SPSO Scottish Public Services Ombudsman

The Scottish Public Services Ombudsman Act 2002

Investigation Report

UNDER SECTION 15(1)(a)

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Scottish Parliament Region: Lothian

Case ref: 201603725, Lothian NHS Board - Acute Division
Sector: Health
Subject: NHS Boards and Authorities / Appointments / Admissions (delay / cancellation / waiting lists)

Summary
Mrs C complained about the delay in arranging an endoscopy procedure for her late husband (Mr C). She said that although Mr C's GP requested an urgent referral for him, the required procedure was not undertaken until more than three months' later. At this time, a malignant tumour was found in his oesophagus which was later determined to be inoperable. Mr C died seven months after this.

Mrs C complained to the board who said that as Mr C's review was not marked 'urgent suspicion of cancer', it was not upgraded to be seen with the highest priority at a time when there were substantial waiting time delays for endoscopy procedures to be carried out. The board accepted that there had been a delay and said that they were planning to put procedures in place to increase their capacity to meet endoscopy waiting time targets.

We obtained independent clinical advice and found that the board's approach had not been a reasonable one in that there were too many priority streams for grading the urgency of endoscopies. There was already sufficient clinical information available for Mr C's case to have been triaged as a suspected cancer case and, from the available guidance, it appeared that Mr C's GP had followed the instructions given. We upheld the complaint.

Redress and Recommendations
The Ombudsman's recommendations are set out below:

What we are asking the Board to do for Mrs C:

What we found	What the organisation should do	Evidence SPSO needs to check that this has happened and the deadline
There was a delay in arranging an endoscopy for Mr C	Send Mrs C a written apology for the unreasonable delay in arranging the endoscopy	Provide a copy of the letter of apology by 21 July 2017

We are asking the Board to improve the way they do things:

What we found	What should change	Evidence SPSO needs to check that this has happened and deadline
Delays in the provision of endoscopies	The delay should be reduced	Evidence of the steps being taken to meet Scottish Government standards by 21 August 2017
There were too many different priority streams for grading the urgency of endoscopies and the Board's guidance did not flag the pathway 'urgent suspicion of cancer'	Remove the referral 'urgent suspicion of cancer' or make it absolutely clear that an alternative referral route is required	Evidence of the replacement/new guidance by 21 July 2017
There were problems with triage	Urgently review their triage process to ensure that patients with dysphagia are appropriately triaged	Evidence that a review has taken place by 21 July 2017

Evidence of action already taken

The Board told us they had already taken action to fix the problem. We will ask them for evidence that this has happened:

What we found	What the organisation say they have done	Evidence SPSO needs to check that this has happened and deadline
Delays in the provision of endoscopies	Provided a nurse endoscopist/ additional staffing from December 2016	Immediate confirmation that the additional staff are now in place This has been provided.

Who we are

The Scottish Public Services Ombudsman (SPSO) investigates complaints about organisations providing public services in Scotland. We are the final stage for handling complaints about the National Health Service, councils, housing associations, prisons, the Scottish Government and its agencies and departments, the Scottish Parliamentary Corporate Body, water and sewerage providers, colleges and universities and most Scottish public authorities. We normally consider complaints only after they have been through the complaints procedure of the organisation concerned. Our service is independent, impartial and free. We aim not only to provide justice for the individual, but also to share the learning from our work in order to improve the delivery of public services in Scotland.

The role of the SPSO is set out in the Scottish Public Services Ombudsman Act 2002, and this report is published in terms of section 15(1) of the Act. The Act says that, generally, reports of investigations should not name or identify individuals, so in the report the complainant is referred to as Mrs C and her late husband is Mr C. The terms used to describe other people in the report are explained as they arise and in Annex 1.

Introduction

1. Mrs C complained to my office about Lothian NHS Board – Acute Division (the Board)'s delay in arranging an endoscopy procedure for her late husband (Mr C). The complaint I have investigated is that there was unreasonable delay in the Board arranging an endoscopy procedure for Mr C (*upheld*).

