Case 200600197: Greater Glasgow and Clyde NHS Board

Summary of Investigation

Category

Health: Hospital; Spinal

Overview

The complainant (Mr C) is 16 and was born with a progressive spinal deformity, for which he was reviewed in Glasgow between the ages of five months and 13 years. When he was 13, the service was transferred to Edinburgh. At review there, five months later, Mr C was told that an operation some years previously could have prevented his current, permanent, deformity. Mr C complained, therefore, about not having had such an operation in Glasgow.

Specific complaints and conclusions

The complaint which has been investigated is that it was unreasonable not to have performed an operation at an early age (*not upheld*).

The investigation has involved consideration of a number of issues to do with clinical practice and arrangements for the provision of health services which, although not all specifically raised in Mr C's complaint, are relevant to any assessment of how his healthcare needs have been addressed. Paragraph 1 of the main report outlines these issues.

Redress and recommendations

The Ombudsman has no recommendations to make.

Main Investigation Report

Scope of the investigation

1. The complaint from Mr C which I have investigated is that it was unreasonable not to have performed an operation at an early age. As the investigation progressed, I identified that the notes from Mr C's last review in Glasgow (in October 2004) said that he should be reviewed again in six months' time. In fact, he was next reviewed, in Edinburgh, in September 2005 (11 months later). I have, therefore, considered whether the delay in receiving a first review in Edinburgh was avoidable (see paragraphs 21 to 29).

2. As he had heard there was a lack of resources for scoliosis at the Royal Hospital for Sick Children, Yorkhill, Glasgow (the Hospital), where he was reviewed between 1991 and 2004, Mr C felt this was why he had not received an operation there and he included this in his complaint. However, the investigation has focused on whether Mr C should have had an operation because that is the crucial question. If the answer to that is 'no', the question of resources becomes irrelevant. In other words, if a patient is judged, on clinical grounds, not to need an operation, the question of whether the patient's hospital would have had the resources to do an operation is academic. As will become apparent from this report, there is no evidence at all in Mr C's clinical records to suggest that the decisions not to operate were based on anything but clinical grounds. Nor have I found any other evidence that treatment decisions were based on anything other than clinical judgement. Given this, I shall make no further comment about resources.

Form of the investigation

3. I was assisted in the investigation by two medical advisers to the Ombudsman – a consultant orthopaedic surgeon and a consultant orthopaedic and spinal surgeon, whom I shall refer to as the Advisers. Their role was to explain and comment on the complaint's medical aspects. We examined medical records and other information provided by:

- Mr C and his family (by writing, telephone and at a meeting);
- Greater Glasgow and Clyde NHS Board (the Board);
- the Scottish National Paediatric Spine Deformity Service (explained at paragraph 7);
- the Scottish Government Health Directorates (previously called the Scottish Executive Health Department, both of which I refer to in this report as SGHD); and

 NHS National Services Scotland (National Services), a government agency who are responsible for commissioning nationally designated services.

The complexity of the case also prompted extensive discussions within the Ombudsman's office (the Office) at senior level.

4. In line with the practice of the Office, the standard by which the events were judged was whether they were reasonable, in the circumstances, at the time in question. This approach is discussed in detail in the report's conclusion (see paragraph 15) because an understanding of it will help in the understanding of the Office's decision on the complaint.

5. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. An opportunity to comment on a draft of this report was given to Mr C, the Board and (on part of the draft) SGHD, National Services and the Scottish National Paediatric Spine Deformity Service.

Background

6. A reminder of the abbreviations used in this report is at Annex 1. I briefly summarise here Mr C's spinal history until the time of his complaint to the Board at the end of September 2005. Mr C was born in 1991, six weeks prematurely and with a range of medical conditions, including scoliosis, an abnormal curve of the spine. He was seen on many occasions about other aspects of his condition, but I shall refer in this report only to the scoliosis aspect. That was reviewed at least annually at the Hospital. For some years the reviews were done by a consultant orthopaedic surgeon, Consultant 1, until he retired in 1996. Two other consultant orthopaedic surgeons, Consultant 2 and Consultant 3, were then involved in Mr C's care for a time, liaising with each other about his treatment. Consultant 2 then became the sole consultant reviewing Mr C. Annex 2 summarises the reviews, indicating the progression of the scoliosis and the doctors' views on it over the years.

