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## THE HISTORY OF INFORMATION INFRASTRUCTURES: THE CASE OF THE INTERNATIONAL CLASSIFICATION OF DISEASES

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### INTRODUCTION

The information sciences have this century grappled with new ways of configuring, storing and retrieving information. We are clearly at a point today where we are witnessing the birth of information technology as fundamentally new as was the printing press in its day (see Eisenstein, 1979 for the latter). This paper examines the problem of writing the history of one key component of this scientific development—the development of information infrastructures—by taking the example of one particularly robust and successful infrastructure, the International Classification of Diseases (ICD).

There is no simple way to tell the story of the complex theoretical and practical work that goes into the development of an information infrastructure. Star and Ruhleder (1996) argue that an infrastructure has five properties:

- embeddedness (“it is ‘sunk’ into other structures”)
- transparency (“it does not have to be reinvented each time”)
- reach or scope (it is not a “one-off event or one-site practice”)
- being learned as part of membership (it is associated with a community of practice).
- being linked with conventions of practice (it “both shapes and is shaped by the conventions of a community of practice”).

The information superhighway that is perhaps the crowning practical achievement of the information sciences this century has all these properties.

There are few tools available to the historian for grasping this new development theoretically. One of its key features is that it is doing more than making work easier, faster or more efficient; it is changing the very nature of what we understand by work. Scientists tell us that the nature of their disciplines are changing. Stephen Hawking in his inaugural lecture as Lucasian Professor at Cambridge (a post held by Newton) expressed a belief that by the turn of the century, work in theoretical physics would be essentially performed by computers—humans would not be able to understand the mathematics, but they could aspire to interpreting its consequences (Hawking, 1980). Pure mathematicians now adopted a method of existence proofs that would have been unmanageable before the development of the computer. Not only the scientist and the mathematician are affected. Ruhleder (1995) has shown how the community of classical scholars has had to learn a new set of techniques (dealing with complex searches on a computer) and indeed pose a new set of questions of their data since the construction of the *Thesaurus Linguae Graecae*, which houses the complete canon of classical Greek literature on compact disk. J. David Bolter, amongst others, has commented that the novel form is undergoing radical change under the development of hypertext (Bolter, 1991). And more generally, as Beniger (1986) amongst others reminds us, the structure of industry is changing such that “information work” has become the dominant mode of work in industrialized economies. Thus the world of knowledge or the world of industry really are not the same worlds after the development of this new information infrastructure as they were beforehand. In order to explain what has happened, the historian has to range freely between the “inside” (looking at knowledge

within physics, mathematics, classics and so forth) and the “outside” (looking at changes in work practice and information management that hold over many fields at once).

The story of information infrastructures is not the history of “great people”: much of the work has been done “offstage” by communities of hackers and engineers. It cannot be restricted to the history of ideas (though ideas are clearly important): creating an infrastructure as defined here is as much social, political and economic work as it is theoretical work. The central purpose of this paper is to explore ways of writing the history of information infrastructures.

I will not attempt to give an overview of all the infrastructural work that has made this, to use the unfortunate phrase, an “information age”. “Unfortunate” because those who write about this as the information age tend to immediately retrospectively define all of human history as the history of information processing: and thus to effectively deny specificity to the age that they are defining—see Beniger, 1986 for a classic example. Further, the phrase itself draws attention away from the material bases and work practices that are analyzed in this paper, where I shall argue that “information” cannot analytically be released from these contexts. Rather I will look at a single example of the construction of an information infrastructure in the form of a standard, universal medical classification system: the International Classification of Diseases. This system is used worldwide by states (on death certificates), by insurance companies and within hospitals. The creation of this classification system is infrastructural work. Indeed the ICD fits perfectly into Star and Ruhleder’s definition of infrastructure. It is embedded (in a myriad databases), transparent (it acts as an invisible support to medical work), has very wide spatial reach (all countries in the world operate with a version of the ICD—though not always the same version!), is learned as part of membership in the medical profession, and is linked with conventions (Fagot-Largeault, 1989 has described coding practices on death certificates in superb detail).

#### THE CASE OF MEDICAL CLASSIFICATIONS

The discipline and practice of statistics grew up during the nineteenth century (Hacking, 1990). As the word’s etymology indicates, it was a discipline intimately connected with the rise of statehood. Political and economic life in the industrializing countries of Europe was becoming ever more complex, and states experienced the need to gather and keep information about their citizenry. Medical statistics grew up as part of this burgeoning information-gathering activity.

