

REVIEW OF CARDIAC SURGERY

Feedback from Public Meetings in
Newry, Craigavon & Dungannon

February 2001

Southern Health & Social
Services Council



1. BACKGROUND

In November last year, the Department of Health, Social Services and Public Safety requested the Southern Health and Social Services Council to organise a consultation event to input into the ongoing review of cardiac surgery. In response to this request the Council arranged and facilitated three meetings throughout the Board's area during January 2001.

Meetings were held in Newry, Craigavon and Dungannon. Each meeting was advertised in the local newspapers, churches and GP practices. In Newry and Craigavon the Council linked up with the local cardiac support groups in order to ensure a core group of participants. This was not possible in Dungannon because no local support group existed. In total 111 people attended the three meetings. Each meeting lasted approximately 2 hours and participants were very open about their personal experiences.

2. THEMES

A wide range of issues were raised by participants in each of the meetings. However a number of themes were common across the groups. These are outlined below.

2.1 Waiting Lists

Participants raised the issue of the lengthy waiting lists for cardiac surgery. Comparisons were made between the length of time patients in Northern Ireland can expect to wait for surgery to the length of time people in other European countries and in the USA can expect to wait. One man explained that his father had two heart attacks in 1996 – he then had to wait two years for a referral to a cardiologist and following this he waited until January 2001 for surgery.

Patients and their families were anxious that their condition would deteriorate while waiting for surgery. One man outlined that he used to walk to keep his

weight down but while waiting for surgery his condition has deteriorated so much that he was no longer able to do this. A woman recounted that her mother suffered a major coronary while waiting for surgery. Participants felt that the anxiety of waiting for surgery or to receive an appointment for surgery was detrimental to the individual's health.

There was also some confusion as to when a person actually joins the waiting list for cardiac surgery. This was due to the common patient pathway involving more than one referral. The preliminary contact is usually with the GP who in turn makes a referral to a cardiologist. The cardiologist then refers the individual for cardiac surgery. Some people were confused as to when they joined the waiting list – when the GP made the referral to the cardiologist or when the cardiologist referred for surgery.

2.2 Information and Communication

Lack of information was a recurring theme in all three meetings. Some participants highlighted that there was a lack of information about medical interventions such as angiograms and angioplasties. Patients and relatives had not received any information as to the activities they should or should not do while waiting for their surgery nor had they received any health promotion advice in the intervening period.

One woman pointed out that she had found a great source of information in the British Heart Foundation but she had had to seek this organisation out herself. It was suggested that if information and support could not be provided by the service providers directly then they should at least be able to refer patients and their families to appropriate sources, such as Chest Heart and Stroke and the British Heart Foundation, where they could receive the necessary advice and support.

In addition, many patients and their relatives were frustrated by not knowing when their surgery would take place. In some instances a date was provided but not met. One man told how he was ready to have his operation when he was informed that an

emergency had occurred and he was asked to return home for the week-end and to come back the following Tuesday for his operation. He explained that he did not receive his operation for a further three years during which time he found it difficult to get any information. Another man explained how his surgery had been postponed but he had not been told about this until he contacted the Royal Victoria Hospital himself. He felt that had he not taken the initiative and contacted the hospital when he did he would not have found out about the postponement. He felt that the responsibility should be on the hospital to keep patients informed rather than patients having to constantly check themselves.

In other cases no date was provided and the onus was placed on the patient to check to see whether an appointment had been made for them. One man told of how for the past thirteen months he had been telephoning the Royal every month to check whether an appointment had been scheduled for him. Each time he was told that they did not have a date for him and he was asked to phone again the next month.

Many other participants expressed their frustration at not knowing when their surgery would take place and where they were placed on the waiting list. They felt that the anxiety experienced at having to wait for surgery was heightened because of two factors. These included: -

- a lack of information as to when the surgery would occur, and
- a lack of communication – the onus being placed on the patient to try to seek out this information which was usually not forthcoming.

2.3 Cardiac Surgery Liaison Nurse

Amidst the negative aspects highlighted above, the Cardiac Surgery Liaison Nurse – Joyce Spence – was considered to be a very valuable source of information and support to patients while they waited for their surgery. Participants at the meeting referred to instances where Joyce was able to provide them with much needed information. The service provided by Joyce was also considered valuable because she was an identified point of information and support in a system where

the cardiac surgery consultants were rarely contactable and GPs were not kept informed about when the patient's surgery would take place. However participants did not think one such post was adequate to serve all patients awaiting surgery throughout Northern Ireland. They considered that the increasing demand for Joyce's services would make her less accessible. Questions were also asked as to why this post was not funded by health and social services instead of being provided by a charitable organisation.

2.4 Contact with GPs

The patient's contact with their GP was another issue which was frequently raised as GPs were often a primary contact point for information. Some participants said they had received contradictory information from their GP and the surgeon with regards to when surgery would take place. In one instance a GP had informed a patient that it would be 12 months time but the surgeon said it would be 6 months. Some patients and their families felt that GPs were not very well informed. One person highlighted that she asked her GP about the possibility of travelling to HCI in Glasgow for her surgery but her GP was not aware of these arrangements. The importance of relaying accurate information to GPs so that they could inform patients and respond to their queries accurately was stressed.

