

Six lives: the provision of public services to people with learning disabilities

Part three: the complaint made by Mr and Mrs Cox

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-III
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

- 1 This is the final report of my investigation into Mr Cox's parents' complaint against the Harold Road Surgery (the Surgery), a GP employed by South East Health Ltd (the Out of Hours GP), East Sussex Hospitals NHS Trust (the Trust) and the Healthcare Commission. The report contains my findings, conclusions and recommendations with regard to Mr Cox's parents' areas of concern.
- 5 On Friday 24 September 2004 Mr Cox's father rang the Surgery for more medication for his son's seizures. During that day Mr Cox got no better. In the early hours of 25 September 2004 his parents noticed that his stomach had swollen up and called the Out of Hours service.

The complaint

- 2 Mr Cox was a 30 year old man with severe learning disabilities. His parents describe him as a very happy and contented young person with a great sense of humour and a love for everyone. They explained that he was usually very fit. He lived at home with his parents who were his carers. Mr Cox had very little speech, but he could make himself understood to his family.
- 3 Mr Cox's parents say they were first aware their son was in discomfort on 3 August 2004. They were worried because he was making a repeated noise, although normally he was quiet. They telephoned the Surgery on 4 August 2004, and three doctors from there visited over the next five days. Mr Cox seemed to recover, but his parents feel that this episode was in fact caused by a 'grumbling appendix' (a term sometimes applied to people who have episodic abdominal pain and who eventually undergo an appendectomy – surgical removal of the appendix).
- 4 On 21 September 2004 Mr Cox again had difficulty sleeping. The following morning he had a bad epileptic seizure and his parents telephoned the Surgery and spoke to the First GP. The First GP visited and examined Mr Cox. She told his parents he had a viral infection. On 23 September 2004 Mr Cox's father rang the First GP to say how worried he was.
- 6 The Out of Hours GP attended and said Mr Cox would need an X-ray to determine whether or not he had a bowel obstruction. His parents decided it would be better to wait until the X-ray department was open in normal working hours. However, Mr Cox deteriorated so they rang the Out of Hours service again and an ambulance was called.
- 7 Mr Cox was admitted to the Medical Admissions Unit of the Trust early on the morning of 25 September 2004. He had an X-ray and had just returned to the Medical Admissions Unit when he suffered a cardiac arrest. Sadly, the resuscitation attempt was unsuccessful and he died. A post mortem was carried out which concluded that he had died of aspiration pneumonia (caused by inhaling vomit into the lungs) and paralytic ileus (cessation of normal bowel activity), following peritonitis (inflammation of the lining of the abdomen).
- 8 Mr Cox's parents were profoundly shocked and saddened by the sudden death of their son. They strongly believe doctors failed to listen to their concerns about the extent of their son's distress or to their view that he might have been suffering from either a bowel obstruction or appendicitis. They believe that if they had been listened to their son might not have died. Mr and Mrs Cox's recollections and views about the care and treatment provided for their son are set out in detail in later sections of this report.

- 9 Mr Cox's parents have given permission for Mencap to act as their representative.

The overarching complaint

- 10 Mr Cox's parents believe their son's death was avoidable and that he received less favourable treatment for reasons related to his learning disabilities. I have called these aspects of their complaint 'the overarching complaint'.

Complaint against the Surgery

- 11 Mr Cox's parents complain that:

Complaint (a): during August and September 2004, doctors at the Surgery failed to diagnose that their son had appendicitis and failed to carry out further investigations when it was clear he was in pain and they were expressing concern about his condition.

Complaint (b): the Surgery did not act on a letter from a learning disability nurse about their son's epilepsy medication.

Complaint (c): the Surgery did not provide a reasonable response to their complaint.

Complaint against the Out of Hours GP

- 12 Mr Cox's parents complain that:

Complaint (d): the Out of Hours GP did not tell them how serious their son's condition was and the delay in calling an ambulance and getting him to hospital may have affected the outcome of his illness.

Complaint against the Trust

- 13 Mr Cox's parents complain that:

Complaint (e): their son should have been treated with greater urgency. They say his pain was not managed; communication was poor; they did not receive an explanation about what was happening; their questions were not answered; their concerns were not listened to; and staff were insensitive. They also complain that they were excluded from the room when attempts were being made to resuscitate their son and, as a result, they were unable to comfort him and lost the opportunity to say goodbye.

Complaint (f): the Trust did not provide a reasonable response to their complaint.

Complaint against the Healthcare Commission

- 14 Mr Cox's parents complain about:

Complaint (g): the way the Healthcare Commission handled their complaint. In particular, they do not consider the Healthcare Commission's report bore any relation to their complaints and they are concerned that the Healthcare Commission did not take account of the specialist clinical advice they submitted with their complaint.

- 15 Mr Cox's parents believe they have not had answers to all their questions and they hope my investigation will provide them with those answers. They do not want others to go through the same experiences as their son.

The Ombudsman's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

- 16 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of my wide discretion I may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.
- 17 When considering complaints against an NHS body, I may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.
- 18 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.
- 19 When considering complaints against GPs, I may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.
- 20 I may carry out an investigation in any manner which, to me, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as I think fit.
- 21 If I find that service failure or maladministration has resulted in an injustice, I will uphold the complaint. If the resulting injustice is unremedied, in line with my *Principles for Remedy*, I may recommend redress to remedy any injustice I have found.

Remit over the Healthcare Commission

- 22 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within my remit.

Premature complaints

- 23 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach I have taken in the majority of NHS complaints made to me.

- 24 However, section 4(5) makes it clear that if, in the particular circumstances of any case, I consider it is not reasonable to expect the complainant to have followed the NHS route, I may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for my discretion after proper consideration of the facts of each case.
- 25 In this instance, Mr Cox's parents had not complained directly to the Out of Hours GP, although they had asked the Healthcare Commission to investigate the care and treatment provided by the Out of Hours GP. In order to obtain a complete picture of the events leading up to Mr Cox's death and to provide the complainants with a full response to their complaint, I exercised my discretion to investigate the complaint against the Out of Hours GP under the provisions of the Act which govern my work.
- 27 I obtained specialist advice from a number of professional advisers (my Professional Advisers): Dr T Owen and Dr E Ward, both GPs (my First and Second GP Advisers); Dr E M Phillips, a consultant gastroenterologist (my Gastroenterology Adviser); Mr D Richens, a consultant surgeon (my Surgical Adviser); Dr T Malpass, an Accident and Emergency consultant (my A&E Adviser); Ms L Etherington, a senior hospital nurse (my Nursing Adviser); and Ms M Setterfield, a learning disability nurse (my Learning Disability Adviser).
- 28 My Professional Advisers are specialists in their field and in their role as my advisers they are completely independent of any NHS body and the Healthcare Commission. Their role is to help me and my investigative staff understand the clinical aspects of complaints.
- 29 In this report I have not referred to all the information examined in the course of my investigation, but I am satisfied that nothing significant to the complaint or my findings has been overlooked.

The investigation

- 26 During the investigation my investigator met Mr Cox's parents and their representatives to ensure I had a full understanding of their complaint. I examined complaint correspondence between Mr Cox's parents and the Surgery, the Trust and the Healthcare Commission, and documents relating to the attempted resolution of the complaint as well as health records from the Surgery, the Out of Hours GP and the Trust. The Surgery, the Trust and the Out of Hours GP all provided additional information in response to my enquiries.

My decision

- 30 Having considered all the available evidence related to Mr Cox's parents' complaint, including their recollections and views and their response to my draft report, and taken account of the clinical advice I have received, I have reached the following decisions.

Complaint against the Surgery

- 31 Although doctors from the Surgery did not diagnose Mr Cox's appendicitis, I find **no service failure** in the care and treatment they provided for him. The GP visits and telephone consultation were of a reasonable standard in the circumstances and doctors at the Surgery were aware of the need, highlighted by his parents, to consider a bowel obstruction and appendicitis. Nor do I criticise the Surgery regarding his epilepsy medication. I find **no maladministration** in the way the Surgery handled Mr Cox's parents' complaint. I **do not uphold** the complaint against the Surgery.

Complaint against the Out of Hours GP

- 32 I find **no service failure** in the care and treatment provided by the Out of Hours GP. I find he carried out a comprehensive examination, acted appropriately in asking the Surgery to review Mr Cox later that day, provided suitable medication, put measures in place to monitor him and acted promptly when his parents telephoned again. I find the Out of Hours GP could not have predicted that Mr Cox would deteriorate rapidly. I **do not uphold** the complaint against the Out of Hours GP.

Complaint against the Trust

- 33 I find **no service failure** in the care and treatment provided by the Trust. I find the observations and investigations carried out when Mr Cox was admitted to the Trust were reasonable. I acknowledge it would have been better had Mr Cox received pain relief earlier but, in the light of the extensive tests which were being undertaken, I do not regard this as a

service failure. I do not criticise the decision not to allow Mr Cox's parents to stay in the room while their son was being resuscitated. I find **no maladministration** in the way the Trust handled Mr Cox's parents' complaint. I **do not uphold** the complaint against the Trust.

Complaint against the Healthcare Commission

- 34 I find **maladministration** in the way the Healthcare Commission reviewed the complaints against the Surgery and the Trust. This maladministration meant Mr Cox's parents did not get a proper review of their complaint. This is an unremedied injustice. I **uphold** the complaint against the Healthcare Commission.

The overarching complaint

- 35 I have found no evidence that Mr Cox received less favourable treatment for reasons related to his learning disabilities and I do not conclude his death was avoidable.
- 36 In this report I explain the detailed reasons for my decision and comment on the areas where Mr Cox's parents have expressed particular concern.

Section 2: the basis for my determination of the complaints

Introduction

37 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, I generally begin by comparing what actually happened with what should have happened.

38 So, in addition to establishing the facts that are relevant to the complaint, I also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. I call this establishing the overall standard.

39 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

40 Having established the overall standard I then assess the facts in accordance with the standard. Specifically, I assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.

41 If so, I then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

42 The overall standard which I have applied to this investigation is set out below.

The general standard

Principles of Good Administration

43 Since it was established my Office has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 I published these established principles in codified form in a document entitled *Principles of Good Administration*.