All statistics rest on a classification system. Such systems are developed in a given historical context and bear signs of this origin. Desrosières (1990) discusses, for example, the range of socioprofessional categories that arose in England, France and Germany during the nineteenth century and continue to act as a basis for census data, legal definitions and job descriptions today. If nation states remain relatively isolated, then this is not a problem: any classification system that does its job internally can suffice. People cannot be moved around distributed empires unless they can be tested and classified into well-defined categories (see Desrosières, 1993 for a development of this theme). Thus classifications must be standardized when information needs to travel across a boundary, be it an institutional boundary (Roth, 1963) or a national one (as in the case of medical classifications in an era when diseases are not confined to a single locale but travelled as fast as the fastest means of transportation).

Thus a series of local medical classifications developed during the nineteenth century were superseded at the turn of the century. During its meeting in Vienna in 1891, the International Statistical Institute charged a committee, headed by Jacques Bertillon (chief of Statistical Works for the City of Paris) with preparing a classification of causes of death. Bertillon presented his classification, based on the classification his own office used, to the ISI meeting in Chicago in 1893, which adopted it; he then through the ISI and the International Office for Public Hygiene (based in Paris) promoted his system internationally; it was adopted differentially by various governments’ statistical agencies: the Mexican, Canadian and American agencies took it up immediately for example. The first three revisions (ICD-1, 2 and 3) were adopted in 1900, 1909 and 1920. It received widescale international acceptance in the period after World War 1, when it was taken over by the League of Nations (though with the United States not being a member

of the League, there was an unusual bureaucratic tangle with the Americans working with the original French office). Moreover the ISI continuing to consider itself charged with producing the revision and did not accept the League's role. In the interwar period, the fourth and fifth revisions were developed—ICD-4 and ICD5 respectively, in 1929 and 1938. After World War 2, the newly formed World Health Organization took over development of the classification, a role that it has retained to this day. Revisions have been largely decennial, although the latest iteration (ICD-10) was longer in the making.

There is on the face of it nothing so simple and flat as the list of causes of death produced by the World Health Organization under the rubric the ICD. The smooth face of the flat list hides a complex story. The very name is, its developers point out, a misnomer. The ICD is a nomenclature, not a classification. There is no single organizing principle, rather etiological (disease origin), topographical (disease site), operational (test for disease) and ethical/political factors each play complex, frequently conflicting, roles in establishing the list. A single disease can be coded in more than one way (Rothwell, 1985, p. 171). Further, though originally conceived as a list of causes of death, it has since taken on not only morbidity but also the category of having been in contact with someone with a communicable disease (Blois, 1984, p. 127). At no time has the ICD been universally and consistently applied. New versions are taken up differentially—thus for example the Nordic Medical Statistics Committee, representing Scandinavian countries, held up the adoption of ICD-9 for several years, deeming that the cost of transfer to the new version outweighed the advantages (Fagot-Largeault, 1989, p. 97). Countries have felt themselves underrepresented in the classification: a frequent complaint in early years was the non-representation of tropical diseases. Even when the classification has been adopted, its implementation has differed depending on the available medical infrastructure: who fills in the death certificates, and how, is quite variable.

As the ICD has developed this century, so have the international coordination of medical practice and a new kind of information technology that can handle the massive data processing needs of this coordination. We cannot understand the classification produced unless we look at this work of coordination and at this technology. In general, integral to the development of information infrastructures is the often ignored, demeaned work of creating and maintaining stable classifications.

Medical categories are not pre-ordained and discovered: they vary widely by culture and over time. There is a work practice associated with developing them and that work practice influences the nature of the classification produced. In this paper, we will see that such a simple thing as a list of causes of death is in fact complex, negotiated and historically contingent.

#### MEDICAL CLASSIFICATION AND THE STATE

Large modern states have this century found themselves forced into developing complex classification systems in order to promote their political and economic smooth functioning. Producing these classifications is tedious, long, committee work. It is non-heroic work, carried out by bureaucrats. For many, such work does not have a history. The archives of the World Health Organization in Geneva preserved in black boxes on bright steel shelves, the records of the struggle against smallpox. Western medicine defeats ancient enemy! The bosses stand proudly on the shelves, a battery of headlines waiting for a chronicler. Typically for an information infrastructure, the achievement of producing and maintaining a standard international list of causes of death—a massive bureaucratic, scientific, technical, statistical, epidemiological, human achievement—is not recorded. When every 10 years a new edition is produced, records of the negotiations leading up to that edition are destroyed. For it appears that in this case what is interesting scientifically is the agreed-upon outcome, not the error-strewn path leading to it.