Investigation

2. In order to investigate Mrs C's complaint, my complaints reviewer considered all the information provided by Mrs C and the Board (including the complaints correspondence and Mr C's relevant clinical records); they made further formal enquiries of the Board; and, obtained independent advice from a consultant gastroenterologist (the Adviser). All this information has been taken into account and, in this case, we decided to issue a public report because of the significant injustice caused and the wider public interest.

3. This report does not include every detail investigated but I am satisfied that no matter of significance has been overlooked. My complaints reviewer carefully considered all the information provided during the course of the investigation and Mrs C and the Board were given an opportunity to comment on a draft of this report.

Complaint: There was unreasonable delay in the Board arranging an endoscopy procedure for Mr C

Background

4. On 17 March 2015, Mr C's GP made an urgent referral for him to be seen by a gastroenterologist. The GP asked for him to be seen 'soonest'. Three months later (on 19 June 2015), Mr C had a gastroscopy and a malignant tumour was found in his oesophagus. Early the following month this was confirmed as inoperable and, regrettably, in February 2016, Mr C died.

5. Mrs C complained to the Board on 16 May 2016 about Mr C's 13 plus week's wait for a gastroscopy. She said that this was well outwith required waiting times and that had Mr C been diagnosed earlier, his chances of effective treatment would have been improved.

6. The Board replied on 14 June 2016. Essentially, they apologised for the acknowledged delay, which they said was unacceptable. However, they said that because the endoscopy service was significantly challenged, and as Mr C's

referral had not been marked 'urgent suspicion of cancer', it had not received the highest priority. However, in view of Mrs C's complaint, the Board reported that they had begun a Serious Adverse Event review into the delay. Meanwhile, they said that they were supporting the Endoscopy Service to increase capacity and reduce waiting times. They added that they were truly sorry that this would not change Mr C's experience but hoped that the information would provide some assurance that the matter had been taken seriously and was being actively addressed. Mrs C was signposted to me in the event that she was dissatisfied with the outcome of her complaint and as she remained unhappy, she complained. She said that she wanted to ensure that the same did not happen to another family.

The Board's response

7. In their complaint response to Mrs C (see paragraph 6), the Board referred to having started a Serious Adverse Event review and so my complaints reviewer requested sight of this. In fact an Adverse Event Review was undertaken in May 2016 and referenced the concerns Mrs C raised in her complaint letter. In their review, the Board identified the key issues as being that the GP did not refer Mr C as a patient with 'urgent suspicion of cancer'; the triage-er did not upgrade the referral to 'urgent suspicion of cancer'; and there were substantial waiting time delays for endoscopy in the Board's area. In conclusion, the Board recommended that they would continue to increase their endoscopy capacity to meet waiting time targets; GPs who suspected cancer should refer patients as 'urgent suspicion of cancer'; and triage consultants who suspected cancer should upgrade referrals to 'urgent suspicion of cancer'.

8. In view of this, my complaints reviewer asked the Board whether, at the time of Mr C's referral in March 2015, GPs were aware that there was a category of referral marked 'urgent suspicion of cancer' and whether they had been notified of the Board's recommendations. Similarly, whether triage consultants had been advised to upgrade their referrals. The Board replied at the beginning of December 2016, providing a web link to their Referral Guidelines on Gastro - Intestinal Services/Dysphagia (swallowing difficulties) which they said had been in place since 2015, which would assist GPs. They commented that GPs were aware of it and used it regularly. Further, all appropriate surgical consultants who triaged were reminded of the web link/address at the Multi-Disciplinary Meeting which had discussed Mr C's case.

