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ORIGINAL ARTICLE

Clinical Outcomes in the Google Era

The PB Desai Oration, ASICON 2013

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Abstract This article is based upon the PB Desai Oration which was given by the author in Ahmedabad on 28th December 2013 at the National Congress of the Association of Surgeons of India at the invitation of the Executive Board of the Indian Association for Surgical Oncology.

Keywords Information technology · Surgical outcomes · Funnel plots · Clinical informatics

Introduction

The digital revolution and the spread of its enabling technologies are transforming lives and societies across the planet. As consumers and users of desktop and laptop computers, phones, mobile Personal Digital Assistants and Digital Tablets, we are all familiar with the flexible and near instantaneous access to the massive volumes of data which are the characteristics of the Internet. There are now billions of internet enabled devices in use, and technology—literacy is widespread even in poorly educated populations and pre-school children.

This data revolution is further characterised by the negligible apparent cost of many data transactions to end users, providing significant social, political and intellectual empowerment.

Governments & public data repositories are increasingly moving on-line, providing better and more efficient services to populations, and opening up a whole new world of information services.

Historically, control of clinical information and knowledge has been the monopolistic preserve of the medical profession. This has allowed protection of individual patient confidentiality, but it has also protected the profession from the illumination of problems in care, service delivery and specialist practice. In the UK, as elsewhere in the "wired world", a "paradigm shift" is now occurring in civic and professional life, whereby public demands for more information about clinical services and outcomes have encouraged governments in turn to require the release of huge volumes of healthcare information into the public domain.

One consequence of this trend is that in 2013, surgeons across ten subspecialities in the UK were obliged to follow the precedent of their cardiac surgical colleagues and were required to publish individual outcome data in the public domain. This information is now available to members of the public and to any agency or media outlet which wishes to analyse it in greater detail.

Professor Norman Williams, President of the Royal College of Surgeons of England, stated in the College Newsletter of December 2013, that:

> A great deal of time was spent working in partnership with the Surgical Specialty Associations in preparing for the publication of individual surgeons' data earlier this year.
> It was a watershed moment; the first time in the world that any healthcare system has achieved such a level of transparency and detail around surgical results. It was a huge challenge to all involved to analyse and present outcomes that are accurate and meaningful for patients.
> I was extremely proud that we took this decisive step and made the commitment to an open dialogue with both patients and the public.
> Despite the understandable concerns and flaws we now have more reliable audit data than ever before. This will improve as we go forward and it is vitally important that we continue to take professional ownership and develop the system over the coming years.

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The process of open publication has represented a transformation in the status of information guardianship in the medical profession and for surgeons in particular. In this essay, I consider some of the factors which have contributed to this change, which will ultimately be demanded in all countries of all professional groups, including the surgical profession in India, now that the transparency genie is out of the bottle.

The Scope of Clinical Information

Administrative and Public Health Data

Many groups and organisations are stakeholders in clinical information. Politicians, planners and the financiers who are responsible for the distribution of finite resources to meet potentially infinite demand for healthcare must be able to be assured the efficient allocation of money and skills to meet local, regional & national strategy & priorities. Managers & administrators of hospitals, family practices, and health networks must thus collect and distribute accurate data on clinical demand, activity and costs to meet these organisational needs. The data so generated addresses questions such as Who? When? Where? What? And How much?

Public priorities for health care must be informed by efficient epidemiology and disease surveillance across all forms of acute and chronic diseases of childhood and adulthood. Moreover, as populations age, so the hugely expensive requirements for the humane care of older people with chronic and degenerative illnesses are forcing a merging of strategies for health and social care.

Information transparency also promotes comparative analyses of activity and productivity between institutions and even countries, prompting further demands for the implementation of the most efficient and effective health services and outcomes, provided by those most competent to provide them.

Informatics and Clinical Service Delivery

Clinical informatics allows for the much more efficient delivery of clinical services. Within hospitals, the electronic collation and transmission of documents, diagnostic results & imaging allow surgeons to work more efficiently. Data which is entered once electronically in the outpatient clinics and operating theatres, can be used subsequently in many practical ways, such as in the automatic generation of clinical activity reports, and in the automatic creation and distribution of discharge summaries.

We can foresee a time when individual patients will take much greater ownership of their personal health data, through downloads of the same information, test results and images to their phones and PDAs, so as to maintain and control their own personal health records. This is particularly important in countries such as India, where there is not a well developed primary/family physician infrastructure.

