



The Association of Coloproctology
of Great Britain and Ireland

A Patient's Guide to Surgeon Outcome Reporting in Colorectal Cancer

Information on the results (outcomes) of individual surgeons working in Coloproctology (disorders of the rectum, anus and colon) for an operation for bowel cancer is now being collected and released for the first time. The data relates to the period from 1st April 2010 to 31st March 2012. The initial intention was to release data by the end of June 2013. However, because of the complexity of the project, release of this data has been delayed until the autumn.

Below are some questions which you may like to ask about this process.

What data is being published?

The data focuses on the operation for a major resection of the bowel (this is when a patient has cancer and the diseased part of the bowel is removed)

The data is organised by Hospitals throughout England. It gives the total number of patients who underwent planned (non- emergency) surgery for bowel cancer and the number of these patients who died within 90 days of their operation. In addition the same information is presented for individual surgeons who performed more than 10 operations for bowel cancer at that hospital.

Why is this data being published?

This information is part of the Government initiative to help patients make a choice about their care (NHS Patient Choice website).

It is very important that the data is correct, so that patients can make choices based on good information. It is because of concerns about the accuracy of data for some surgeons that publication has been delayed whilst the data is checked.

Bowel Surgeons support the publication of these results, and believe that this data should be made clear to patients (transparent and open reporting).

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This data may also give clues as to why some patients do better than others, and lead to better results in the future.

Research also shows that in just publishing the data, even if not used in any other way, helps surgeons to examine their work and this leads to improvements in outcome.

Who is involved in collecting the data?

Hospitals have been collecting data on Bowel Surgeons on the results of bowel cancer treatment for some years, but this looks at a much wider range of care involved in recovery, and it is not really suited to information on individual surgeons. They have been working closely with NHS trusts whose administration provides most of the data trying to match surgeons with operations and their results.

Why is information on this one operation being used?

This major resection of the bowel has been chosen because it is carried out by most specialist colorectal surgeons. However, it is far from ideal as the majority of surgeons do not do this operation enough times in one year to allow for accurate comparison between surgeons.

Why is 90 days taken as the time?

The Bowel Cancer Audit undertaken by the Bowel surgeons themselves previously measured 90 day survival across trusts. It is recognised that most patients who die following bowel cancer surgery, do so within 90 days of their operation.

Why are only planned operations being looked at?

When patients are rushed into hospital in an emergency, they do not have a choice of their care.

Why can't I find a particular surgeon in this information?

Not all surgeons who operate on bowel cancer are included in this information. There are a number of reasons for this. Many will not have performed enough operations to be able to calculate a survival figure. Some surgeons are colorectal surgeons who specialise in other diseases of the bowel rather than colorectal cancer. Some surgeons will not be members of the Association of Coloproctology, the organisation publishing this information and have not been contacted about this project. A few surgeons will still be concerned with the accuracy of the data used to calculate their outcome that they have withheld the information until the data can be corrected.

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What makes information submitted to the Audit produce correct results?

It is essential that data is accurate and that it includes every surgeon who operates and every operation of this kind undertaken. This is called data completeness. The information put into the data base also needs to be correct (valid).

Is the data correct? Are there any problems with the data? Why?

There has only been 4 months from notification that this data must be produced by the specialist surgical associations to the date of its publication.

Trust data bases were not set up to identify which surgeon undertook an operation, so that some of the data needed to match surgeon to operation is missing, and the audit data system itself has left out some cases. The fewer the number of operations recorded for a surgeon, then the higher their mortality rate may seem.

Trusts also collect data in many different ways, and the short time given for this task means that while some data may be accurate, other data is not correct and needs further work

There have been many complex issues in the data collection system and these are still being worked on during the delay in publication of the data.

Surgeons may also work jointly or in teams so that it can be hard to identify one surgeon as being in charge of one operation. Although this is an operation undertaken by most colorectal surgeons, very few do a sufficient number, even over the two year period for this data, to enable reliable comparison between surgeons.

Whilst a lot of work has gone into extracting the data, the results this year will not tell us the real situation and will not be completely accurate for some surgeons. However, every unusual case will be looked at and further analysis undertaken.

In this short period of time, it has not been possible to include all colorectal surgeons who undertake this operation, so not everyone is included this time and the data is not regarded as complete.

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What has been the result of the data collection?

Wide variation in both numbers of operations undertaken and mortality (death of the patient within 90 days) has been shown between surgeons because of the problems with data collection using a system not designed for this purpose, and where too few operations have been included. What can be said is that on average, just over 1 in 30 patients undergoing elective surgery for large bowel cancer die within 90 days from the operation

Why is there such variation in the outcome data between surgeons?

This can be down to one of a number of factors. It has already been stated that the accuracy of the data varies from surgeon to surgeon. Some surgeons may take high risk patients or those whose cancer is advanced, and this means that they may have higher death rates than other surgeons. Some surgeons will have had a few deaths clustered together in this time period by chance alone. Their own data on a much larger number of patients show that overall their results are acceptable. In future it is hoped to use five years worth of data which will flatten the variation and clustering effects.

What else is important for good results and recovery for patients?

To look at the operation alone is not the whole picture in recovery. Many other specialists are involved in care both before and after the operation and during the 90 day period. This will include such people as anaesthetists, critical care specialists and nurses. They are all vital members of a team which works for the survival of the patient after the operation, and their good recovery.

All patients are different. Some patients will have a much greater chance of survival while others will have a greater risk of dying. This may be because they are overweight, have another serious illness as well, or are in an older age group. The data needs to be adjusted to take into account the greater risk to some patients, but working out the risk for an individual patient is very difficult.

What does the data not tell us as patients?

It does not tell us about how good a whole unit or department is – which is important to patients who want to know that all their care from arrival in hospital to going home will be good. Patients want to know that the whole team is good. Also it tells us nothing about the quality of care the patients receives, such as did people treat me with respect or, were there people with whom I could discuss my concerns?

Also, in a whole department, with several surgeons working together, the number of operations carried out would be higher and the data would be statistically significant.

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What will happen in the future?

Surgeons will be involved by inputting their own data about patients they operation on and this will give a more accurate picture than the various different ways in which Trusts currently gather information. Data will continue to be collected. It is hoped that data will also look at survival over different time periods, including in the longer term.

Are there any possible problems in collecting this data which will affect patient care?

It is hoped that those surgeons who now undertake the care of higher risk patients will not be concerned by publication of their results. It is hoped that surgeons will not feel under pressure to avoid such patients and select only low risk patients.

Conclusion

When the data is published, it will not show the full picture of patient care, and must be seen as something of a simplification, as the combined work of other hospital staff and other factors count towards the good recovery of patients

The time available to produce the data has been short and matching surgeons to operations has been very difficult. Whilst some of the data is accurate, it is not the case that all of it is correct. The data is expected to be more accurate in future, and patients need to be aware of the particular problems with this initial release of data.

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