44 The document organises the established principles of good administration into six Principles. These Principles are:

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right, and
- Seeking continuous improvement.

45 I have taken all of these Principles into account in my consideration of Mr Cox's parents' complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:¹

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

- ⁴⁶ In October 2007 I published a document entitled *Principles for Remedy*.²
- ⁴⁷ This document sets out the Principles that I consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how I think public bodies should put things right when they have gone wrong. It also confirms my own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- ⁴⁸ I have taken the *Principles for Remedy* into account in my consideration of Mr Cox’s parents’ complaint.

The specific standards

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- ⁴⁹ The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- ⁵⁰ Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- ⁵¹ Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- ⁵² It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

² *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 53 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 54 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 55 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 56 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale) which, although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 57 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 58 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.

- 59 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.
- 60 On its establishment in 2000, the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 61 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':
- 'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'*
- 62 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the code says:
- 'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'*
- Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)**
- 63 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 64 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 65 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.

66 The fifth stated objective of the Government was to *'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'*.

67 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

68 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

69 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

70 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services

and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

'... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.'

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

71 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

'The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.'

In practice

72 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.

73 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

74 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.

75 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

76 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the

particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

77 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.

78 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

79 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

- Article 2 Right to life
- Article 3 Prohibition of torture, or inhuman or degrading treatment
- Article 14 Prohibition of discrimination.

Policy aims

80 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

81 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

82 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

83 The policy implications for the healthcare services are also apparent, as one aspect of that aim of using human rights is to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

84 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

85 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

- 86 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights: it will also mean that there has been maladministration or service failure.
- 87 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).
- 88 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Healthcare

National guidance

- 89 In 1996 the Resuscitation Council (UK), a charity whose aim is to improve patient outcome after cardiac arrest, issued good practice advice, *Should Relatives Witness Resuscitation?*. The advice is not statutory but was guidance current at the time of the events complained about. The report recognises that the presence of relatives during attempted resuscitation is a controversial issue. The advice also recognises that when someone collapses elsewhere than in A&E there may be fewer staff, space and privacy available to enable family members to be properly supported through the traumatic event. It states that this should not preclude the adoption of a flexible policy, balancing local difficulties against the relatives' needs.

Professional standards

The General Medical Council

90 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of work, including record keeping. Key sections of the booklet current at the time of this complaint are set out at Annex A.

91 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

92 In 2002 the Nursing and Midwifery Council (the body responsible for professional regulation of nurses) published a booklet, *The Nursing and Midwifery Council code of professional conduct* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

93 Paragraph 1 of the Code of Conduct current in 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

94 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

‘...’

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

95 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in a team.'

'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

Complaint handling

NHS complaint handling

- 96 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the providers' terms of service.
- 97 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints
- 98 *Complaints against NHS bodies* The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory, and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.
- 99 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

Complaints against GPs

- ¹⁰⁰ Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for General Practices*. This is intended to be a good practice guide and sets out a model for a practice-based complaints procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:
- Practice-based procedures should be managed by the practice.
 - One person should be nominated to manage the procedure.
 - The procedure must be in writing and must be publicised (and should include details of how to complain further).
 - Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.
- ¹⁰¹ The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and ‘user-friendly’ for patients and practices alike.

Complaint handling by the Healthcare Commission

- ¹⁰² Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

- ¹⁰³ Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with ‘*having regard to*’ a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.
- ¹⁰⁴ If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation ‘*as soon as is reasonably practicable*’), the

Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

- 105 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations, summarise its conclusions, including any findings of fact, its opinion on the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

106 I have outlined the background to the complaint in Section 1 of this report. I say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

Information about appendicitis

107 Information about the nature of appendicitis is central to an understanding of Mr Cox's illness and the actions of healthcare professionals involved in his care. It is, therefore, relevant to my consideration of Mr Cox's parents' complaint. My Gastroenterology Adviser provided the following information about diagnosis of acute appendicitis:

Diagnosis of acute appendicitis is extremely difficult. Only 1 to 3% of patients presenting with abdominal pain will have acute appendicitis and many patients with appendicitis will have atypical symptoms. The symptoms may be very mild, or they may be symptoms not normally associated with appendicitis. There is little or no evidence in the medical literature to support the existence of a diagnosis of 'grumbling appendicitis'. The majority of people who experience episodic abdominal pain and eventually undergo an appendectomy have a normal appendix removed and the abdominal pain is attributed to other causes.

Symptoms are variable in all patients so the precise nature of the symptoms is very important in pointing towards a diagnosis of appendicitis. The classical symptoms are loss of appetite, abdominal discomfort in the upper area which moves between 36 to 48 hours later to the central abdomen and then to

the lower right side of the abdomen. Fever is often not present early on. If the patient is admitted for investigation even the tests in hospital may not confirm a diagnosis. For example, the white blood cell count is not raised in every patient and abdominal CT scan is not diagnostic in around 4 to 20% of cases.

Research has shown that appropriate clinical diagnosis is often not made until after at least two visits from a doctor. Delay in diagnosis is directly related to complication rates. Increased complications, such as intra-abdominal sepsis (serious infection), peritonitis, wound sepsis, chest infections, septicaemia (infection in the blood stream) and death are all associated with perforation of the appendix.

The complaint against the Surgery

Complaint (a): diagnosis and investigations

108 Mr Cox's parents complain that GPs at the Surgery failed to diagnose their son's condition and failed to carry out further investigations when it was clear that he was in some pain and they were expressing concern about his condition.

Key events

109 Mr Cox was usually fit. However, he suffered from epilepsy, for which he received medication. He was also prone to constipation and needed enemas on a regular basis. When they first moved to the area his parents had found it difficult to obtain bowel care for him. Therefore, Mr Cox's parents had taken care of his bowel problems for five years prior to his illness in August 2004.

110 Mr Cox's parents first noticed their son was unwell on the evening of 3 August 2004. When his distress, which was indicated by a repeated noise in his throat, continued the next day they thought his pain might have been caused by an incident when the seatbelt in the car had tightened round him. They telephoned the Surgery and the First GP conducted a home visit later that day. The First GP concluded that Mr Cox may have had some bruising from the seatbelt incident. In response to Mr Cox's parents' concerns, the First GP said that she did not think the cause of the pain was an intestinal blockage, either because of constipation or a problem with his appendix.

111 On 6 August 2004 Mr Cox was still making the same repeated noises, which his parents felt indicated that something was wrong with him and he was in pain. Mr Cox's father rang the Surgery and requested a home visit. The Second GP visited and examined Mr Cox. She concluded that he did not have an intestinal blockage or appendicitis.

112 When Mr Cox was still making the repeated noises on 9 August 2004, his father rang the Surgery and asked the Third GP to visit. The Third GP examined Mr Cox. Mr Cox's father has said that the Third GP assured them there was nothing wrong with his son.

113 The Surgery's records also indicate a telephone conversation with the Second GP on 9 August 2004. This says Mr Cox's father had called to say his son was feeling better.

114 On 21 September 2004 Mr Cox had difficulty sleeping again. He had a bad epileptic seizure the following morning and his parents rang the Surgery and spoke to the First GP. The First GP advised them to administer the epilepsy medication rectally and she visited later that day.

Mr Cox's parents said that their son was making a slight coughing noise, was having difficulty in swallowing and his abdomen was tender. The First GP diagnosed a viral infection. Later that day there was a telephone consultation between the family and the First GP which was not documented.

115 On 23 September 2004 Mr Cox's father called the Surgery and spoke to the Third GP. This telephone conversation was not documented by the Surgery.

116 The following day, 24 September 2004, Mr Cox's father telephoned the Third GP to request a prescription for more rectal epilepsy medication, as Mr Cox was still having seizures and was not able to take his oral medication. His father picked up the prescription later the same day. There was no further contact with the Surgery before Mr Cox was admitted to hospital.

Mr Cox's parents' recollections and views

117 Mr Cox's parents said the possibility of a bowel obstruction was always a matter of concern for them because sometimes an enema did not relieve their son's constipation. Mr Cox's mother explained that she had also been worried about the possibility of him developing appendicitis. She had read an article about a girl who had died as a consequence of a failure to diagnose appendicitis and she was concerned that her son would not be able to let them know if he developed this condition.

118 Mr Cox's parents said that after 30 years of caring for their son they knew when he was trying to communicate that something was wrong. His mother said he was always quiet, so if he made a noise or appeared agitated it meant something was wrong.

- 119 Mr Cox's parents said they knew their son was in pain when he was ill in August 2004 because he had been up a great deal in the night. He was also making strange noises in his throat, had difficulty swallowing and he was off his food. They recalled that when the Second GP visited she assured them that their son did not have appendicitis and that he was '*just being Warren*'. The Third GP, who usually saw Mr Cox, also visited. He could find nothing wrong and Mr Cox's parents were reassured. They said their son was unwell for about a week to ten days and then improved. They said they felt relieved by his improvement. However, with hindsight, they were convinced that he had experienced a 'grumbling appendix'.
- 120 Mr Cox's parents said that when their son became ill in September 2004 his symptoms were more severe. His mother said she had difficulty in giving him his epilepsy medication because he was not eating, and consequently he was having quite severe seizures.
- 121 On 22 September 2004 Mr Cox's parents called the Surgery. They recalled their son was having a bad seizure at the time of the call. They said the First GP told them to give rectal epilepsy medication and that she would visit. When the First GP attended they told her that the last enema, a couple of days previously, had not been successful and so they asked whether their son might have an obstruction or appendicitis. They said the First GP felt Mr Cox's stomach and said his colon was tender. She told them he had a high temperature. They said the First GP suggested that they try another enema and she told them their son had a viral infection which would cause him pain.
- 122 Mr Cox's parents said that the next day, 23 September 2004, their son was not eating and could not therefore take his medication or paracetamol for the pain. Mr Cox's father said he had never seen his son look so ill. He said he telephoned the Surgery and spoke to the First GP. He told her how ill and distressed his son was, that he was having difficulty with his throat, could only drink a small amount and could not swallow anything whole. The First GP told him his son would look ill as he had a virus and that he would be aching all over. She suggested they remove some of Mr Cox's clothes and open a window to cool him down. Although his parents were still worried, they said they understood he had a virus and hoped to see some improvement in the next day or two.
- 123 Mr Cox's father said he rang the Third GP on 24 September 2004 to ask for a prescription for rectal epilepsy medication as his son was still having bad seizures and was not taking the medication he would normally take with his food. He recalled that when he collected the prescription from the Surgery later that day the Third GP said to '*keep up the good work*'.
- 124 Mr Cox's parents said they had no further contact with the Surgery until two days after their son's death.