7. Annex 2 also summarises Mr C's first review in Edinburgh, which was in September 2005, by Consultant 4, a consultant orthopaedic spine surgeon. I should explain here the transfer of the scoliosis provision to Edinburgh. Treatment of scoliosis is highly specialised, and it was considered that a specialist service, with the surgery concentrated in one location, would enable young patients across the whole of Scotland to benefit from the care that a national service could provide. In October 2004, therefore, a decision was taken, on the advice of the National Services Advisory Group, by the then Health Minister to create the Scottish National Paediatric Spine Deformity Service (the National Spine Service). The service started on a national basis on 1 April 2005, based in the Royal Hospital for Sick Children, Edinburgh, with Consultant 4 as its Director.

Complaint: It was unreasonable not to have performed an operation at an early age

8. In his complaint, Mr C summarised his history. He said that, at his first review at the National Spine Service in Edinburgh, Consultant 4 said he should have had an operation some years before and that, as he was now 14, his spine was permanently deformed and all that could be done was to prevent further damage.

9. Turning to the question of why Mr C received no surgery in Glasgow, I set out comments from various sources in this paragraph and at paragraphs 10 to 13, followed by the Advisers' comments. Here, I summarise Consultant 2's comments to the Board in October 2005 about Mr C's complaint there:

Regarding the spine, a MRI scan indicated that there seemed to be no obvious abnormality within the spinal cord itself. So the primary aim in this condition was to try and control the spinal curves well enough to maintain as cosmetically satisfactory a situation as was feasible, whilst balancing the risks of any interventions with the benefits. When younger, [Mr C] was treated with a series of plaster jackets and spinal bracing. It was always acknowledged that surgery could have a role. During most of his childhood, growth did not seem to alter the situation significantly, and it was accepted that the final period of more rapid growth in adolescence would be the last test of this. For surgery, the risks as well as the benefits of what would be a major procedure need to be considered, as well as the alternatives. The reason that he was not subjected to spinal surgery was that the drawbacks and hazards did not seem to be balanced by sufficient benefit to him, but the situation was subjected to follow-ups. I do not think a decision in these matters is either straightforward or unambiguous. The issues cannot be simplified unduly and, in advising on any particular surgical procedure, its nature, appropriate alternatives and any significant side-effects which may result, need to be weighed.

10. I requested comments from the Board, who said that, during the setting up of the National Spine Service, a question had been raised about the possibility of Consultant 2 as being conservative in his clinical management of cases. Therefore, the Board arranged for two external reviews of most of his scoliosis cases. The reviews did not include Mr C's case. The Board said that the reviewers had commented that views about the use of surgery in scoliosis varied significantly amongst surgeons and centres. They also said that the reviewers saw Consultant 2's overall approach as being at the conservative end of a range of options, rather than outside normal practice. I consider that it would be inappropriate to discuss the reviews in more detail in this public document, except to say I am satisfied that Consultant 2's performance was not considered to have been unacceptable.

11. Consultant 4 also provided comments to me, including:

It is probable that this curve had been progressing since [Mr C] was first diagnosed at the age of six weeks and ideally he would have benefited from surgical treatment, including the insertion of a growth rod, possibly ten years before I saw him. This treatment would have slowed down the progression of his deformity but would not have completely controlled it: he would still have had a significant deformity, although not as severe as leaving it untreated.

12. In a letter to me, National Services said, 'Spinal scoliosis surgery in children and young people is highly complex, and bears a significant risk of serious complications'.

13. The Board told me that Consultant 2 had referred to two documents as having contributed to his clinical practice at the time in question. The first document was a 2003 briefing about a review of the management of children with spinal deformity. I have seen this paper and summarise two particular points:

- the management of spinal deformity in young children may include a range of options: no intervention and watchful waiting; spinal positioning; posture management, using seating and other equipment; bracing; plaster jackets; and surgery;
- there is neither a professional consensus nor any definitive literature as to what precisely is the best or most effective treatment for spinal deformity in children who [as in this case] also have other disorders.