The ICD's lack of archives does not mean that it lacks history. Inscribed in the form and content of the list are a series of technical, social, political and economic decisions taken at different moments. These decisions, taken at particular times for a given set of reasons are paradoxically often more entrenched in the ahistorical ICD than they would be in some other

form of historical object. This is because in order to maintain comparability of items in the classification from one revision to the next, and thence in order to carry out large scale longitudinal public health and epidemiological surveys, you need to have the list change as little as possible from one edition to the next. Thus the preface to the fifth revision (1938) notes: “. . . the Conference endeavored to make no changes in the contents, number and even the numbering itself of the various items, so that statistics based on the successive Lists should be as comparable as possible, and employees of the registration and statistical services of the different countries should have their habits of work changed as little as possible. Many possible improvements in matters of form and order were abandoned in order to achieve this practical object” (League of Nations, 1938, p. 947). As smallpox was eradicated from the face of the earth, its archives swelled; as the ICD grew larger, the archives disappeared but the list folded in on itself—becoming ever more ramified and complex.

The health of the citizen is central to the modern state—as Ewald (1986) and others have shown. The equation can be brutal. One doctor responded in 1984 to a questionnaire on missed diagnoses (believed from autopsy analyses to be about 10% of all cases) that these “be quantitated on the basis of functional units, e.g. number of productive work-years lost or number of symptom-free months lost” (Anderson, 1984, p. 492). It can also be richly human. Thus “in 1974, New Zealand became the first country in the world to accept responsibility for the safety of its inhabitants for 24 hours every day, 365 days every year, from birth until death. At the same time, the Accident Compensation Corporation became the first organization in New Zealand, and possibly in the world, to become responsible for the prevention of accidents to all inhabitants as well as for compensating, and where necessary rehabilitating, those who suffered personal injury by accident” (Heidenstrom, 1985, p. 69). The state pits itself against the passage of time, and tries, in its own interest, to legislate immortality for its citizens. The benign side is health and quality of life, the darker side surveillance. Much has been written about the state’s role in classifying and monitoring mental health (see, for example, Kirk & Kutchins, 1992); much less about the classifying and monitoring of physical health. Yet this latter work has been just as politically fraught; and just as imbricated in the rise of the modern state. As mentioned above, the International Classification of Diseases was developed following an international conference in 1893 in Paris. This conference in turn followed on from a series of conferences to deal internationally with cholera. Why cholera? A series of epidemics in the late nineteenth century were being caused by pilgrims returning from the pilgrimage to Mecca infected with the cholera bacillus. In early years, returning on foot and by sailboat they had died before they returned to France. Now they were returning by rail and steamboat, and were able to bring the disease with them back into the metropolis before dying. So as communication between the countries of the world increased at the apogee of the imperialist age in the 1890s, so did the need to monitor health and welfare on an international scale.

When the classification was drawn up, it was based on one of the few pre-existing classifications: Bertillon’s list of causes of death in Paris (see Bertillon, 1990). The center of the French empire imposed its own classification scheme on its colonies—and other imperial powers followed suit. This fact was remarked upon at the time by many—e.g. South African doctors who noted that tropical diseases were under-represented. It remains a sore point to this day, when doctors in Africa have complained about providing AIDS statistics to first world countries, when these statistics cannot be of use internally: yet their compilation takes up valuable time. This is because AIDS is only one of a series of endemic causes of death; one that it will only be worth singling out and treating once appropriate medical services are in place and general urban sanitary conditions are improved. Until then, the need that Western doctors have to trace the genesis and development of the disease is not felt so urgently,

Thus by one reading the ICD was set up in an age of imperialism and imposed an imperialist reading of disease on the rest of the world. More subtly, and more interestingly, management of the ICD played a part in the creation of the modern state.