The Surgery's position

- 125 The Surgery's position is set out in the First GP's letter of 3 December 2004, in which she responded to Mr Cox's parents' complaint. In that letter the First GP described the actions taken by GPs at the Surgery and the rationale for those actions. Overall, she said that the GPs had '*examined [Mr Cox] fully and carefully and options were considered, both when we saw him with abdominal discomfort in August and again when we saw him in late September*'.

The Surgery's response to my enquiries

126 My investigator made further enquiries of the Surgery. The First GP responded on 10 December 2007. She said she had taken Mr Cox's previous bowel problems into account when forming her diagnosis and she believed she would have considered guidelines on caring for people with learning disabilities during her consultations with him. She also confirmed that she did visit Mr Cox on 22 September 2004 and received a telephone call from his father later that day. She said on the basis of that telephone consultation she decided a further home visit was *'not indicated at that time'*. She said she had not taken a call from Mr Cox's father on 23 September 2004, but that this call was taken by the Third GP.

The advice of my Professional Advisers

My GP Advisers

127 My GP Advisers both agreed that the events of August 2004 were unlikely to have been directly related to Mr Cox's final illness in September that year.

128 My First GP Adviser said the First GP's notes for 22 September 2004 were typical of what might be recorded at a consultation involving abdominal pain. Both my GP Advisers said the GP records show that Mr Cox had refused food and that he had a slightly raised temperature. The notes say his ears, nose, throat and chest were clear and the abdominal signs and symptoms seemed to be low down on the left side. My First GP Adviser explained that with appendicitis he would expect pain in the lower right quadrant of the abdomen and would have expected some reaction if Mr Cox had been tender there. Both GP Advisers considered that the First GP's initial examination and diagnosis were reasonable, although my First

GP Adviser said he would have expected to see a record about whether guarding (tensing of the abdominal muscles identified during examination of the abdomen) was present and a record of bowel sounds (noises made by the gut which can be heard through a stethoscope). He also noted that as constipation had been a frequent problem, a rectal examination would have been appropriate.

129 Both my GP Advisers drew attention to the special circumstances of Mr Cox's case. My First GP Adviser said Mr Cox would not be able to convey information such as any change in the site of pain, which would have helped diagnosis. He said clinicians should respond in three ways to a potential lack of information: (i) listen carefully to what carers have to say; (ii) pay more attention to objective findings arising from examination and tests; and (iii) allow a sufficient safety margin by putting arrangements in place to enable a review of the diagnosis. He said these arrangements could include further visits or advising carers to contact the GP after a specified period of time, or if the patient's condition did not improve or deteriorated. He said the doctor could also initiate a telephone follow-up to check on improvement.

130 My First GP Adviser said that in cases such as this where assessment was difficult and pain appeared to be a continuing feature, he would have expected a GP to have a low threshold for going to visit. However, he found no suggestion in the medical notes that a review was arranged. He said (particularly given that there appeared to have been further telephone consultations about Mr Cox's parents' concerns) it would have been reasonable for the family to have expected a GP to have visited again to review the diagnosis.

- 131 My First GP Adviser could not say with certainty at what point appendicitis had developed in September 2004. He also could not say for certain whether or not the outcome would have been different for Mr Cox had appendicitis been identified sooner and an earlier admission arranged.
- 132 My First GP Adviser was critical of the lack of documentation about the telephone conversations.
- My Gastroenterology Adviser*
- 133 My Gastroenterology Adviser said none of the symptoms or signs of appendicitis were present when Mr Cox was ill in August 2004. She explained that loss of appetite is usually the most common and earliest symptom to develop with appendicitis and she noted that in August 2004 Mr Cox was recorded as eating well and his bowels were open with enema assistance. He had no temperature and there were no abnormal abdominal signs. There was, for example, no deep tenderness recorded in the medical notes. She concluded therefore that his illness in August 2004 was unrelated to the later development of acute appendicitis.
- 134 My Gastroenterology Adviser said she found no evidence to indicate that the doctors had dismissed Mr Cox's parents' view that their son was ill in September 2004. She said they could not have conveyed to the doctors the precise nature of their son's pain – where it started, whether it had moved to another part of the abdomen or whether the pain was constant or intermittent. She said it is the lack of such detail which makes the diagnosis of appendicitis difficult when people have communication difficulties.
- 135 My Gastroenterology Adviser considered that the GP's diagnosis of a viral respiratory infection had resulted from misleading symptoms including difficulty in swallowing and a cough. She noted that on 22 September 2004 Mr Cox was refusing food and had a slight fever for which no cause could be found when he was examined. She also noted his abdomen was not distended, but was tender on the left-hand side and it was not unusual for Mr Cox to be constipated. He had no history of vomiting or diarrhoea. My Gastroenterology Adviser said the finding of abdominal tenderness on the left side is very unusual in appendicitis and could be misleading. She said this might be interpreted as a sign of a more generalised abdominal tenderness associated with other conditions.
- 136 My Gastroenterology Adviser said the clinical signs of acute appendicitis had not fully developed at the time of the First GP's visit on 22 September 2004. However, she said that it would have been prudent to examine him again within 12 to 24 hours to assess any development in his symptoms.

My findings

- 137 Mr Cox's parents are dissatisfied with the care provided by the Surgery. They say the GPs should have carried out more investigations and paid more attention to their concerns about their son. They believe that, as a consequence, the GPs failed to diagnose appendicitis.
- 138 Mr Cox's parents are correct in that the GPs did not diagnose their son's appendicitis. We know this because he was admitted to the Trust for investigations of his distended abdomen for which no specific cause had been established. However, the fact that the GPs did not reach a definitive diagnosis does not necessarily mean their actions were unreasonable. This is because

it is not always possible for GPs to make a diagnosis on the basis of the limited information which may be available to them.

139 In order to make an assessment of the GPs' actions I have looked at the treatment the Surgery offered Mr Cox in comparison with the standards set out in Good Medical Practice and considered the guidance in Valuing People and Once a Day.

140 My Professional Advisers have explained why acute appendicitis is difficult to diagnose. Mr Cox's communication difficulties made diagnosis of appendicitis even more difficult. It is against this background that I consider the actions of GPs at the Surgery in August and September 2004.

141 My GP Advisers and my Gastroenterology Adviser have advised me that Mr Cox's illness in August 2004 was not a 'grumbling appendix' and was unrelated to his subsequent illness in September 2004.

142 Having taken account of my Professional Advisers' advice, I am also satisfied that the First GP's examination of Mr Cox on 22 September 2004 was adequate, that the diagnosis was reasonable and that the likelihood of a bowel obstruction and appendicitis was properly considered.

143 The critical question is what did happen, and should have happened, when Mr Cox's parents telephoned the Surgery on 23 September 2004. The absence of a record of that telephone conversation makes my assessment more difficult. The failure to record this consultation is contrary to the Good Medical Practice principle of keeping clear, accurate, legible and contemporaneous patient records. However, there seems to be broad agreement about what

was said. Mr Cox's parents said how ill their son seemed, that he was still not eating and was not able to take his medication. They were assured by the Third GP that these symptoms were consistent with a viral infection. He did not visit Mr Cox.

144 I have received mixed advice on whether the decision not to visit on 23 September 2004 was reasonable. Mr Cox had been examined only 24 hours previously and there were no new symptoms, so in normal circumstances it would seem reasonable that the GP did not visit. However, both my GP Advisers drew attention to Mr Cox's learning disabilities and suggested that, following the examination on 22 September 2004, a further visit, or telephone call, or advice to his parents to contact the Surgery after a specific time could have been considered. My Gastroenterology Adviser similarly said that when assessing a person with communication difficulties and Mr Cox's symptoms, more than one assessment over a period of time would have been prudent.

145 I am conscious that all three of my Professional Advisers have said GPs at the Surgery could or should have considered more proactive management. They did not say definitively that the GPs should have visited Mr Cox on 23 September 2004. Also, I have seen no policy or guidance which says a GP must visit in such circumstances. Furthermore, given the difficulty of diagnosing acute appendicitis, there can be no certainty that a further visit would have resulted in a firm diagnosis at that time or, indeed, a different outcome for Mr Cox. I conclude that, whilst it would have been good, proactive management for a GP to visit Mr Cox on 23 September 2004, the fact that a GP did not visit **does not amount to service failure**.

Complaint (b): epilepsy medication

¹⁴⁶ Mr Cox's parents complain that the Surgery did not act on a letter from a learning disability nurse about their son's epilepsy medication.

Mr Cox's parents' recollections and views

¹⁴⁷ Mr Cox's parents said their son had seen a psychiatrist in 1996. Since then he had not had a neurological examination for his epilepsy and they had simply obtained repeat prescriptions. They recalled that there had been a telephone call from the Surgery to check that his medication was alright.

¹⁴⁸ Mr Cox's mother recalled that a nurse from the Community Learning Disability Team had called about 18 months prior to her son's last illness and said she would write a letter requesting a review of his epilepsy medication, but nothing had subsequently happened and no review had taken place.

The Surgery's position

¹⁴⁹ In her response of 3 December 2004 to Mr Cox's parents' complaint about their son's care and treatment at the Surgery, the First GP explained about his epilepsy medication. She said he was followed up regularly until around 1996 when the hospital consultant said he did not need regular review. She said once someone is balanced on their epilepsy medication there is usually no need to review them unless they suffer more seizures or their weight changes significantly. She noted that Mr Cox's parents had been asked by the Surgery about their son's epilepsy in May 2004 at which point he was having two to four seizures a month. She said the Surgery had no record of a letter from the learning disabilities service, or any other contact, about Mr Cox's epilepsy.