The second document was *The Management of Spinal Deformity in the United Kingdom: Guide to Practice* – a 2001 paper by the British Scoliosis Society (the professional group of clinicians and scientists with a special interest in scoliosis). Again, I have seen this and note, in particular:

Many patients attending clinics for the assessment of spinal deformity will not require surgery. A proportion will require treatment with orthotic devices and regular follow-up until at least the end of growth when progression of spinal deformity will generally have ceased.

14. I summarise in this paragraph the Advisers' comments (which need to be considered with my conclusions, rather than in isolation):

The initial approach to treat Mr C with plaster was entirely reasonable because Mr C's kidney and foot conditions were still being considered and because he was still too young for major spinal surgery, particularly in view of his premature birth and respiratory distress syndrome. During this time, his deformity changed very little and his plan for the future was drawn. This comprised careful observation and consideration of the possibility of spinal surgery if there was spinal deterioration (see Annex 2 – October 1993). The MRI scan (see Annex 2 – July/October 1993) was a completely correct action to exclude any spinal cord abnormalities, particularly in view of the foot deformity.

The final plaster jacket was removed in January 1994 (see Annex 2). Scoliosis is an abnormality in vertebral body formation and segmentation which, when combined with growth, causes a progressive spinal deformity. It was, therefore, predictable (as the two affected areas of significance were both on the same side of Mr C's body) that this curve would progress with his growth. Surgery (a cutting out or fusion of the vertebrae in question) between ages two and four would have produced a well balanced spine and probably a predictable and stable outcome, balancing the growth between both sides of the spine. It is a relatively minor procedure, and, rather than wait for the deformity to develop, it is certainly better to do something like this at an early age - ideally between the ages of one and three. So an opportunity was missed at this point. However, the clinical notes record (see Annex 2 - for example, October 1993 and January and April 1994) that the spine was looking satisfactory. Where there is a complex deformity of this sort, it is justifiable to wait and see whether the spinal curve progresses, provided there is careful follow-up and the possibility of surgery is not ignored. Therefore, we consider that it was acceptable not to operate at this point: the consultant's approach simply reflects one of various possible and acceptable views about managing this kind of complex deformity.

The second opportunity to consider surgery was at around age ten or 11 before a main growth spurt would be expected - when it would be technically correct to say that the deformity was progressing – although it was happening so slowly that, at the time, one could have argued about whether it was a progression. There is no question that, in hindsight, it would have been better to have operated on Mr C before such a growth spurt. But we do understand how the treating team in Glasgow were lulled into a sense of security by the curve's apparent lack of progression.

When Mr C was seen by Consultant 4 in Edinburgh in September 2005, it was clear that there had been a major progression in the spinal curve. Consultant 4 had the great benefit of being able to look back at this case in hindsight, knowing how things had turned out. In part, that outcome of Mr C's deformity was predictable. However, we do not think anyone would have predicted that Mr C's progression at that time would have been as severe as was the case.

In conclusion, with hindsight, Mr C should have been treated surgically at around age ten and would probably have been better treated at around the age of two to three, with possible further surgery during adolescence. But Mr C's spinal deformity was very difficult and complex, and in some cases the only way one can know the outcome is to wait and see. What is obvious now was not obvious at the time, and we do not believe that it was unsatisfactory that - without the benefit of knowing what would happen - the Glasgow surgeons did not operate.

Crucially, one must never forget that this was a very difficult and complex spinal deformity; surgery would have been very far from simple - and could have killed Mr C.