Clinical Informatics and the Study of Results and Outcomes

Surprisingly little is known about the true relationships between the benefits and limitations of therapeutic inputs and final outcomes in a wide variety of chronic diseases. Clinical trials have significant limitations and exclusions in the study of "real world" populations. Modern informatics and data mining systems allow for a much more detailed evaluation of complex clinical research and academic questions than have previously been possible using conventional paper and card records. To a greater degree than ever before, clinicians can now extract actionable knowledge and insights from raw data & information. This should in turn lead to the development of new treatment methods, tools and drugs. In the clinics, surgeons will have a much better understanding of the consequences of their actions.

Clinical Informatics and Workforce Development

Clinical informatics is also important in workforce planning and development for the health services at State and National Level. Once the demands for health care are more accurately known, it becomes much easier for policy makers, Universities & Colleges to plan the size, development and requisite skill mix of healthcare workforces, including nurses, doctors and allied health professionals.

Clinical Informatics for Patients as Consumers

The consequence of these improved information flows is that consumers, as patients and their families, are able to make much more informed choices as to the nature of their illnesses, the proposed treatments and the individuals undertaking those treatments, which in turn becomes a driver to better quality of care.

Clinical Informatics and Clinical Governance

Clinical Governance describes the state of mind of health professionals, health organisations and health systems which is focused at all times and in all circumstances on optimising the safety of clinical practice and health care delivery. Clinical governance is driven by excellence in data collection and by transparency in health care practices and decision making. It describes health systems where practice is evidence based, both in terms of the published evidence base and in terms of the performance of the particular clinicians, clinical teams and health care providers who are providing that care. Good clinical information also drives effective comparative performance of institutions & clinicians.

The debate on safety-centric and safety-critical clinical practice has been widely informed by practice in the engineering and transport industries, which include no-fault tolerant processes and open, root source analysis of all problems. These practices are particularly well refined in the Airline and Maritime transport industries, where lessons from accidents and near misses are continually and rigorously learned and implemented.

The Electronic Patient (Health) Record (EPR or EHR)

One significant element of the clinical data revolution has been the concept of the Electronic Patient (Health) Record (EPR or EHR), within which all significant information relating to a patient's medical history from birth to death is incorporated into a single data system. The EPR may in turn be under the control of the clinical data authorities and health providers, or under the control of the patient himself or herself.

In practice, it has proved extremely difficult to develop a single unifying EPR for each and every patient in the UK or elsewhere, and there are no readily available commercial solutions. The range, variability and heterogeneity of clinical data for any one individual is huge and the additional complexities of following and collating data on large numbers of individuals in mobile populations over the entire lifetime of each and every person has so far proved insurmountable for programmers.

Progress to the "Clinically Wired State" in the UK

The UK has a population of some 70 million people, which is approximately equivalent to that of a typical Indian state. The country has an advanced communications and computer infrastructure. The centrally controlled and coordinated health system, which places the National Health Service (NHS) and independent health care providers under common regulation, allows health and policies to be harmonised nationally. All hospitals and primary health care providers have established local data systems, and the country has an IT—literate workforce.

Centrally directed development of effective clinical IT systems has nevertheless proved challenging, and hugely expensive. The NHS National Programme for Information Technology (NPfIT) was initiated in 2005 and terminated in 2013. The NHS "Connecting for Health" project aimed for a unitary patient record system for 300 major hospitals and some 30,000 family practitioners. However, the plans proved to be technologically overambitious, and the project was terminated in favour of local and market-led solutions in 2013.

Nevertheless, much was achieved in establishing a national health data network, and an NHS e-Mail system. Substantial volumes of health data are now collected and analysed. Much of this data is also released to trusted data analysis companies such as "Dr Foster", which undertake comparative performance analyses and publish data nationally.

The Requirements of Clinical Data Systems in the "Wired World"

There is a progressive move to replace paper health records and to make digital data records he norm. Conventional paper records (rightly or wrongly) will progressively be replaced by the Electronic Patient Record, on the assumption that Computers and data access systems will be universally available and accessible at all times. Systems will need to be universally interoperable, as is now possible with Internet Protocols, and the system interfaces with human operators will continue to be improved to optimise efficiency.