The advice of my Professional Advisers

¹⁵⁰ My First GP Adviser noted that Mr Cox was having two to four seizures a month despite being on three types of epilepsy medication. He said he did not consider Mr Cox's epilepsy was well controlled because a patient with well controlled epilepsy would have no seizures or only very occasional seizures.

¹⁵¹ Both my GP Advisers noted that there had been a telephone assessment of Mr Cox's epilepsy medication in the past year. They said that, although this would not conform to today's standards, it reflected the approach taken at the time. They said records contained no evidence of correspondence from a learning disability nurse.

My findings

¹⁵² Mr Cox's parents are dissatisfied with the way the Surgery managed their son's epilepsy medication and they say the Surgery did not respond to a letter from a learning disability nurse regarding epilepsy medication.

¹⁵³ First, my Professional Advisers could find no evidence of a letter about epilepsy medication and the First GP said there was no such correspondence in the Surgery's documents. Although I do not doubt Mr Cox's parents' version of events, I cannot comment further on this matter without seeing the letter and this piece of evidence has not come to light.

¹⁵⁴ Secondly, I consider the way in which Mr Cox's epilepsy was managed. The Surgery has confirmed that it was usual practice not to carry out regular reviews for a person with epilepsy and I note the First GP told Mr Cox's parents in her response to their complaint that the consultant managing Mr Cox's epilepsy

had said this was not necessary. However, in the same letter the First GP said that Mr Cox's epilepsy had been discussed during a telephone conversation with the Surgery in May 2004.

155 Having considered the advice of my Professional Advisers, I am concerned that there appears to have been no regular review of Mr Cox's epilepsy between 1996 and 2004 and a telephone consultation, such as that which apparently took place in May 2004, would not now be considered adequate. That said, my Professional Advisers have told me that, although this standard of monitoring would not be accepted today, it was accepted practice at the time of the events complained about. Therefore, I find no reason to criticise the Surgery on this point. I find **no evidence of service failure**.

Complaint (c): complaint handling by the Surgery

156 Mr Cox's parents remain dissatisfied with the way the Surgery handled their complaint.

Key events

157 On 13 October 2004 Mr Cox's parents complained to the Surgery about the care and treatment provided to their son. There were five main areas of complaint:

- the GPs had not diagnosed Mr Cox's condition, despite the fact that his family had raised concerns about a bowel obstruction and appendicitis;
- the GPs had not carried out further investigations despite Mr Cox's pain;

- Mr Cox's medication had not been regularly reviewed;
- no action had been taken on the letter about constipation and epilepsy; and
- the GPs had not paid sufficient attention to the views of Mr Cox's parents, who were best placed to understand him when he was not well.

158 In November 2004 the Surgery offered to meet Mr Cox's parents to address the issues complained about but they declined because they preferred to receive a written response.

159 On 3 December 2004 the First GP responded in writing to the complaint. She apologised for the delay, explaining that time had been taken to discuss the case at a meeting of Surgery staff. She said she had reviewed all Mr Cox's GP records and spoken to the pathologist who had carried out the post mortem.

160 In her response the First GP explained the sequence of events in the Surgery's care and treatment of Mr Cox in August and September 2004. She explained in detail what the GPs had done during consultations, what they had found and the reasons for their decisions. She said the Surgery had no record of a letter from a nurse about Mr Cox's constipation and epilepsy and explained why Mr Cox's medication had not been reviewed routinely. She said the hospital consultant had decided Mr Cox's epilepsy medication did not need to be reviewed regularly and it was usual that once a person was established on drugs there was no need for regular review if their condition was stable.

161 The First GP said:

'I fully understand your concerns about your son but I feel that I did treat his condition seriously, did assess him and was fully aware of the difficulties in assessing a man who was unable to communicate fully with me. I think he was examined fully and carefully and options were considered, both when we saw him with abdominal discomfort in August and again when we saw him in late September.'

162 She expressed her sympathy to Mr Cox's parents and offered to meet with them if they would like further explanations as she realised that it was difficult to explain things fully in a letter.

My findings

163 In Section 2 of this report I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Surgery's actions with those Regulations.

164 I find the Surgery acted appropriately in offering to try and resolve the complaint at a local resolution meeting and in offering a further meeting once it had provided a written response.

165 I find the Surgery took appropriate action to investigate Mr Cox's parents' concerns by looking at recorded evidence, seeking further evidence about the cause of death and discussing the case with professional colleagues. I also find the First GP's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation. The tone of the response was sensitive and conciliatory.

166 The Surgery took around six weeks to respond to the complaint which is outside the timeframe set out in the Regulations. However, it is clear that the Surgery initially hoped to resolve Mr Cox's parents' concerns through a meeting which was offered in November 2004. Furthermore, the First GP apologised for the delay and explained why the response had been delayed.

Complaint handling by the Surgery: my conclusion

167 In terms of complaint handling, I find the Surgery acted in line with the Regulations and demonstrated good practice as set out in my *Principles of Good Administration*. I conclude that there is **no evidence of maladministration** in the way in which the Surgery responded to Mr Cox's parents' complaint.

The complaint against the Surgery: my conclusion

168 I have studied the evidence about Mr Cox's parents' complaint against the Surgery regarding his care and treatment in August and September 2004, and the management of his epilepsy medication. I have considered the complainants' recollections and views and the professional advice I have received. I am satisfied that the actions of GPs at the Surgery were reasonable and I find **no evidence of service failure** on their part. I have also considered the way in which the Surgery responded to the complaint made by Mr Cox's parents and I find **no evidence of maladministration**.

169 Therefore, I **do not uphold** Mr Cox's parents complaint against the Surgery.

The complaint against the Out of Hours GP

Complaint (d): actions of the Out of Hours GP

¹⁷⁰ Mr Cox's parents complain that the Out of Hours GP who saw their son on 25 September 2004 did not tell them how serious his condition was and they believe the doctor's delay in calling an ambulance may have affected the eventual outcome of his illness.

Key events

¹⁷¹ In the early hours of the morning of 25 September 2004, Mr Cox deteriorated and his parents put him to bed. They then noticed his stomach had swollen up. At 1.30am they called the Out of Hours service. A GP visited 45 minutes after he received the call. He examined Mr Cox and advised that an X-ray was needed. Mr Cox's parents asked whether it was necessary to take their son to hospital immediately because they were concerned that there might be a considerable wait for the X-ray department to open. They felt this would be distressing for him and would have made the management of his epilepsy more difficult. The Out of Hours GP gave Mr Cox pain relief and advised his parents to contact the Out of Hours service again if there was any change or they continued to be worried.

¹⁷² Mr Cox's parents contacted the Out of Hours service again at 3.46am and said their son seemed worse. The Out of Hours GP received the details of the second call just before 4.00am. He arranged for an ambulance to take Mr Cox to hospital urgently. The ambulance record shows that a 'GP urgent' call was received at 4.00am. The ambulance arrived to collect Mr Cox at 4.27am and reached the hospital at 4.41am.

Mr Cox's parents' recollections and views

¹⁷³ Mr Cox's parents said they called the Out of Hours service on 25 September 2004 because they were so worried about their son. They said they expressed their concerns to the service about a bowel obstruction or appendicitis. Mr Cox's father said he noticed how distended his son's stomach was and that he had never seen anything like it. He said his son could not bend his legs and was clearly in great discomfort. Mr Cox's father said when he rang the Out of Hours service, he got the impression that the Out of Hours doctors thought Mr Cox's parents had got matters out of proportion and there was a reluctance to visit.

¹⁷⁴ Mr Cox's parents understood that the reason why the Out of Hours GP had suggested an X-ray should be taken was to determine whether or not Mr Cox had a bowel obstruction. They said that at no time had the Out of Hours GP indicated to them that their son was dangerously ill. Because they had previously attended the hospital outside normal hours and had a long wait for the X-ray department to open, they had asked the Out of Hours GP if it would be better for Mr Cox if they waited until the X-ray department would definitely be open. They said they had also taken into account, when asking this question, the fact that they could not give their son his epilepsy medication while waiting in a hospital corridor for an X-ray. They were anxious to prevent him having seizures if possible. They recalled that the Out of Hours GP had said he would be off duty in half an hour and if they were still worried by their son's condition they should give him a call within that time. They said they did contact him again and they recalled he had said that he would call an ambulance straight away,

but it took an hour to arrive. Mr Cox's father said that by the time the ambulance arrived his son was in considerable distress, and the wait seemed to last for an eternity. He said the time they had waited had indicated to them that their son was not being treated as an emergency.

- 175 Mr Cox's mother said she thought her son had displayed the classic symptoms of appendicitis, which was why they had drawn their concerns about this and a possible bowel obstruction to the attention of all the doctors who had seen him.
- 176 Mr Cox's parents said that had the Out of Hours GP conveyed to them an urgency in the need to take Mr Cox to hospital they would have done so immediately.

Information from the Out of Hours GP

- 177 The Out of Hours GP recorded that Mr Cox was seen 45 minutes after the call was received on 25 September 2004. He noted that he had been informed that Mr Cox appeared to have breathing difficulties. His record of the examination says he advised admission to A&E but Mr Cox's parents '*would prefer analgesic and review, if no better will need a visit later today*'.
- 178 In correspondence with my investigator, the Out of Hours GP said the visit of 25 September 2004 was the only contact he had had with Mr Cox's parents. It was now over three years since the events occurred and he could only provide information based on his contemporaneous records and say what he would usually do. He explained that he would have been concerned by Mr Cox's condition, otherwise he would not have advised admission to hospital. He believed he had informed Mr Cox's parents of his concerns at the time. However, he had also taken into account their anxiety about

admission and their desire to minimise any distress caused to their son. As a result, he agreed to try pain relief and to review the situation if Mr Cox did not improve. He noted that Mr Cox's parents had understood that further investigations should be conducted because they called back later. He thought he had explained that he was arranging an ambulance to arrive within the hour and this would have indicated that he thought Mr Cox needed urgent attention.