Conclusion

15. Some of the points in paragraphs 10 to 14 imply criticism of the Glasgow clinicians. That raises the question of why we have not upheld the complaint. Paragraph 4 mentions the standard by which the Office judge events, and this now needs to be explained. The standard by which we judge doctors' actions is

whether they were reasonable, in the circumstances, at the time in question. We do not apply a standard of perfection. Rather, we consider whether the decisions and actions taken were within the boundaries of what a reasonable doctor, from a similar area of medicine, at a similar grade, would consider to have been acceptable practice in terms of knowledge and practice at that time. The fact that, in the same circumstances, one doctor might do one thing and another doctor might do something different does not necessarily mean that either is wrong – or even that one is better than the other. Both actions might be considered to fall within this range of reasonable practice – and both actions might even be equally reasonable. It should be clear, therefore, that, in considering one doctor's actions, we do not compare them with the actions of other doctors in the case. It would be inappropriate for us to compare any of the Glasgow consultants with those at the National Spine Service, and I make no attempt to do this.

16. Additionally, it would not be appropriate for the Office to judge the doctors' actions in Mr C's sad situation by using hindsight. In other words, our decision should not be based on how things had turned out for Mr C by the time of his first review in Edinburgh. The Office's approach is to consider what evidence and information (for example) was available to a patient's doctor at the time in question and whether his or her actions were reasonably based on that information. This is because that is the only information on which the doctor could have based his or her decisions at the time.

17. I turn now to the question of whether the doctors' actions fell within a range of reasonable practice in Mr C's case.

18. Annex 2 summarises the situation at Mr C's reviews in Glasgow and the consultants' thinking, showing that their approach was one of watchful waiting. 'Wait and see' is a common approach in medicine. Patients often prefer what appears to be a more active approach, such as drugs or surgery, wrongly believing that watchful waiting means that nothing is being done. However, it means seeing a patient at appropriate intervals and actively considering what has been happening to their condition since the previous consultation – for example, considering whether there are new clues that might indicate a change of plan. In other words, it is active watchfulness. It is relevant to mention here the risks of a particular surgical operation are greater than the potential benefits, or whether the risks of 'wait and see' outweigh the risks of surgery. Many of the

comments at paragraphs 9 to 14 refer to the risks and to this balancing of risks against benefits. In itself, therefore, watchful waiting is a perfectly acceptable medical practice and, indeed, in some cases, is more appropriate than drugs or surgery.

Amongst the criticisms in paragraphs 10 to 14 are the Advisers' comments about two possible missed opportunities to operate. However, it must also be noted that the many comments in paragraphs 10 to 14 also recognise the complexity, not only of Mr C's spinal condition but also of his overall medical condition, and the complexity of any operation. And the comments make many references to the need (discussed at paragraph 18) to weigh the risks of surgery against the potential benefits. Additionally, the reviewers who were brought in by the Board for the two reviews of Consultant 2's scoliosis patients had a clinical duty to take action if they considered that Consultant 2's performance presented a potential danger to patients. It is relevant that they did not reach such a view. I note also the comments that there was no agreement amongst doctors in the United Kingdom about how best to treat patients with scoliosis or those who also had other medical conditions (see paragraphs 10 and 13). And I note the various comments about the range of options open to the Glasgow doctors and about watchful waiting as one of those options (for example, see paragraph 13). It is by no means the case that the recommended option is automatically surgery. For example, the Advisers said (see paragraph 14), '... the consultant's approach simply reflects one of various possible and acceptable views about managing this kind of complex deformity'.

20. This report has referred to doctors as having to weigh up risks and benefits. In considering this complaint, we, too, have had to weigh things up – in our case, arguments for and against the Glasgow doctors' actions. This has been particularly difficult and has involved senior staff in the Office, including the Ombudsman. A particularly telling point for us is the fact that one simply cannot say that if Mr C had had surgery, things would definitely have turned out well for him. Instead, the consequences could have been tragic and final: as the Advisers said, Mr C could have died. On balance, then, we consider that the decisions of Consultant 1, Consultant 2 and Consultant 3 not to operate were reasonably based on the evidence available to them and, although close to the border, were within the range of reasonable practice, in the circumstances, at the time in question. I do not, therefore, uphold the complaint.