Most importantly, there must be a disciplined and robust political, legal and managerial framework, "central intelligence" and "competent authority", for the oversight and regulation of clinical data collection, distribution, analysis and interpretation. In the UK, this is a function of Central Government, which is in part delegated to the separate administrations for Wales, Scotland and Northern Ireland. In India, such control would presumably and logically reside at State level in the first instance, because of the scale of the challenges in implementing effective clinical data systems.

National Politics & Clinical Accountability in the UK

For a number of reasons and in consequence of a number of health care "scandals" which have attracted intense media and political coverage, UK medical professionals are no longer trusted with self-regulation. A number of regulatory processes have been developed, which are overseen by the General Medical Council, which in turn is answerable to Parliament through the Departments of State. An expectation of transparency of clinical activity now applies individual doctors, where productivity & outcomes can be measured; to Clinical Units and Departments; to Hospitals and to Clinical Networks.

Drivers for change and for the universal implementation of efficient and cost effective practices have included the growing constraint on resources relative to (infinite) demand in a service which is free at the point of use; the belated realisation that clinical performance & clinical outcomes are variable and sometimes "scandalously" so.

These events have emphasised the need for clarity as to what is going on, both for management executives in the health system, and for the politicians who are answerable to

the patients and consumers of health services. There is growing accountability of individual doctors and organisations for their clinical outputs and outcomes, and growing public demand for a power shift from the "health care producers" to the "health care consumers".

Towards National Publication of Surgeon-Specific Outcomes in the UK

2013 heralded a tectonic shift in the political drive to secure the reporting of surgeon—and institution—specific outcomes in the public domain in the UK. The background to this was that cardiac surgeons had moved to nationwide reporting of individual outcomes after the Bristol Paediatric Cardiac Surgery "Scandal" in 1990s. Sir Bruce Keogh, a Consultant Surgeon who had been closely involved in the development of these reporting systems, is now the Medial Director of the NHS.

In consultation with the UK surgical subspeciality Associations, the decision was finalised in mid 2013 to move rapidly to publish surgeon-specific activity and morbidity rates in the ten surgical specialities, associations and societies where data had been collected. The decision was necessarily pragmatic, as data collection was incomplete. For example, substantial volumes of operations in some fields are thought to be undertaken by surgeons who are not yet members of the relevant societies and hence signatories to the relevant databases, and whose data is not therefore captured.

The process was placed under the direction of the UK Healthcare Quality Improvement Partnership, and data was reported for Adult Cardiac Surgery, Vascular, Endocrine, Interventional Cardiology, Orthopaedics, Bariatric Surgery, Head and Neck Surgery, Urology, Bowel Cancer and Upper Gastrointestinal Surgery. Surgeons in those specialities were given no practical choice but to comply, and there was a period of little more than 3 months from proposal to publication. There was an initial very brief spasm of press interest, misreporting and misinterpretation of data in the national media which lasted for 1 week, since when the airwaves have been quiet. The presumption is that local units and institutions will move quickly to analyse and act upon outlying data and address issues with the individuals concerned.

Concerns about Surgeon-Specific Data in the UK

Many clinical outputs are now multidisciplinary. There were legitimate concerns that in many cases, outcomes are the consequence of team efforts rather than directly due to the successes and failings of individual surgeons, who would thus be unfairly penalised (or praised) for outcomes over which they did not have complete control. Data collection is (often) inaccurate, as for example in the mis-attribution of cases to one surgeon rather than another. Nationwide data coverage is currently incomplete, arbitrary and pragmatic. Many UK surgeons have had little control to date over the data that is collected about them by health service administrative teams.

A Note on Funnel Plots

Funnel plots are a powerful statistical and graphical tool for the study of performance and variation between organisations, units or individuals. Funnel plots have been a key tool in the presentation and study of clinical outcome data from units and