The advice of my Professional Advisers

My GP Advisers

- 179 My First GP Adviser said there were clear signs that Mr Cox was seriously unwell by the time the Out of Hours GP was called. He said Mr Cox's abdomen was distended which was a potentially serious examination finding, and he had a raised pulse and raised temperature with reduced bowel sounds. My First GP Adviser said the records indicate clearly what the Out of Hours GP had said and that during the consultation he advised that Mr Cox should be admitted to hospital at that point. He had advised the family to call back if Mr Cox's condition worsened, but he also logged a request for a GP from the Surgery to visit the following day. My First GP Adviser said when Mr Cox's parents called him for a second time the Out of Hours GP promptly arranged admission to hospital.
- 180 My First GP Adviser considered that the Out of Hours GP had made an appropriate examination, kept good records and put in place a strategy for monitoring Mr Cox whilst taking account of his parents' views about not wanting to attend hospital in the early hours of the morning. Furthermore, he had acted promptly when they called a second time. He said there were no grounds for criticism of the Out of Hours GP.

My Gastroenterology Adviser

- 181 My Gastroenterology Adviser considered that the Out of Hours GP made a comprehensive assessment. She said the Out of Hours GP had noted that Mr Cox had not eaten for more than 48 hours, his bowels were not open and on rectal examination there was no stool present. She also said the Out of Hours GP had noted that an enema had not produced any result, that Mr Cox had a fever and a raised pulse rate, and his abdomen was grossly distended and painful. My Gastroenterology Adviser said these factors would point to a diagnosis of intestinal obstruction and the Out of Hours GP advised appropriately that Mr Cox should attend hospital for abdominal X-ray.
- 182 My Gastroenterology Adviser noted that in the light of Mr Cox's parents' concerns, the Out of Hours GP gave Mr Cox a rectal painkiller and advised that they should call again if they were still worried.
- 183 My Gastroenterology Adviser said it was clear that the signs of intestinal obstruction were well established when the Out of Hours GP saw Mr Cox, but it would not have been possible for him to give a definitive diagnosis without further investigation. She concluded that the Out of Hours GP's attendance was timely, that his assessment was thorough and his recommended action was appropriate. She said the analgesia chosen was correct for a patient where the diagnosis was not yet fully established.
- 185 My First GP Adviser and Gastroenterology Adviser agree that the Out of Hours GP provided a good standard of care. He carried out a comprehensive examination, acted appropriately in asking the Surgery to review Mr Cox later that day, provided suitable medication, put measures in place to monitor Mr Cox and acted promptly when Mr Cox's parents telephoned again. Both Professional Advisers remarked that the Out of Hours GP took appropriate note of Mr Cox's parents' concerns about taking their son for an X-ray in the early hours of the morning.
- 186 I understand that Mr and Mrs Cox maintain the view that, had the Out of Hours GP conveyed to them that their son needed to be taken to hospital urgently, they would have done so immediately. I do not doubt the integrity of Mr and Mrs Cox's recollection that they were not told about the seriousness of their son's illness. At the same time I can understand why the Out of Hours GP thought he had conveyed to Mr and Mrs Cox, through his actions and advice described above, that their son was very ill.
- 187 I can also understand why Mr Cox's parents thought the Out of Hours GP did not call an ambulance immediately, because it did not arrive for around half an hour. However, there is clear evidence in the ambulance record that, having spoken to Mr Cox's parents for a second time, the Out of Hours GP immediately called for an urgent ambulance to take Mr Cox to hospital.

The complaint against the Out of Hours GP: my findings and conclusion

- 184 Mr Cox's parents say the Out of Hours GP did not inform them their son was dangerously ill. They say they did not expect him to be admitted to hospital, only that he would attend for X-rays.
- 188 I consider it is reasonable for the Out of Hours GP to have thought he had conveyed the urgency of the situation to Mr Cox's parents. I can also appreciate that their son's very rapid decline after admission to hospital might have led Mr Cox's parents to think that the Out of Hours GP had not acted quickly enough to arrange the admission. However, it is clear to

me that, at the time of his visit, the Out of Hours GP could not have predicted Mr Cox's subsequent rapid deterioration and that his actions were therefore appropriate at the time. Moreover, I have not found that, had Mr Cox been admitted to hospital immediately after the Out of Hours GP's first visit, his life could have been saved.

189 Having considered all the available evidence and the advice of my Professional Advisers I am satisfied that the Out of Hours GP acted reasonably. I conclude that there is **no evidence of service failure** by the Out of Hours GP.

190 Therefore, I **do not uphold** Mr and Mrs Cox's complaint against the Out of Hours GP.

191 In reaching this conclusion I would like to make clear, for the avoidance of any doubt, that I have seen nothing in any of the evidence which suggests that Mr and Mrs Cox were in any way to blame for the death of their son. On the contrary, I have no doubt that at all times they acted in what they understood and believed to be his best interests.

The complaint against the Trust

Complaint (e): care and treatment at the Trust

192 Mr Cox's parents complain that their son should have been treated with greater urgency when he reached hospital. They also say communication was poor, their concerns were not listened to and staff were insensitive. They complain that they were excluded from the room when attempts were being made to resuscitate their son and, as a result, they were not with him when he died. They consider he

received less favourable treatment for reasons related to his disabilities and that his death was avoidable.

193 I have considered all the complaints about care and treatment together because the events complained about and the evidence available are closely linked.

Key events

194 Mr Cox arrived at the Trust and was received by nursing staff in the Medical Admissions Unit at 4.43am. He was seen within ten minutes by a junior doctor, who started tests and sent him for an X-ray. The duty specialist registrar (a more senior doctor) was called.

195 Observations made at 5.00am show Mr Cox had a rapid pulse, but normal blood pressure and his temperature was only slightly raised. A monitor showed that the level of oxygen in his blood was normal. A saline drip was started at 5.20am and blood was taken for testing at 5.46am.

196 At 6.15am, following the X-ray, Mr Cox began to vomit while a nurse was getting drugs to treat his pain. The junior doctor recorded that at about 6.00am he was called from writing up his notes to help turn Mr Cox on his side because he was vomiting. He returned to his work only to hear the arrest alarm a few minutes later.

197 The junior doctor recorded a cardiac arrest call at 6.24am. Records about the resuscitation set out the actions and drugs given from 6.23am until attempts to resuscitate Mr Cox were stopped at 6.43am when he was declared dead.

Mr Cox's parents' recollections and views

- 198 Mr Cox's parents said when they arrived at the Trust they were surprised that they were taken to the Medical Admissions Unit as they had expected just to attend for an X-ray. They recalled that staff looked anxious but no one explained how ill their son was. Mr Cox's father said the doctor who was on duty did not appear to have a good command of English. He had not explained anything to them and they could not understand what he was saying. Mr Cox's mother said she had to ask for pain relief for her son.
- 199 Mr Cox's mother said when they went to the X-ray department they were asked if their son bit or scratched, which she thought was insensitive. She said the radiographer had told them they were right about a blockage in Mr Cox's abdomen but had said nothing about anything else, although he had been X-rayed in the chest area as well as the abdomen.
- 200 Mr Cox's mother said she had placed a pillow under her son's head while he was in the X-ray department because his head had fallen back and increased his discomfort. When they left the radiographer had taken the pillow saying, *'you can't take that we will never get it back'*. Mr Cox's mother said it was clear that her son was uncomfortable and she thought the radiographer's comment showed a lack of concern for his comfort and distress.
- 201 Mr Cox's mother said she had also asked nurses in the Medical Admissions Unit about giving her son his epilepsy medication and had been told she could not do this because it might be dangerous. She noted that she did not mean medication should be given orally because she knew Mr Cox could not swallow. She felt that no attempt had been made to take her son's epilepsy into account.
- 202 On return from X-ray Mr Cox's parents noticed that staff still looked anxious. With hindsight, they were sure staff were aware that Mr Cox was very ill. His mother said she asked one nurse what was the matter but then Mr Cox started to vomit and there had been a rush for a bowl. She said there appeared to be more concern that he might be sick in the bed than concern about his wellbeing.
- 203 Mr Cox's mother recalled that she had handed the X-ray notes to a nurse. There was no doctor present at the time and she understood he had gone to write up his notes. She then saw her son's colour was changing and drew the nurse's attention to this. The nurse had said *'oh my God'* and rang a bell, and repeatedly shouted at Mr Cox's father to pass tubes to her. Mr Cox's father said there were several tubes to hand and he did not know which ones she meant. They said they were then pushed out of the room and a lot of people attended including a different doctor who had said *'it's big'* and left them. They said they could hear their son crying out as attempts were made to resuscitate him. This caused them considerable distress. They said they were informed their son had died and told that if he had lived he would have needed major surgery which he would have been unlikely to survive.
- 204 Mr Cox's parents said they had been left bewildered by the events of 25 September 2004 and still had unresolved questions about their son's care. They attended hospital thinking this admission would mirror previous ones. They had expected to be going home after Mr Cox had been X-rayed and received appropriate treatment, which they had anticipated would be an enema. Instead they had been pushed out of the room when their son had stopped breathing, they had had to listen to his distress as attempts were made to resuscitate him and had not been present when he died. They said they had,

therefore, lost the opportunity to say goodbye. They believe that had they been present during resuscitation they would have been able to comfort their son and perhaps might have been able to have given him the will to live.

The Trust's position

205 The Trust's position about the care and treatment provided for Mr Cox on 25 September 2004 is set out in its responses to his parents' complaints.

206 In summary, the Trust said Mr Cox received '*expedient and correct*' care and treatment. It said he was admitted as an emergency and had been seen by a doctor within ten minutes of arrival. Examinations, tests and investigations had been carried out urgently and a diagnosis of intestinal obstruction reached. After an X-ray was performed Mr Cox returned to the Medical Admissions Unit and a senior doctor was called. However, his condition deteriorated unexpectedly. His heart stopped and he stopped breathing. The Trust said when resuscitation attempts began Mr Cox's parents were led away to a nearby seating area.

207 The Trust also said the nursing team on the Medical Admissions Unit were experienced in dealing with patients with learning disabilities.

The advice of my Professional Advisers

My Surgical Adviser

208 My Surgical Adviser said when Mr Cox arrived at the Trust he received timely and appropriate treatment. He did not believe anything more could have been done in the limited time that was available. He considered any shortfalls in the service provided by the Trust appeared to be related primarily to communication with Mr Cox's parents. He noted the Trust had accepted this and had apologised for some of

the failings. However, he thought there were some areas where further explanation would have been helpful, for example to address their concerns about the way Mr Cox was resuscitated.

