her removal, other family members should not automatically be removed as well.

Our casework shows that some GPs are not following this guidance. In the cases we have seen, GPs have applied zero tolerance policies without listening to and understanding their patients or considering individual circumstances. Decisions to remove a patient from their GP’s list can be unfair and disproportionate and can leave entire families without access to primary healthcare services following an incident with one individual.

It is not easy for frontline staff to deal with challenging behaviour, and aggression or abuse is never acceptable. However, patients must normally be given a prior warning before being removed from a GP’s list. The relationship between a GP practice and their patient is an important one which may have built up over many years. Despite this, we have seen cases where practices have removed entire families after a few angry words from one individual, without giving them a warning or taking the time to understand the cause of the anger and frustration.

The case studies that follow tell the stories of patients and their families who were removed from GP patient lists during periods of great anxiety about the terminal illness of a loved one or the health of a young child. In one case, the decision to remove the patient was made by the member of staff involved in the altercation. As GPs prepare for the increased commissioning responsibilities outlined in the Government’s health reforms, it is essential that they get the basics of communication right.

For more information about the total number of complaints about GPs received, accepted for formal investigation and reported on please see Figures 6, 10 and 12 (pages 35, 41 and 43).
‘The decision to remove a patient from the list should be considered carefully and preferably not made in the heat of the moment.’

British Medical Association guidance
Miss F’s mother was terminally ill. Miss F is a registered nurse and she and her sister cared for their mother at home. One evening, the battery failed on the device which administered Miss F’s mother’s anti-sickness medication. Miss F did not want to leave her mother without medication while waiting for the district nurse to call, so she changed the battery herself and successfully restarted the device.

The next day, a district nurse told the family’s GP Practice about this. The Practice discussed the incident with Miss F and decided that the doctor-patient relationship with the family had broken down. The Practice asked the local primary care trust to remove all three family members from their patient list.

Miss F and her sister complained to the Practice about the removal decision, but were unhappy with the response. They asked the Ombudsman for help. Miss F said that, as a nurse, she knew her mother was dying and that she needed care around the clock. She was therefore very upset at spending precious time visiting the Practice, trying to persuade them to change their mind. She would rather have spent that time caring for her mother. Miss F also said the family’s removal from the list left their mother ‘totally distraught’ when she died just a few weeks later. She felt strongly that the Practice had let down her mother and was ‘totally devastated and distressed by our continual uncalled for treatment by professionals/GPs’.

Our investigation found that the Practice had given Miss F’s family no warning that they risked being removed; they did not communicate their concerns about the doctor-patient relationship properly; and failed to consider other courses of action. The Practice also took Miss F’s mother off their list even though she had not been involved in the disagreement. They did not consult her or give her any choice in the matter. All of that left Miss F and her sister having to find a new GP for the whole family at a hugely stressful time.

The Practice’s poor complaint handling compounded the family’s distress. For example, when Miss F and her sister pointed out that no warning had been given and questioned why their mother had been removed at such a critical time, the Practice said that they did not wish ‘to go into specific details’. This failure to answer reasonable questions unnecessarily drew out the complaints process.

The Practice apologised to Miss F and her sister for the distress and inconvenience they had caused. They also drew up plans setting out how they would avoid a recurrence of their failings.
Mother and baby removed without warning

Ms D’s baby daughter was due to be immunised. The day before the jabs were due, the GP Practice said they had miscalculated baby J’s age and could not immunise her for another week. Ms D’s family were going abroad in a few days, expecting baby J to have been immunised by then. Ms D was worried about travelling and rearranged the flights.

The day before she was due to fly out, Ms D took baby J to the Practice’s baby clinic. Unfortunately, the nurse was off sick and no one else was available to immunise baby J. Ms D was annoyed and upset by this. She allegedly said ‘what part of flying tomorrow do you stupid people not understand?’ and was said to have deliberately knocked over a vase. Ms D denied both allegations. She returned from her holiday to find a letter from the Practice telling her that her behaviour had been unacceptable, and both she and baby J were to be removed from the list.

The Practice’s hasty actions shocked and frustrated Ms D, and gave her no chance to improve relations with them. Baby J needed regular monitoring, and Ms D was worried that her daughter’s health was put at risk by their removal from the Practice list. Also, Ms D has epilepsy and needs regular prescriptions, so the need to find a new practice was also a concern to her.

Ms D was unhappy with the way the Practice dealt with her complaints about what had happened and she came to the Ombudsman.

We investigated Ms D’s complaint about the Practice’s decision not to immunise baby J and found that they had acted reasonably on both occasions. We also found that the Practice had responded quickly to Ms D’s subsequent complaint and provided evidence-based reasons for not immunising baby J. We did find, however, that the Practice had removed Ms D and baby J from their list without warning. The Practice also failed to follow professional guidance which says removal should be carefully considered and only used ‘if all else fails’; and that other family members should only be removed in rare cases.