One individual raised the issue of hereditary conditions. In cases where patients had a family history of heart conditions, it was considered important that the GP take this seriously in considering possibly diagnoses and making referrals for tests.

2.2 Equity

Participants raised the issue of equality of access to services. Residents in the Southern Board's area perceived that the Royal was less accessible to them than to people who were living in its catchment area for local hospital services. Because of the lack of transparency in waiting lists for surgery, some participants perceived that 'nepotism' occurred. They felt that people who 'knew the system' or

who 'knew the right people' were more likely to be placed at the top of the waiting list.

Some participants were concerned about patients who needed cardiac surgery and who did not have any family or anyone to speak up for them. One young man explained that after a lengthy wait and much persistence he eventually acquired a direct line number to the cardiac surgeon. He told the surgeon that he felt he was at breaking point – his mental health was suffering because of his heart condition. This resulted in him receiving an appointment for surgery. Another man explained that his father had been offered the possibility of travelling to Glasgow to have his surgery but was then removed from the list because he was considered unfit to travel by the cardiologist. The cardiologist requested that his case be prioritised by the Royal but this was refused. The man's son, angry that his father had been waiting a number of years for surgery telephoned the office of the Chief Medical Officer to raise his father's predicament. This proactive approach resulted in his father travelling to Glasgow for surgery.

People from the South Tyrone area felt isolated because of the removal of services from South Tyrone Hospital.

2.6 Local Provision of Services

Participants at the Craigavon meeting questioned why cardiologists from Craigavon Hospital had to travel to Belfast to perform angiograms, angioplasties and stenting. They thought that such procedures should be provided locally. This would shorten the waiting time for referrals to a cardiologist and therefore ultimately impact upon the waiting time for cardiac surgery.

2.7 Staffing

Participants were not very sympathetic with explanation for the current waiting list problems as due to the extra demand for Cardiac Surgery Intensive Care Beds. The felt that this problem could be dealt with by increasing the number of

intensive care beds and increasing nursing staff accordingly. They felt that difficulties in recruiting nursing staff could be overcome by offering greater incentives as part of the recruitment drive.

2.8 Surgeons' Lists

Participants raised the issue of varying waiting lists for different surgeons. One man explained that he had a heart condition for 20 years and was prioritised as urgent for surgery. His brother on the other hand also needed surgery but had only experienced the problem for one year and was not categorised as urgent. The surgeon whose list the man's brother was on, retired and his workload was distributed among other surgeons. The end result was that the brother who required the operation urgently was still waiting at the time of the meeting while the other brother had already undergone his operation.

The issue was raised about moving to a composite waiting list for cardiac surgery rather than separate waiting lists for individual surgeons. It was noted this was supposed to have occurred following the last review in 1992 but had not been done.

2.9 Transfer to Other Areas

Participants generally were in favour of offering patients the opportunity to have their surgery elsewhere if it meant they received it sooner. One woman was concerned that proper contract arrangements would be made. She explained how her husband had been sent home from London 7 days after he had surgery even though he was ill. The reason for his return home was that the contract was only for 7 days. The individual was concerned that this would not happen to other patients.

A number of people had travelled to the HCI in Glasgow and were very satisfied with their or their relative's treatment. They found the quality of medical and nursing care very good as well as the hotel facilities for travelling relatives. One issue which did cause some people concern was the lack of information about who

would be conducting the surgery. Patients and their relatives would have liked to have received this information in advance of travelling to Scotland.

Some participants perceived that there was a chance that surgeons from the Royal Hospital may have performed their surgery in Glasgow. They questioned the reason behind this and considered it inappropriate.

2.10 Private Patients

The issue of people paying privately for cardiac surgery was raised. One man outlined that he was fortunate that he could afford to pay privately and was seen and treated straight away and found the system very efficient. Other participants questioned the impact of people paying privately on the NHS waiting list. They were not convinced that one did not affect the other.

2.11 Rehabilitation

Participants stressed the importance of follow-up and rehabilitation after surgery. One man said that he had not received any follow-up since his surgery in July 2000. Another man felt that he was forgotten about by the hospital after he was discharged and no attempt was made to either check his progress or offer any rehabilitation. Reference was made to the cardiac rehabilitation services which had recently been developed in Armagh as part of the Primary Care Commissioning Pilot. Participants considered it important that people, regardless of where they live have equal access to rehabilitation services as well as surgery.

3 SUMMARY

A large number of people turned out to the three public meetings on the cardiac surgery review in the Southern Board's area. The participants raised many important and valid points and were very open about their personal experiences. The Council considered the meetings very worthwhile and informative and they have allowed us to submit the above key themes which patients and relatives have

stated must be considered by the Review Group. The Council hopes that the Review Group found the meetings equally beneficial and that the above summary of the key themes will help in reorganising services for the benefit of patients.