Delay in receiving a first review in Edinburgh

21. As noted in paragraph 1, as this investigation progressed, I identified that the notes from Mr C's last review in Glasgow (in October 2004) said that he should be reviewed again in six months' time (that is, April 2005). In fact, he was next reviewed, in Edinburgh, in September 2005 (11 months later). I have, therefore, considered whether the five-month delay of April 2005 to September 2005 in receiving a first review in Edinburgh was avoidable. (I should note at this point that Mr C said that two six-monthly reviews in Glasgow would instead have been annual if his (Mr C's) mother had not intervened. The clinical records would form the only source of firm evidence from which to establish the facts about this. As the records do not cast any light on it, I am unable to form a view and will, therefore, make no further comment about whether the six-monthly reviews were prompted by Consultant 2 or by Mr C's mother.)

22. To recap, then, Mr C was to have a six-month review with Consultant 2 in April 2005. This was cancelled because the National Spine Service started at that time in Edinburgh, where Mr C had his first review in September 2005.

23. SGHD said to me that, once a Minister's approval is given to the creation of a national service, responsibility for managing the transition to such a service rests with the National Services Division of National Services. (Paragraph 3 explains National Services.) SGHD said that national services always start on 1 April and that it is SGHD's responsibility to ensure that the timing of Ministerial approval allows enough time before the following April for the relevant national service to be set up. They also said that they considered that enough time had been given to National Services in this case, as the Minister's decision had been taken the previous October. And they said that there was more of a caseload for the new National Spine Service than had been expected because the number of Glasgow patients whom doctors at the National Spine Service decided to treat by surgery was greater than had been expected. SGHD also told me that National Services alerted them, as was their responsibility, to the National Spine Service's difficulties in dealing with the large number of patients, and that urgent action was, therefore, taken by National Services, under the direction of SGHD, to improve the situation. This included enabling some patients to have surgery in England, and Mr C was one of these.

24. Throughout my correspondence with National Services, there has been no suggestion from them that they felt they should have been given more time to

plan and set up the National Spine Service. They talked about the funding, staffing and clinic resources that had been put into the National Spine Service but, like SGHD, indicated that the fact was that there were a great many patients, many of whose conditions were complex and required lengthy assessment.

25. I also asked Consultant 4 about Mr C's wait for his first review in Edinburgh. Consultant 4 had already been providing a scoliosis service in Edinburgh and said that the creation of the National Spine Service meant he had to see around 150 Glasgow patients in addition to his others. The Glasgow patients all had complex problems, whose review was a major undertaking, involving a considerable number of extra hours of work for about a year. He said that the complexity of all the Glasgow cases – some of whom had even more severe problems than Mr C – meant that he could not have seen Mr C any earlier.

Conclusion in respect of the delay in receiving a first review in Edinburgh

26. I note the Advisers' comments (see paragraph 14) that there was a serious worsening of Mr C's spinal curve between 2004 and 2005 but that they did not consider that the severity of that particular progression could reasonably have been predicted.

27. The clinical notes for April and October 2004 (see Annex 2) show that Mr C had grown but, in October, the curve had not changed. By the time of his Edinburgh review, in September 2005, the picture was much worse. We cannot say that the extra five months that he had to wait definitely had a negative effect. But we can say that he lost the chance of that earlier assessment while he was at a critical age, in terms of the likely development of his scoliosis.

28. I have, therefore, considered whether that lost chance was the fault of any of the bodies in this case. I am satisfied that there was no fault by SGHD. They have satisfactorily explained that the Minister's decision to set up the National Spine Service allowed enough time for National Services to do their work. National Services have not argued that they were not given enough time, and the investigation has revealed no evidence of fault by them. Nor do I see evidence of fault by the National Spine Service. It is clear that Consultant 4 and his team were faced with a large number of patients with complex conditions, which took time to handle. I also note that, when significant delays were identified, action was taken, resulting in, for example, the offer to some patients

of surgery in England. I am also satisfied that no responsibility for the delay can be placed on the Board, whose role by this time had ended.

29. In conclusion, I recognise that the delay meant that Mr C did not have the chance of an earlier assessment. But it is not possible to know whether an appointment in April 2005 would have shown a change in his condition sufficient to merit a change in his management. And I do not consider that the delay was due to any avoidable fault by those concerned. Rather, I am satisfied that it was simply a reflection of the number, and complexity, of cases that required more time than could reasonably have been envisaged.