The Practice did not consider why Ms D was so distressed and how the relationship could be rebuilt. The Practice also did not think about baby J’s needs.

This case was all the more alarming because the Ombudsman had previously investigated a similar complaint about the same Practice in 2006. At that time the Practice said they would follow the rules in future, but they clearly did not do so in Ms D’s case. We asked the Practice to prepare plans to prevent a recurrence. They have since reviewed their procedures and arranged training for clinicians. The Practice also apologised to Ms D and paid her compensation of £250.
Patient removed after disagreement with the practice manager

Mrs L and her husband had been registered with their GP for over 15 years. While she and her husband were waiting for their flu jabs, Mrs L became involved in a disagreement with Practice staff about unanswered telephone calls. After the incident Mr L wrote to the Practice to complain about the practice manager’s attitude to his wife and to ask for an apology. He said the practice manager had twice said he would ‘get you [Mrs L] struck off for this’.

Mrs L then received a letter from her GP saying that she had been abusive and used strong language. This had ‘intimidated’ and ‘humiliated’ Practice staff, who asked the GP to get Mr and Mrs L removed from the patient list. The GP suggested to Mrs L that the situation might be retrieved if she apologised to the practice manager.

Mrs L wrote back ‘shocked and horrified’ by the letter, saying ‘never before have I had a cross word with anyone in your practice’. She was particularly upset by the threat to remove her husband and did not see why he should be penalised for what had happened. Mrs L said she was happy to meet the practice manager, but refused to apologise. The practice manager then sent Mrs L a letter signed on behalf of the senior partner, informing her that she was being removed from the list. (Mr L left the Practice of his own accord.) Mrs L then escalated her complaint to Stockport Primary Care Trust (the Trust), which made enquiries of the Practice and agreed with their actions.

Upset about being removed from the list because of a ‘simple disagreement’, Mrs L came to the Ombudsman. She said she had ‘been made to feel like a criminal of some sort’, and that the Trust had simply sided with the Practice.

Our investigation showed that the Practice had removed Mrs L without warning and had not followed their own zero tolerance policy. On top of that, the removal letter was signed by the practice manager, the very person Mrs L had complained about. The Practice also failed to deal with all of Mr and Mrs L’s complaints. For their part, the Trust did not check if the Practice had followed the rules or their own policies and they did not fully respond to her complaint. They missed the opportunity to ask the Practice to put things right.

The Practice and the Trust each apologised to Mr and Mrs L and paid them compensation totalling £750. The Practice appointed a new complaints manager and updated their guidance on removing patients. The Trust also revised their policies on removing patients, to prevent a recurrence of their failings.
Removal after a dispute about missing medical records

Mrs M got into a dispute with her GP Practice when they could not find some of her medical records which had been transferred to them by another practice a year earlier. Mrs M waited at the Practice for about an hour while staff rang round trying to find her records. In fact, the Practice already had the records in question, but they had not recorded receipt on their computer system and had then misfiled them. Mrs M was very worried about the apparent loss of her records and felt that Practice staff were not taking her concerns about that seriously. She disliked the receptionist’s manner towards her and left the reception saying that she would be making a complaint.

On receipt of Mrs M’s complaint the Practice carried out a thorough search for the missing records and eventually found them. They then set up a meeting with Mrs M to go through her records and to discuss her complaint. Mrs M telephoned to cancel the meeting as it was extremely short notice and she felt things were being rushed. The Practice later noted that Mrs M’s manner during the call was unpleasant. The next day Mrs M received a letter from the Practice saying that staff had been trying to resolve her concerns about her records, but were upset by what they described as her intimidating attitude and manner. The Practice said Mrs M’s ‘persistent belligerence’ gave them no option but to ask her to find another GP, as her relationship with the Practice had obviously broken down.

Mrs M disputed that she had been belligerent, and felt the Practice were not taking her concerns seriously. The letter from the Practice left Mrs M feeling ‘upset and again stressed further’. She was ‘totally aghast’ and ‘dismayed’ at the way the Practice had treated her and ‘saddened that actions had been escalated to this stage’. She complained to the Ombudsman, seeking an apology from the Practice.

We resolved Mrs M’s complaint quickly, without the need for a formal investigation. After we spoke to the Practice, they apologised to Mrs M for removing her from their list without warning. They also explained that they had changed their procedures and would follow the rules about removing patients in the future. We gave Mrs M further assurance by sending her the Practice’s new procedures for recording receipt of incoming medical records.