209 My Surgical Adviser commented on the timing of Mr Cox's admission and its impact on the outcome of his illness. He said the earlier Mr Cox was admitted, the greater the chances of his survival would have been. Having studied the post mortem report, he concluded that Mr Cox had developed appendicitis and a few days later the appendix had ruptured leading to generalised peritonitis. My Surgical Adviser said had Mr Cox been admitted prior to the development of peritonitis he would have had a better chance of survival. However, he also said it is impossible to establish exactly when the appendicitis began.

My A&E Adviser

210 My A&E Adviser said the observations and investigations carried out on admission were acceptable and an appropriate history was taken. She said the working diagnosis of intestinal obstruction was in keeping with the history and examination findings and Mr Cox's vital signs (measures including pulse, respirations and blood pressure) did not indicate that cardiac arrest was imminent.

211 With reference to Mr Cox's parents' complaint that no one informed them that their son was dangerously ill, my A&E Adviser said he was only in the unit for a little over 90 minutes, during which time a range of essential tests were carried out. She said that although it would have been evident on admission that Mr Cox was seriously ill, it would not have been possible to predict the subsequent sequence of events. In the light of this it was reasonable for staff to wait for a senior doctor to make his assessment

and confirm the junior doctor's diagnosis before discussing Mr Cox's care with his parents. The senior doctor would have been in a position to explain any surgery required and give them a clearer idea of prognosis. My A&E Adviser noted that a senior doctor had been called, but unfortunately by the time he arrived Mr Cox had already collapsed. She confirmed this was an event that could not have been foreseen.

212 That said, my A&E Adviser commented that the junior doctor and nurses should have updated Mr Cox's parents about their plan of care, including asking a senior doctor to review their son, the actions they were taking to address immediate problems, investigations such as hydration and blood tests, and answered any questions as far as it was possible.

213 With regard to Mr Cox's epilepsy, my A&E Adviser said staff had appropriately focused on his immediate needs. She said once a drip had been inserted this could have been used to control any seizures which may have occurred. She did not consider there had been any major failing in this respect.

214 My A&E Adviser said Mr Cox's abdomen was distended and tender and he would have been in considerable discomfort. She considered Mr Cox was known to be in pain when he was admitted and he should have been given pain relief then.

215 My A&E Adviser noted that many hospitals now have an open attitude to the presence of relatives during resuscitation. However, whether relatives can be present depends on available space and staff. She said if there are not enough staff to support relatives and if space is limited, the resuscitation effort must take precedence. She also said it is clear that the resuscitation had been very traumatic for Mr Cox's parents

and she considered an explanation of what happened at the resuscitation attempt would have been helpful for them.

216 My A&E Adviser's overall conclusion was that, with the exception of the management of pain relief and some shortcomings in communication, the medical treatment Mr Cox received on admission was appropriate and reasonable.

My Gastroenterology Adviser

217 My Gastroenterology Adviser confirmed that Mr Cox's condition could not have been assessed more quickly and initial treatment with intravenous fluids was speedily followed by further assessment with blood tests and X-rays. She said the junior doctor's clinical diagnosis was accurate but that further treatment, such as placement of a nasogastric tube, would not have been appropriate until the X-ray had confirmed the diagnosis.

218 My Gastroenterology Adviser also said had Mr Cox not collapsed he would not have gone for an operation immediately, but would have required further assessment and treatment with intravenous antibiotics before a decision was made about his fitness for surgery.

219 My Gastroenterology Adviser explained that normal practice would have been that as soon as Mr Cox returned from X-ray he would have been reviewed by a senior doctor. Clinical assessment and review of the X-rays would have followed, a further management plan would have been drawn up, and there would have been a discussion with Mr Cox's parents about the diagnosis and the severity of his illness. She said the severity of Mr Cox's condition could not be confirmed until the X-rays had been examined. Unfortunately, Mr Cox arrested and this discussion did not occur.

220 My Gastroenterology Adviser noted that when Mr Cox collapsed he had no pulse or blood pressure and no electrical activity in his heart. She said very few patients survive such an event, despite resuscitation attempts. My Gastroenterology Adviser said Mr Cox would not have been able to cry out when he was being resuscitated because he was unconscious and unable to make sounds. She noted that his parents had thought he was crying out in distress, but this was likely to have been noises associated with the attempt to revive him.

My Nursing Adviser

221 My Nursing Adviser found it was clear from entries in the health record, that the nurse who first assessed Mr Cox recognised his poor condition and contacted the doctor immediately. My Nursing Adviser noted further nursing assessments and plans were incomplete, for example nothing was recorded about management of his epilepsy medication and she said more frequent basic observations, such as pulse and respiratory rate, should have been recorded. However, my Nursing Adviser also said, given the circumstances, she did not consider the failure to fully complete the nursing assessment was unreasonable. She said it would have been appropriate and acceptable for the assessment to have been completed, and for a care plan to have been written once his condition had been stabilised.

222 My Nursing Adviser was concerned about the management of Mr Cox's pain. She noted he was not given pain relief until just before he collapsed. She could find no appropriate assessment of his pain although there was space on the assessment chart for this. Although she recognised the difficulty of the circumstances, such as the need for urgent X-ray, she considered the lack of pain assessment may have been partly the reason

why he was not given pain relief when he was admitted.

223 My Nursing Adviser noted that Mr Cox's father had been distressed at being asked to pass 'tubes' to the nurse. She said that while having to ask carers to act in this way might not be ideal, in an emergency situation such as this, she could not criticise the nurse for her actions.

224 My Nursing Adviser explained that allowing carers and family to witness resuscitation has been shown to result in a positive outcome for the majority of people when they can be supported properly. However, she also said that to allow people to witness such a potentially distressing and traumatic event unsupported by trained staff may have lasting negative effects. She also noted that in A&E staff are often warned in advance of the arrival of a collapsed patient and have time to prepare, whereas the environment in a Medical Admissions Unit is likely to be very different. This is because a cardiac arrest cannot always be anticipated and there may not be enough staff to offer sufficient support to witnesses. She agreed with my A&E Adviser that except in A&E, it is difficult to involve witnesses at cardiac arrests.

My Learning Disability Nursing Adviser

225 My Learning Disability Nursing Adviser noted that there are still a number of terms used internationally in relation to people with learning disabilities and this can be confusing. She said it was only in 2004 that the term 'mental handicap' stopped being used in the coding systems of the NHS to be replaced by the term 'learning disability'. While she found it disappointing to see that 'mental handicap' had been written in Mr Cox's health record, she felt that the use of this term had not necessarily reflected a poor attitude towards him.

My findings

226 Mr Cox's parents are dissatisfied with the care and treatment their son received when he was admitted to the Trust on 25 September 2004. Shortly after he was admitted he suffered an unexpected cardiac arrest and died, so I can fully understand why they question whether his death could have been avoided if he had received different care and treatment.

227 Understandably, Mr Cox's parents' key question is whether more urgent treatment should have been initiated. My Professional Advisers have told me that Mr Cox was very ill when he was admitted and that staff recognised this and took appropriate action to assess him quickly before arranging urgent investigations and a review by a senior doctor. Regrettably, before the senior doctor arrived Mr Cox collapsed. My Professional Advisers have told me that this collapse was a sudden event which could not have been predicted and which he was unlikely to survive. Having studied all the evidence about events in the early morning of 25 September 2004, including Mr Cox's parents' recollections, and taken account of the advice of my Professional Advisers, I find there is no reason to believe that Mr Cox would have survived if different or quicker treatment had been provided by staff at the Trust.

228 Mr Cox's parents are particularly concerned that their son may have been in pain when he was admitted and that his pain was not treated appropriately. Health records show Mr Cox had been in the Trust for around 90 minutes before he was given pain relief. My A&E Nursing Adviser commented that Mr Cox's pain should have been assessed and pain relief should have been administered earlier. However, my other Advisers were less critical, recognising that

the staff had focused on the urgent action to diagnose and treat Mr Cox. I recognise it is likely that Mr Cox was in pain and pain relief should have been given more quickly to alleviate his distress. However, in the circumstances, especially in the light of the extensive tests, diagnosis and treatment which were taking place at the time, I do not consider this shortcoming amounted to service failure.

229 Mr Cox's parents remain distressed by remarks in their son's health records, particularly the reference to him being 'mentally handicapped' and they ask whether this indicated he was treated less favourably with regard to his learning disabilities. I have considered this issue in the light of the advice of my Learning Disability Nursing Adviser and, although I consider the remarks were insensitive, I do not find they indicated that Mr Cox was treated less favourably by the doctor concerned. The Trust has acknowledged and apologised for the distress this insensitivity caused Mr Cox's parents.

230 I now turn to the way staff communicated with Mr Cox's parents about his medical condition. My Professional Advisers have told me that medical staff would not have been in a position to provide much information about their diagnosis and proposed treatment plan until X-rays and tests had been completed. However, I share my A&E Adviser's view that it would have been preferable if more information could have been provided about Mr Cox's immediate management when he arrived at the Medical Admissions Unit. That said, I recognise there was a great deal of activity at the time and staff were focusing on assessing and investigating Mr Cox's condition. Therefore, I consider that, on balance, it was reasonable for staff to wait until tests had been completed before discussing Mr Cox's

condition with his family. Staff could not have predicted he would collapse suddenly and they expected they would have time to gather more information before explaining their findings and treatment plan to his family.

231 Mr Cox's parents feel deeply that they should not have been asked to leave the area where their son was being resuscitated. They feel they should have been allowed to be with him when he died and that they would have been able to comfort him at this time. In considering this issue I have taken account of advice from my Professional Advisers and referred to the guidelines about whether relatives should be present to witness resuscitation.

232 First, I consider whether Mr Cox's parents should have been allowed to stay with him during the attempted resuscitation. As I have said in paragraph 89, the Resuscitation Council (UK) issued good practice advice in 1996. This advice recognises that outside A&E departments there may be insufficient space and staff available to enable family members to be supported properly when resuscitation is being attempted. It is clear to me that this was the case when Mr Cox was being resuscitated in the Medical Admissions Unit at the Trust. Although I sympathise with Mr Cox's parents' wish to be with him when he died, I do not feel that I can criticise the decision to ask them to leave the area where he collapsed so staff could focus their effort on attempting to save his life.