Annex 1

Explanation of abbreviations used

Mr C	The complainant
The Hospital	The Royal Hospital for Sick Children, Glasgow
The Advisers	Medical advisers to the Ombudsman
The Board	Greater Glasgow and Clyde NHS Board
The National Spine Service	The Scottish National Paediatric Spine Deformity Service
SGHD	The Scottish Government Health Directorates
National Services	NHS National Services Scotland, a government agency
The Office	The Ombudsman's office
Consultants 1, 2 and 3	The consultants who dealt with Mr C's scoliosis at the Hospital
Consultant 4	The consultant who reviewed Mr C in Edinburgh in September 2005

Summary of part of Mr C's clinical records

November 1991 [age 5 months] - Appears to have VACTERL syndrome [an association of various abnormalities]; has kidney, anal and foot problems, mild thoracic curve. X-rays show multiple vertebral malformations in the spine. Unfortunately most of these are on the left so are unlikely to balance themselves out satisfactorily. The important thing about the spinal aspect is to try to preserve spinal alignment. I would suggest we do this by plaster casts. I do not think there is any surgical option here. On waiting list for corrective plaster jacket.

December 1992 [age 1 year 6 months] – Mother concerned because she felt [Mr C]'s back had a curve which she had not noticed before and I have reassured her that this is the curve that has always been there.

February 1993 [age 1 year 8 months] – I think the sensible thing would be to see if we can improve his alignment again in a further corrective cast – have put him on the waiting list.

July 1993 [age 2 years 1 month] – His plaster jacket is giving good correction of his scoliosis. The plan for [Mr C] must be to consider long-term management, which would really require to be spinal stabilisation if there was any evidence of progression. Therefore, I think it is now time to explore the possibility of a MRI scan to see his spinal canal to see if any intraspinal malformations.

October 1993 [age 2 years 4 months] – The MRI has shown no evidence of clear intraspinal problems. The scoliosis remains unchanged and cosmetically [Mr C]'s back looks satisfactory. I am really not certain how much we are achieving with a jacket now. I think we could take it off in 3 months and carry out careful observation; if there is any deterioration in his spine, we would need to consider the possibility of spinal surgery.

January 1994 [age 2 years 7 months] – Jacket been removed. Back, cosmetically, very nice. See in 3 months.

April 1994 [age 2 years 10 months] – Spine remains satisfactory without jacket's support. Curve is exactly the same as on first visit, November 1991. Well balanced shape. See in 4 months.

August 1994 [age 3 years 2 months] – No cosmetic or radiological change in spine. Obviously a little imbalance but in view of the multiple nature of the anomalies I would not feel we should interfere here unless absolutely necessary. See again 6 months.

February 1995 [age 3 years 8 months] – Spinal curve seems to be slowly progressing and I think we need to put him in a Milwaukee brace to try to control the trunk alignment. The workshop will send for him so that this can be made. I have a slight concern that there may be a slight progression in the scoliosis and I will look carefully at all the x-rays then to decide if we need to interfere in any way.

August 1995 [age 4 years 2 months] – Has had brace about a month. Continue weaning [Mr C] into it and see in 3 months.

November 1995 [age 4 years 5 months] – Remains nicely balanced with no increase in spinal deformity; no need to interfere. Brace needs adjusting today. See in 6 months.

May 1996 [2 reviews] [age 4 years 11 months] - Nice alignment. X-rays been reviewed: if anything, curve looks a bit straighter. No cause for concern, therefore. See in 6 months.

[The above reviews were all done by Consultant 1, who left in 1996. Consultants 2 and 3 were then involved in the reviews for a while, liaising with each other.]

November 1996 [age 5 years 5 months] – The curve seems to have been stable over the past year or two. The brace has not been worn for a few months as the fit became poor. I spoke to [Consultant 2] after the clinic and it was agreed there was probably little value in continued bracing. We simply have to wait and see how things develop as in a spine like this it is simply impossible to be sure just how the bones will behave. See in 6 months.