This becomes clear when one looks at the highly complex bureaucratic work involved in developing and maintaining the ICD. It is used by many groups for many different purposes. Medical insurance companies need a standard list of causes of death and of morbidity in order to work out standardized scales of payment for different treatments, and to work out the risk of

different subscribers (and thence their charges). The ICD is also used by epidemiologists: in order to track down the causes of a given new disease, one needs a standard terminology and good records. Only with these in place can one determine that the disease only affects those who eat a certain kind of food, or have a certain genetic (racial) heritage and so forth. Government health officials need good records in order to determine public health policy. For example, if tuberculosis is a major problem in a given area, then one might set up a clinic, or organize free X-rays there.

In order to maintain a good system of medical classification, a huge amount of information is needed about not only the citizens of a particular state, but about citizens of countries it is in contact with. No information is irrelevant. The state must have better information than the family itself. In 1927, in order to prevent the under-reporting of death by alcoholism and like causes, the Dutch state instituted a privacy clause on death certificates so that a diagnosis could be passed on to the family that preserved the social niceties—but an anonymous certificate would be sent to the state statistical service giving the real cause of death. As a result: “there was a considerable increase in Amsterdam of cases of death from syphilis, tabes, dementia paralytica, aneurism, carcinoma, diabetes, diseases of the prostate and suicide, while deaths from benignant tumors and the secondary diseases such as encephalitis, sepsis, peritonitis etc. showed a falling-off” (League of Nations, 1927). Anonymity became the norm (though it is reckoned that such deaths are still massively under-reported).

The state’s need for information is effectively infinite: here is a wishlist from 1985 for a national medical information system in the U.S.A.: “The system must capture more data than just the names of lesions and diseases and the therapeutic procedures used to correct them in order to meet these needs. In a statistical model proposed by Kerr White, all factors affecting health are incorporated: genetic and biological; environmental, behavioral, psychological, and social conditions which precipitate health problems’ complaints, symptoms and diseases which prompt people to seek medical care; and evaluation of severity and functional capacity, including impairment and handicaps. To accomplish this, a series of interlinked classifications would be required, designed so that all of the information is stored in a common data base. The entire spectrum of medical terminology would be included, from the layman’s language used to describe ill health and terms used by professionals at the institutional level to molecular terms from each of the basic sciences and terms related to causes of death used at the international level. Feinstein, in a recent paper, proposed to capture even more data consisting of the observations and quantitation of such clinical phenomena as the type and severity of symptoms, the rate of progression of illness, the severity of co-morbidity, the functional capacity of the patient, the reasons for medical decisions, problems in maintaining therapy, the impact of the ailment and its treatment on familial and interpersonal relationships, and other aspects of the physical activities and mental functions of daily life” (Rothwell, 1985, pp. 169–170). There is no foretelling what information will be relevant: “. . . to classify a chisel, a hand drill, and a spanner together as ‘hand tools’, or the first two as ‘cutting and piercing instruments’ may be obscurantist, or even misleading. Whereas to one accident researcher it is significant that a chisel is edged, a drill pointed, and a spanner neither, to another it may be more important that the chisel is pushed, the spanner turned and the drill operated by rotary motion” (Heidenstrom, 1985, p. 76). In order to properly record information about a given disease at a given time, everything about the social, economic, personal and physical conditions of the patient can be relevant (some will recognize this as a version of Spinoza’s problem).

This expanding wave of information gathering practices is a defining characteristic of the modern state, as Foucault (1991) observes. The production and maintenance of standardized medical records involved creating a uniform set of bureaucratic practices that matched the uniformity of the classification system—without the former, the latter was impossible. It entailed a range of activities from accustoming citizens to the regular collection of information about ever more aspects of their personal lives to establishing a standardized set of procedures so that information could be rendered comparable between situations to encouraging the development of a professional class that could use the information (see Abbot, 1988 for the medical profession as archetypical modern profession). As the general level of sanitation improved during the nineteenth century in industrializing countries, doctors needed ever finer

classification systems in order to do their work—this is the story from within the history of medicine. But by the same token as the modern state developed its view of legitimate government as the management of a large information system, states produced a proliferation of ever finer classification systems and a bureaucracy to manage them in a wide set of domains—of which the medical domain is a chief example. Building the ICD involved building the state as much as developing medical knowledge.