233 I now turn to the issue of whether Mr Cox would have been aware of his parents' presence had they been with him while he was being resuscitated. Mr Cox's parents believe they could hear their son crying out, but they were not allowed to comfort him. However, as my Gastroenterology Adviser has explained, Mr Cox

would have been unconscious because his heart had stopped and he was not breathing so it would not have been possible for him to cry out. Therefore, although I fully acknowledge the distress which Mr Cox's parents suffered at this time, I am persuaded that the noises which they heard were not the result of their son crying out in pain and, regrettably, there is little they could have done to comfort him during the resuscitation attempt.

Care and treatment at the Trust: my conclusion

234 I have studied all the evidence about the actions of staff at the Trust when Mr Cox was admitted on 25 September 2004 and taken account of his parents' recollections and the advice of my Professional Advisers. Although I have identified some areas where the care and treatment could have been better, for example management of Mr Cox's pain and communication with his family, I have found the overall standard of care and treatment provided was in line with prevailing standards. I found no evidence to suggest that Mr Cox was treated less favourably for reasons related to his disability. I conclude that on balance, although there were shortcomings in the service provided by the Trust, these **did not amount to service failure**.

Complaint (f): complaint handling by the Trust

235 Mr Cox's parents remain dissatisfied with the way the Trust handled their complaint.

Key events

236 On 13 October 2004 Mr Cox's parents complained to the Trust about the care and treatment provided to their son. There were seven main areas of complaint:

- they felt unsupported and were not told how ill their son was;
- Mr Cox was not treated urgently enough;
- the admitting doctor did not notice Mr Cox's distended abdomen;
- staff were not concerned about Mr Cox's epilepsy medication;
- Mr Cox was not given pain relief;
- staff did not have an understanding of how to care for people with learning disabilities; and
- some of the radiographer's actions and comments were inappropriate.

237 A few days later Mr Cox's father clarified specific points of the complaint. In particular he said staff did not seem to realise the seriousness of the situation or take appropriate action although his son was in a critical condition.

238 On 22 November 2004 the Trust responded in writing to the complaint. The response referred to written health records and recollections of staff who were involved in caring for Mr Cox. It also referred to a review of events which was conducted by the surgical consultant who was on-call on 25 September 2004. Based on the consultant's review the Trust explained how Mr Cox's condition had developed and what

had happened inside his abdomen. It also noted the consultant had concluded that the care and treatment offered to Mr Cox had been '*expedient and correct*'.

239 The response included an explanation of the sequence of events when Mr Cox was admitted. It gave details about the actions of individual staff and the reasons for those actions. It included an explanation of the way in which the junior doctor had assessed Mr Cox, the examinations he performed and tests he carried out. It also explained that he had diagnosed an intestinal obstruction and had asked a senior doctor to review Mr Cox.

240 In particular, the response addressed the complaint about epilepsy medication and pain control, explaining that it had not been safe to give Mr Cox oral medication, but injections had been given for pain and nausea after the X-ray.

241 With regard to the actions and attitude of the radiographer, the Trust apologised for any unintentional offence which she had caused. The response also said that the team in the Medical Admissions Unit were used to caring for people with learning disabilities. Nonetheless, following the complaint, additional action had been taken to ensure staff were aware of local guidelines for managing patients with learning disabilities.

242 The Trust also offered to meet with Mr Cox's parents if they would find this helpful.

243 In January 2005 Mr Cox's parents made a second complaint because they had found the words '*mentally handicapped*' written in their son's health record by one of the doctors treating him on 25 September 2004. They said this indicated to them that staff were not prepared to put

in extra effort to assess Mr Cox's pain and, therefore, he had received a lower standard of care with regard to his learning disabilities and communication problems.

- 244 On 3 February 2005 the Trust responded offering an apology and explanation. It said the doctor concerned was new to this country and was unaware that he had used what was considered inappropriate language. The response included additional information about initiatives the Trust had taken to improve care and management of patients with learning disabilities. Mr Cox's parents were invited to work with Trust staff on further improvements if they wished.

My findings

- 245 In Section 2 of this report I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Trust's actions with those Regulations.
- 246 I find the Trust took appropriate action to investigate Mr Cox's parents' concerns by looking at recorded evidence and questioning staff involved in Mr Cox's care and treatment. It was also appropriate for the Trust to ask a consultant who had not been involved in the events complained about to review the care and treatment provided.
- 247 I find the Trust's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation. The tone of the response was sensitive and conciliatory. Appropriate apologies were offered relating to acknowledged shortcomings. The Trust also demonstrated commitment to providing a remedy for Mr Cox's parents and

this was in line with my *Principles for Remedy*. In addition to apologies, it gave an explanation about developments at the Trust which were relevant to the matters complained about and invited Mr Cox's parents to help with those developments. The Trust also appropriately offered a meeting to try and achieve resolution of any outstanding concerns.

- 248 Both of the Trust's responses were sent within the timeframe set out in the Regulations.

Complaint handling by the Trust: my conclusion

- 249 In terms of complaint handling, I find the Trust acted in line with the Regulations and demonstrated good practice as set out in my *Principles of Good Administration* and *Principles for Remedy*. I conclude that there is **no evidence of maladministration** in the way in which the Trust responded to Mr Cox's parents' complaints.

The complaint against the Trust: my conclusion

- 250 I have studied the evidence about Mr Cox's parents' complaint against the Trust regarding his care and treatment in the Medical Admissions Unit on 25 September 2004. I have considered the complainants' recollections and views and the professional advice I have received. I am satisfied that the actions of staff at the Trust were reasonable and I find **no evidence of service failure** on their part. I have also considered the way in which the Trust responded to the complaint made by Mr Cox's parents and I find **no evidence of maladministration**.
- 251 Therefore, I **do not uphold** Mr Cox's parents complaint against the Trust.

The complaint against the Healthcare Commission

Complaint (g): the Healthcare Commission's review

252 Mr Cox's parents are dissatisfied with the way the Healthcare Commission (the Commission) handled their complaint. In particular, they do not consider the Commission's report bore any relation to their complaints and they are concerned that the Commission did not take account of the specialist clinical advice they submitted with their complaint.

The basis for my determination of the complaints

253 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mr Cox's parents' complaint I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

My jurisdiction and role

254 Section 1 of this report sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

255 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way the Commission conducted its review. Specifically, I consider whether:

- there were any flaws in the Commission's review process which makes the decision unsafe;
- the Commission's decision at the end of the review process was reasonable; and
- the service the Commission provided was reasonable and in line with its own service standards.

256 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

My decision

257 For the reasons given below, I **uphold** Mr Cox's parents' complaint about the Commission's complaint handling. However, I did not consider it appropriate to recommend a further review by the Commission. Therefore, I decided to investigate the complaint myself.

The Commission's reviews

Key events

258 On 5 January 2005 Mr Cox's parents set out their complaints to the Commission in two separate letters. One letter centred on their complaints about the Surgery and the Out of Hours service; the other on the care and treatment Mr Cox received from the Trust. They included with their letter advice from a learning disability specialist. It is clear from those letters that Mr Cox's parents wanted to establish in particular whether:

- the Surgery had managed Mr Cox's care appropriately from August to September 2004;

- the actions of the Out of Hours GP had been appropriate;
- Mr Cox was seriously ill when he was admitted to the Trust; and
- the outcome would have been different had he been admitted to hospital earlier.

259 On 19 April 2005 the Commission decided to undertake a review of the complaint. The Commission took clinical advice from a GP Adviser and reported its draft decision to Mr Cox's parents on 27 February 2006. The Commission did not regularly update them about progress or any departure from its published timescales for the review.

The Commission's first decision

260 The Commission concluded that:

- the onset of appendicitis would have occurred over a period of a few days, and it was unlikely, therefore, that Mr Cox's episode of ill health in August 2004 related to his final illness in September 2004;
- telephone conversations had not been appropriately recorded by the Surgery;
- Mr Cox's epilepsy medication had been monitored appropriately by the Surgery; and
- the standard of care and treatment Mr Cox had received from the Trust had been appropriate.

261 The Commission made various recommendations to the Surgery including that it improve its record keeping. The Commission did not address Mr Cox's parents' complaint about the Out of Hours GP.

The Commission's final decision

262 On 28 March 2006 Mr Cox's parents wrote to the Commission saying they were dissatisfied with the Commission's findings because they felt no nearer to understanding why, or how, their son had died, which was the very purpose of making their complaint. They were also disappointed that no specialist advice about learning disabilities had been taken despite assurances to the contrary. Following those comments, the Commission decided to undertake further work on their complaint. Clinical advice was taken from a different GP Adviser and the case was discussed with a clinical practitioner with experience in the field of learning disabilities.

263 On 22 August 2006 the Commission reported its final decision. The Commission's findings about the Surgery and Trust, and its recommendations, remained broadly the same as in its draft report. The Commission did not address Mr Cox's parents' complaint about the Out of Hours GP and no mention was made in the Commission's decision of the specialist advice which Mr Cox's parents had submitted with their complaint.

My findings

264 I have explained that I assess the way in which the Commission has conducted its review by considering the review process, the decision and whether the service provided was reasonable.

265 I find the Commission's review process was flawed. Mr Cox's parents' complaint to the Commission had two distinct components: the care provided by the Surgery and the Out of Hours GP; and the care provided by the Trust. Despite two attempts, the Commission did not review the care provided by the Out of Hours GP at all. It also failed to respond to the

main thrust of the complaint about the Surgery and the Trust which was to establish whether the outcome for Mr Cox would have been different had he been admitted to hospital and treated earlier.