Medical advice

9. My complaints reviewer requested that the Adviser review this information, together with Mr C's clinical records. They told me that their view was that the Board's approach in the matter was not a reasonable one and it appeared to them that there were too many different priority streams for grading the urgency of endoscopies. Their view was that as Mr C's referral was marked urgent by the GP, and with the clinical information provided, it should have been triaged at the point of receipt and upgraded to a suspected cancer case. The Adviser also followed the web link provided by the Board (about which they said GPs were aware and aware of the category of referral 'urgent suspicion of cancer') but they said that there was no mention that GPs should refer through a separate pathway 'urgent suspicion of cancer'. They added that this guidance made it very clear that patients with dysphagia should be referred urgently and that there was a significant risk (ten percent of finding cancer. They said that from reading the guidance, it was their view that Mr C's GP had followed the instructions given. They said that had it been necessary for a patient to have been referred separately through a suspected cancer pathway, it should have been flagged on the guidance but it was not.

10. Given Mrs C's concerns that an earlier diagnosis would have increased Mr C's chances of receiving effective treatment, the Adviser was asked specifically to comment. They said that at the time of diagnosis and staging of Mr C's oesophageal cancer, it would not have been possible to provide him with curative treatment because of the spread of the cancer to distant lymph nodes. They confirmed that it was not possible to say whether these distant lymph nodes would have been involved had the diagnosis been made much earlier although this was possible. The Adviser added that if there had been no involvement of distant lymph nodes, Mr C's treatment would probably have been different and may have involved a different sort of chemotherapy (neo-adjuvant – treatment given as a first step to shrink a tumour) with consideration of surgery. Unfortunately, the position would have remained the same, that an overall five year survival following a diagnosis of oesophageal cancer was poor. In summary, they said that it was hard to say whether the delay had an effect on Mr C's eventual outcome.

11. The Adviser noted that, as a consequence of their Adverse Event Review, the Board had agreed to increase endoscopy capacity and reduce waiting times by providing a nurse endoscopist. They said that this could partly deal with the delay and the problems identified but that there had also been problems with

triage. In their view, the guidelines (referred to by the Board) did not flag up the category 'urgent suspicion of cancer' to GPs and gave the impression that patients with dysphagia would be seen or scoped urgently when, in their view, they were not. While the Adviser said that they was satisfied with the care and treatment Mr C received after his diagnosis, they confirmed that they had major concerns about the pre-endoscopy pathway and triage process which led to a significant delay in Mr C undergoing his gastroscopy.

Decision

12. The advice received was that there was an unreasonable delay in arranging an endoscopy procedure for Mr C and for this reason I uphold the complaint.

13. In view of this, I recommend that the Board make Mrs C a formal apology. I further recommend that they either remove the web guidance they referred to or adjust it to make it absolutely clear that an alternative referral route was recommended. In this connection, the Adviser pointed me to the National Institute for Health and Care Excellence (NICE) guidance 12, which was published in 2015 (at about the same time as Mr C was diagnosed), which suggested that all patients with dysphagia were referred through the suspected upper gastrointestinal cancer pathway. Furthermore, the Board should urgently review their triage process to ensure that patients with dysphagia were appropriately triaged; and also consider what other action, if any, they could take to hasten their waiting times for endoscopy services.

14. Finally, while the Adviser had concerns about the delay, they said that they could not confirm whether this delay had an effect on Mr C's eventual outcome, mainly because it was not possible to say whether distant lymph nodes were involved at an earlier stage.

Recommendations

What we are asking the Board to do for Mrs C:

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15. The Board have accepted the recommendations and will act on them accordingly. We will follow-up on these recommendations. The Board are asked to inform us of the steps taken to implement them by the date specified. We will expect evidence (including supporting documentation) that appropriate action has been taken before we can confirm that the recommendations have been implemented.

Annex 1

Explanation of abbreviations used

Mrs C	the complainant
the Board	Lothian NHS Board
Mr C	Mrs C's late husband
the Adviser	a consultant gastroenterologist

Annex 2

Glossary of terms

dysphagia	swallowing difficulties
endoscopy	a medical procedure where a tube-like instrument is put into the body to look inside
gastroscopy	a procedure using an endoscope, an instrument to look inside of the body