This double movement—build an information system and build the state—is an intricate one. In order to create something as basic as an information infrastructure or a scientific standard, that infrastructure or standard already needs in a sense to be in place. From the early days of the modern state, the need for such a bootstrapping operation can be traced with the development of hospitals following the French revolution. Until there was a classification of diseases in place—so that people with one disease would not be mixed in with others—then patients died wholesale, with the hospital serving as a place to share diseases. But a classification could not be developed unless people suffering from a given disease could be isolated from sufferers of other diseases; since the classification work depended on being able to develop specialized information about particular diseases, which could only be obtained through studying cases in a controlled situation where patients were not subject to a wide range of complicating illnesses and infections (Dagognet, 1970). [A famous example of such bootstrapping from the history of science is the story of Newton's prism used for his optical experiments. Italian researchers got different results using different prisms; and Newton only succeeded in establishing the veracity of his experiments once he had succeeded in imposing his prism as the standard—and he could therefore ascribe failures to replicate his experiment to defective prisms. However the only way of choosing between Italian and English prisms was whether or not they gave suitable results to Newton's experiments . . . (Schaffer, 1989)]. To solve the problem of establishing and maintaining the ICD, its designers quite explicitly acted as if ICD statistics were already accurate in the hope that by so doing they would make them so in the future.

Thus when the League of Nations began working on morbidity statistics, they did not try to impose a perfect classification scheme with a functioning bureaucracy. Rather, they admitted: "It is fully realized that much of the information called for in this plan is now utterly lacking in international, or frequently even in inter-urban, comparability. This is evidently the case, for example, in regards to the records of school medical examinations, which are frequently not comparable even between two different examiners in the same town. Experience shows, however, that comparability of statistics has rarely, if ever, been obtained before there was a definite demand for it. Rather than omit from the beginning all data which are not yet satisfactory, the authors have hoped, by including them and utilizing them for what they are worth, to create a demand for their improvement and for international definitions and standards which lead to the development of comparability. Wherever possible, checks have been devised to facilitate evaluation of the data" (Stouman & Falk, 1936, p. 904).

There have been many small ways of building the ICD and its bureaucracy in unison. Laws have been passed in individual countries demanding the reporting of all causes of death by the relevant statistical service. A single standardized death certificate (developed in the 1920s) has been adopted worldwide. Doctors, who have frequently bemoaned the time wasted on searching for the one true cause of death, have been educated in the epidemiological value of a good death certificate. None of these measures by themselves has rendered the ICD a perfect tool. However, both acceptance of the role of the state in garnering statistics, and its bureaucratic competence so to do, has increased drastically over the past hundred years. In the early 1900s in Russia, one priest would have the task of filling in the death certificates for a scattered population of 100,000 rural inhabitants (Fagot-Largault, 1989, p. 242). These results would in no way be comparable with the meticulous statistics collected in Paris. Such discrepancies have, through a slow series of changes, become less marked. The original list of causes of death covered a few million people, the 5th edition (1938) was estimated to cover 630 million, the 10th edition will perhaps be truly universal.

With the state and the rise of statistics playing such a role in the creation and maintenance of the ICD, it is no surprise that the list itself—to the casual glance a flat list of causes of death—has inscribed affairs of state onto its representation of the afflicted human body. From the

beginning, the definition of the moment of birth has been a key battleground. Catholic countries fought to recognize the embryo as a living being, statistically equivalent to an infant; Protestant countries were far less likely to accord the status of life to embryonic citizens. A compromise position reached in 1930 was that a baby must have tried to breathe three times in order to be ranked as an infant mortality rather than a stillbirth. Various editions of the ICD have had special sections devoted to this topic. Equally, the ultimate cause of death is also state-defined. It was made explicit in 1932 that when there were two equal underlying causes of death (e.g. cholera and leukemia) then the cause that would be most useful to the state (in this case cholera, which was a matter of public health concern) would be taken statistically as the underlying cause.

Categories of accidental death and death by suicide have always inscribed a diverse series of government regulations and local bureaucratic contingencies. Consider this set of categories from the 5th revision (1938). In this edition there were many categories for suicide, with categories 163 (Suicide by poisoning) and 164 (Other forms of suicide) being devoted to it. Sub-categories of the latter included:

- 164 f. Suicide by crushing.
  - fa. Suicide on railways.
  - fb. Other suicide by crushing.
- 187 Cataclysm (all deaths, whatever their cause).
- 192 Lightning.
- 193 Other accidents due to electric currents.

This latter is footnoted: “Except accidents from transport, accidents in mines and quarries, agricultural and forestry accidents, or accidents due to machinery, classed under Nos. 169–176, and deaths from operations of war, classed under Nos. 196 and 197”.