266 The Commission may take any advice which is needed for it to make a decision. I would expect that when the Commission reviews complaints about clinical care, it would obtain appropriate advice from a Clinical Adviser with relevant experience and expertise. In reaching its decision, the Commission only obtained professional advice from a GP. Clearly, in order to address Mr Cox's parents' complaints about the Trust appropriately, it was also necessary to obtain advice from a suitably qualified hospital clinician. Following Mr Cox's parents' intervention, the Commission did seek advice from a Learning Disability Nurse Adviser. However, the Commission's Adviser's comments were based on the Commission's Case Manager's oral précis of the case, rather than on a review of Mr Cox's clinical records. There is no evidence that the Commission took into account the professional advice which had been submitted.

267 I consider the clinical advice which the Commission obtained to make its decision about Mr Cox's parents' complaints was inappropriate and inadequate. This renders its decision, in respect of their complaint about the Trust, unreliable and unsafe.

268 I also find the service which the Commission provided was poor. It took the Commission 19 months to complete its review. The Commission's service standard at the time was that, in the majority of cases, the review process should take no longer than six months. Whilst I do not consider that failing to complete the review of Mr Cox's parents' complaints within

the Commission's general timeframe would necessarily amount to poor service, the Commission failed to keep them updated about the progress of their complaint. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should tell people if things are going to take longer than they had stated they would. Failing to do this, and failing to have kept Mr Cox's parents abreast of the progress of their complaint does not reflect good administrative practice or customer service from the Commission.

269 I conclude that the failings I have identified in the Commission's handling of Mr Cox's parents' complaint amount to **maladministration**.

Injustice

270 The injustice arising from the Commission's maladministration is that Mr Cox's parents experienced a further year and a half of uncertainty about the circumstances of Mr Cox's illness and death. They did not get the proper review of their complaint to which they were entitled and I can understand why they remained frustrated and dissatisfied at the end of the process.

271 Therefore, I **uphold** Mr Cox's parents' complaint against the Commission.

My recommendation

272 I **recommend** that the Commission apologise to Mr Cox's parents for failing to carry out a proper review of their complaint. The Chief Executive of the Commission has accepted my recommendation.

Section 4: the Ombudsman's final comments

273 Mr Cox's parents' overarching complaint is that their son's death was avoidable and he was treated less favourably for reasons related to his learning disabilities.

274 In assessing the actions of the bodies complained about I have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. I have taken account of available evidence and considered the advice of my Professional Advisers.

275 I have found no service failure in terms of the care and treatment provided to Mr Cox by the Surgery, the Out of Hours GP or the Trust and, although some insensitive remarks were written in the Trust records, I have found no evidence that Mr Cox was treated less favourably by any of the bodies complained about for reasons related to his disability.

276 I have found no maladministration in the way the Surgery or the Trust handled Mr Cox's parents' complaint. I have upheld Mr Cox's parents' complaint against the Healthcare Commission and I have recommended that the Healthcare Commission apologise to them for failing to carry out a proper review of their complaint.

277 In considering whether to make a finding about avoidable death I assess whether the injustice or hardship complained about (in this case Mr Cox's death) arose in consequence of any service failure or maladministration I have identified.

278 Having considered all the evidence and taken account of Mr Cox's parents' recollections and views, as well as the clinical advice I have received, I have found no service failure or maladministration relating to the care and treatment Mr Cox received from any of the bodies complained about. On that basis, my finding is that Mr Cox's death did not arise in consequence of any service failure or maladministration. Therefore, I cannot conclude that his death was avoidable.

Mr Cox's parents' response to my report

279 In their response to my draft report Mr Cox's parents expressed their great sadness at the death of their son, which they believe could have been avoided. They said they still feel very strongly that the actions of the GPs at the Surgery led to a delay in diagnosing his condition and that the Out of Hours GP failed him.

280 Mr and Mrs Cox raised a series of points and questions in response to my draft report. These principally related to the actions of the GPs at the Surgery and the Out of Hours GP, so I asked my First GP Adviser whether the response contained any new evidence which would cause me to question my findings and conclusions. My First GP Adviser told me he had carefully considered the matters raised in the response to the draft report but had found no new evidence that should cause me to reconsider my judgments in this case. My First GP Adviser also addressed a number of specific clinical questions posed by Mr Cox's parents and I have included this information at Annex B.

My concluding remarks

281 I acknowledge that Mr Cox's parents do not agree with all of my findings and decisions. However, I can assure them that their views have been taken into account, their complaints have been thoroughly and impartially investigated and that my conclusions have been drawn from careful consideration of the evidence, including the advice of independent professional advisers. I hope my report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*
- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*

- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*
- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*

- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

ANNEX B

Specific questions raised by Mr Cox's parents in their response to my draft report

My First GP Adviser provided the following information.

The link between constipation and appendicitis

There is no clear link here. When I say no clear link, what I mean is that there is no recognised association that is clinically useful when trying to diagnose patients. It is known that some cases of appendicitis seem to be associated with and probably caused by a small faecalith. This is a little grain of faeculent matter contained within the appendix that seems to be causing inflammation and hence the appendicitis. One might speculate that perhaps these are more likely to occur in somebody with constipation but there is no clearly recognised association of that sort and nothing that is in general use that links the two when trying to assess and diagnose patients. I am quite happy to state that there is no recognised link between the two that is used clinically at the bedside of patients. I have discussed this with a consultant surgeon who agrees with this view.

The link between a blocked bowel and appendicitis

There is not usually a link of this sort. I think the lay phrase blocked bowel could cover two separate well recognised surgical entities. The first is intestinal obstruction where the lumen of the bowel is blocked by, shall we say, faeces and constipation or a large tumour in cancer. The typical signs here are developing colicky abdominal pain, there may be constipation and vomiting, the abdomen may become distended and the bowel sounds, listened to with a stethoscope, become loud and have a characteristic nature. The other situation is a so-called ileus. This is where the bowel is not

blocked but just shuts down and stops working. The overall effect can be similar in that there can be pain, vomiting and constipation. Distension may be present. Peritonitis resulting from a burst somewhere in the stomach or intestines is a potent cause of ileus. In that case, there would also be generalised abdominal pain, typically not of a colicky nature and absent bowel sounds.

The clinical scenario of intestinal obstruction or ileus is not a feature of developing appendicitis. Once the early stages of acute appendicitis are over, it is possible that this could develop. Most people with acute appendicitis where the appendix is not surgically removed will probably develop a ruptured appendix with peritonitis. A variant of that is that the inflamed mass may be walled off into an abscess in the right lower abdomen. This variant is less serious in terms of the general health of the patient and they are more likely to survive this than perforation and peritonitis. A lot of surrounding structures get drawn into the inflammatory mass and this may cause bowel blockage and obstruction. So as a later feature in a typical case, it is possible. One can also get some of the features of ileus if the developing appendicitis is not recognised, perforation goes on to occur and ileus occurs.

In the comments from Mr Cox's parents, there is mention of the GP examining Mr Cox and identifying the fact that his colon was tender. I think in this case, the fact that he had tenderness on the left side was probably rather misleading for the GP. One of the characteristics of appendicitis is pain and tenderness in the right lower abdomen (often called the right iliac fossa). Tenderness on the other side of the abdomen would obviously lead the diagnosis away from appendicitis. Conditions of the large bowel such as diverticulitis or constipation can particularly cause left-sided tenderness.

The link between swallowing problems and appendicitis

Again, there is no recognised link that is clinically useful in assessing and diagnosing patients here. The only aspect that I can think to mention here is somewhat tangential to the case. Particularly in children, there is a recognised cause of abdominal pain called mesenteric adenitis. This is a situation where abdominal pain that can be similar to appendicitis is presented. However, the underlying cause is swollen lymph glands along the course of the intestinal blood supply. It is thought to be caused by a viral infection that may very easily cause a simultaneous sore throat and sometimes swollen lymph glands in the neck as well. So again, in this case, some of the features such as a reported cough and swallowing difficulties might be ascribed to another condition that can cause abdominal pain. In summary, there is no recognised link that is clinically useful.

The link between vocal sounds, acid reflux and bowel blockage

I have looked at and thought about the complainants' line of reasoning here. I think it is theoretically possible that obstruction and distension could be putting pressure on the stomach and causing acid reflux up into the oesophagus (gullet). If that was happening, it would cause indigestion, heartburn-type symptoms. It is conceivable that Mr Cox had such symptoms and made vocal sounds in response to that pain. However, it is my opinion that the pain from peritonitis and abdominal distension would be of a much greater magnitude than the indigestion experienced by this postulated mechanism. I cannot see, even if one accepts that there is a possibility this occurred, how that would be helpful in diagnosing or assessing the problem for the GP. I do not see how the GP could be expected to think

this was acid reflux in the oesophagus. Even if they did, that would again probably represent some false, misleading localisation of the problem away from appendicitis/peritonitis.

The absorption of rectal epilepsy medication

Again, this is an interesting and thoughtful point from Mr Cox's parents which I have considered carefully. I think it is perfectly reasonable to think from a common sense, first principle viewpoint that the presence of constipation might interfere with rectal absorption and/or that administration of enemas might wash out medication from the rectum and make a difference in that way. The question is whether it would make such a significant difference that the GP should have done something else which, in this case, I think would have to be admission for control of epilepsy by perhaps intravenous medication. Here, although the GP might well recognise the theoretical problem, I do not think they would have access to knowledge about how significant a difficulty this would present. I think that continuing to give the medication by the rectal route, despite this potential problem, would represent reasonable general practice.

The link between seizures and diagnosis

Once again here, I do not think there is any specific link that would have been helpful to the GP. It is known that intercurrent illness and the presence of fever itself can apparently lower the seizure threshold and lead to more frequent or more severe convulsions. That is a generally observed phenomenon by epileptics and their carers. There is nothing there that particularly points to a diagnosis of appendicitis. I think the GP would have accepted immediately that there was some other illness going on which in fact they characterised as a viral infection and they would not be surprised that that led to an increase in seizures of itself. That also, of course, was combined with difficulty in giving oral medication which would have had an effect as well. So there is nothing in that line of reasoning that I can see would have pushed the GP to consider appendicitis which is one particular (actually rather rare) cause for fever seen in general practice.

PHSO-0006

Printed in the UK by The Stationery Office Limited
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ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

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Millbank
London SW1P 4QP

Enquiries:
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Fax: 0300 061 4000
Email: phso.enquiries@ombudsman.org.uk

www.ombudsman.org.uk



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