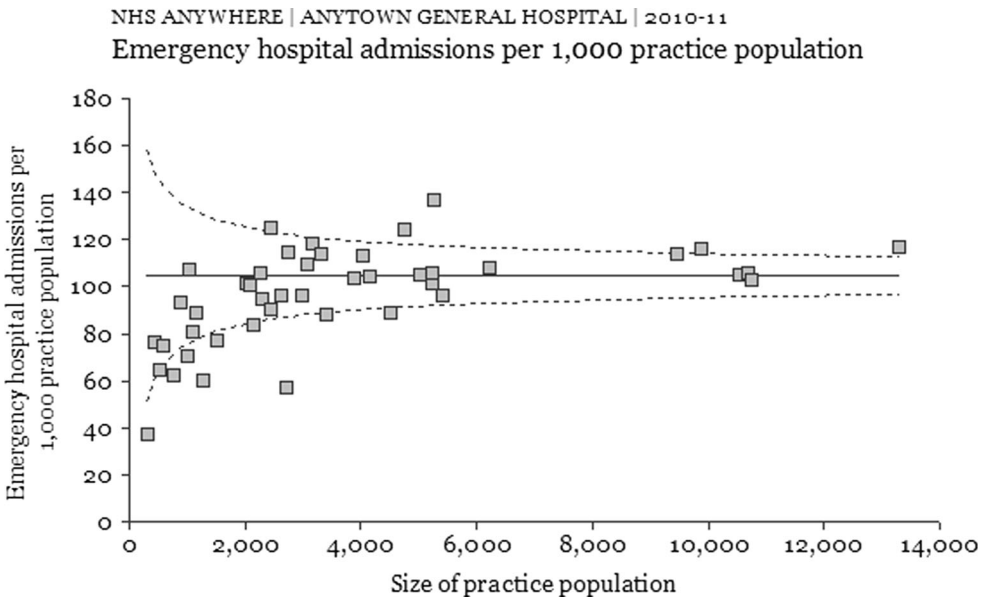

Fig. 1 An illustrative Funnel Plot (courtesy of www.kurtosis.co.uk)

surgeons. They are a form of control chart and a scatter plot. On the X axis, the size of the population (for example, the operative caseload) being studied is plotted. On the Yaxis, the variable which is being studied is plotted. The mean value for the variable under study is plotted as a straight line through the plot. The population data is assumed to be normally distributed throughout, and the funnel plot lines can be set to mark a range of different values, for example the outer (upper and lower) 2.5 % of the normal distribution curve; the confidence intervals, or standard deviations or standard errors. The curves narrow towards the right as the size of the study population increases.

In the example shown, the model is used to study the emergency referral rates to local hospital from 44 primary care (GP) facilities. Those facilities with higher or lower referral rates which fall outside the (arbitrarily established) range limits are regarded as outliers, meriting further investigation of the data. It is important to recognise that a facility may fall into the outlier category for a range of reasons. The data may be inaccurate, or there may be special circumstances to account for the particular referral activity from that facility. In the case of surgical data, it might be that an outlier unit has a reputation and skill in taking on particularly difficult and high risk cases with a higher than average morbidity or mortality (Fig. 1).

In Summary

The technology of the Google Era is transforming the lives of surgeons in advanced health economies, where clinical data is now being used as a powerful tool to promote beneficial change for patients. The work of surgeons is now open to public scrutiny as never before [1], and the pioneering work of health officials in the UK may be expected in due course to create pressures for data transparency in other countries, including India.

The data collection and analysis processes are by no means perfect, and there will be a substantial growth in academic activity in the coming years to analyse the systems and to investigate tools for improvements in the reliability of source data. There is as yet no published evidence to confirm or refute the benefits or otherwise of the recent changes in public health policy, but logic dictates that considerable implicit pressure now exists for all units and surgeons to ensure that their results are optimised. This may mean the closure or amalgamation of smaller units, and changes in practice for some surgeons with low volumes of caseload in particular areas, and relatively poor outcomes. We do not yet know whether any negative changes might flow from the policy, such as from a more defensive approach by surgeons towards more complex or high risk cases. To a certain degree, the move to the publication of outcome data in the UK is an act of faith.

All surgeons and surgical teams need to be aware that you will be held progressively more accountable to your paymasters and the public for your activity, your productivity and your clinical outcomes. The solutions and methodologies will vary from one health economy to another, but the rapid spread of information technologies is empowering all communities and raising health care expectations across the globe. Information transparency will drive up standards everywhere. Information Technology provides new opportunities for research & insight into the Ground Truth of clinical interventions, and the inevitable changes in surgical practice are to be embraced rather than feared.

Reference

1. The UK NHS Choices website at the following web address provides links to a wide range of resources and opinions on matters arising from the recent policy changes in the UK. http://www.nhs.uk/choiceinthenhs/yourchoices/consultant-choice/pages/consultant-data.aspx