March 1997 [age 5 years 9 months] – Review brought forward as staff at [Mr C]'s school felt he was leaning forward more than usual. There is a

noticeable scoliosis. X-rays today confirm a fairly static curve. In view of the various abnormalities, this will have to be watched closely. See in 3 months. [This review was done by a doctor in the orthopaedic department.]

June 1997 [age 6 years 0 months] – X-rays compared with those from the last visit show the curve is not progressing. We need to see in 1 year. [This review was done by a doctor in Consultant 3's clinic.]

May 1998 [age 6 years 11 months] - [Mr C] tends to stand with a tilt of his trunk. I think he is at the borderline stage at present and we should review him again in 1 year. [This review was done by a doctor in Consultant 3's clinic.]

May 1999 [age 7 years 11 months] – [Mr C] stands with quite a marked tilt at the shoulders. Mother is concerned that for past 1 or 2 years he has been tending to lean further forwards. Gets backache. As far as can be seen, the curve measures 8 degrees more than a year ago – but he has a spine which makes it difficult to know exactly where to put the lines for measurement. The trunk is a difficult shape, and I am not sure how easy it would be to brace. On return from holiday I will go through the x-rays with [Consultant 2].

[All the Glasgow reviews from November 1999 were done by Consultant 2.]

November 1999 [age 8 years 5 months] – X-ray does not show any obvious progression: curve seems same as earlier this year. In fact, I note an x-ray from 1991, measuring a more significant curve. The relevant measurements are pretty well in the same range and I do not think they provide any convincing evidence of progression. He is now aged 8½ and I think there is little one would do just now. He needs to be kept under review. If the curve becomes more marked in future, obviously something like an extension osteotomy may be a possibility. See in 1 year.

November 2000 [age 9 years 5 months] – Scoliosis appears unchanged, ie not progressing. See in 1 year.

November 2001 [age 10 years 5 months] – Not easy to see what's happening – certainly not becoming any more obvious, despite his growth. See in 1 year.

December 2002 [age 11 years 6 months] – No appreciable change. See in 1 year.

September 2003 [age 12 years 3 months] – At first the curve looked as though it had increased but when compared with previous x-ray, it seemed more a question of where the measuring line had been placed. We ought perhaps to look at him a little sooner than we usually have and see him in 6 months.

April 2004 [age 12 years 10 months] – [Mr C] has grown 3.5 cm since last seen. Upper curve measurement increased and certainly I think his shoulder is a bit more obvious now. Apart from some muscular aches he is not unduly bothered and I think his mother accepts that this situation is just relating to the growth that he has done. He has got quite a stiff lower back, and whilst obviously we could fuse the upper area to address some of this, overall that might compromise some of what he can do. See 6 months.

October 2004 [age 13 years 4 months] – [Mr C] has still been growing at a fair rate – some 4 cm since last visit. X-ray shows curve remains same. In view of his growth we have to keep him under review. Surgery [fusion of the upper area] was discussed on the previous visit and he and his mother had nothing more to raise on the matter today when I asked them. See 6 months.

[Mr C was not seen in 6 months – April 2005 – because of the transfer of the scoliosis provision to Edinburgh. He was reviewed there in September 2005, and the following summarises the relevant part of Consultant 4's clinical notes.]

September 2005 [age 14 years 3 months] – Young man with extremely severe spinal deformity due to multiple unclassifiable anomalies. Has an extreme scoliosis. Left shoulder markedly raised and upper trunk lists to one side. Pelvis slightly tilted down on one side. Spinal movements are severely restricted by stiffness. I am astonished that his spinal abnormality should have been detected at 6 weeks but no effective treatment given. Ideally, he should have been treated by spinal surgery - probably 10 years ago. He was treated in spinal jackets and a brace, but no treatment was given after age 4. Unfortunately, there is no good solution for the problems that he now has. [Mr C] has an extremely severe rigid deformity and it would be very difficult to obtain significant correction. However, he is skeletally immature and without treatment it is likely that this curve will deteriorate even further. I will arrange a MRI scan of the whole spine and I have put him on my waiting list for corrective spinal surgery.

[end of Annex 2]