The pattern is clear. The railway authorities needed to keep track of the number of bodies they were having to sweep up. For example, the London underground introduced ‘suicide pits’ between the rails (still in use today), and wanted to know the efficacy of these pits in capturing and saving the attempted suicide. Equally, mines and quarries and war were covered by different government departments, and so it was useful to keep these statistics separate—even though the lay observer might see no difference between electrocution on a battlefield and electrocution at home. Finally, categories about which nothing could be done (medical “fait divers” of all sorts did not require detailed treatment: “cataclysm” would do for them all.

This government pressure on medical authorities to develop useful classification has been a constant theme. To take but one example, in Norway in 1981 the Government Action Committee for the Prevention of Child Accidents and public servants dealing with the 1976 Act of Product Control on working with consumer products asked the Health Authorities for a registration scheme so that all consumer products could be brought under a standard classification scheme (Lund, 1985, p. 84)—thus the health authorities got into the business of classifying not only diseases (natural kinds) but also manufactured articles (social kinds)!

It is clear then that a history of the ICD is not only a history of medical progress. Indeed, in a sense it inevitably lags behind the field of medicine in order to maintain comparability. It is also, and inextricably, a history of the formation of the modern state—both at the small scale level of the development of particular bureaucratic structures and at the large-scale level of the installing of and justification for methods to keep populations under surveillance.

#### MEDICAL CLASSIFICATION AND INFORMATION PROCESSING

The ICD is a complex information processing tool. As such it is at any one time associated both with a theory of historical knowledge and a particular configuration of technology. It is associated with a theory of historical knowledge in the sense that it embodies an understanding of what information about the past can and should be retained.

The historical problem is particularly complex since there has been a secular change in the form that death takes. People no longer die the way that they used to at the turn of the century. In 1900, the overriding causes of death were the single great epidemic diseases: tuberculosis,

pneumonia, smallpox etc. Nowadays, people tend to live longer and break down slower. They tend to be carried off not by a single disease, but by a complex of diseases (Israel *et al.*, 1986, p. 161). Matching this trend, the emphasis in applications of the ICD has gone from recording a single underlying cause of death to looking for a complex of causes.

Consider, for example, the standard International Form of Medical Certificate of Cause of Death adopted by the World Health Organization in July 1948 (reproduced in Fagot-Largeault, 1989, p. 72). This was the canonical form which was used to apply the ICD so as to produce epidemiological statistics. It locates a single “disease or condition directly leading to death”, with space for two antecedent causes (“morbid conditions, if any, giving rise to the above cause, stating the underlying condition last”) and then free space for “other significant conditions contributing to the death but not related to the disease or condition causing it”.

Designed and standardized in the 1930s the death certificate echoed the positivist analytic philosophy of the time. Now the trend is toward fractured, postmodern, multiple causation. The history of philosophy, the history of ways of dying and the history of death classification. Three histories or one? This question makes no sense unless we look at the ways the ICD as an information infrastructure knitting together temporal, philosophical and scientific concerns. Similarly, earlier in this century historians effected a closure on the past: they brought an historical actor before the tribunal of history. The original ICD also tried to effect closure: to provide a single, centralized record of disease. Modern historians constantly point to the openness of the past. The past, we are told, is recreated afresh at each instant in the present; one role of the historian is to honor this openness while telling the best story one can (Serres, 1993). Modern medical classification systems, most particularly the ICD rival SNOMED (Système de Nomenclature Medicale) strive in precisely the same way to keep the past open.

To tell the story as one internal to the history of medicine, consider the problem of tracking AIDS through history. AIDS achieved recognition as a disease in a slow process. Researchers at the Centers for Disease Control began to notice increased requests for a drug used to treat Kaposi's sarcoma—a rare condition afflicting certain well-defined groups. Intensive epidemiological work revealed that sufferers were largely male homosexuals (it was called the “gay cancer”); transmission to hemophiliacs indicated that it could be passed on in the blood; then Luc Montaignier and others located a virus that is generally believed (the question remains open) causes the disease. Previous statistics based on the ICD make it virtually impossible to search back through the historical record to find earlier instance of AIDS. The old statistics do not record what were believed to be contributing causes of death (people with AIDS from the 1920s might have died of any of a number of opportunistic infections; and their deaths would by the then current ICD, be widely distributed throughout the classification system), Grmek (1989) discusses at length the evidence for possible former cases of AIDS, which remained in the historical record contingently either because they involved famous figures (e.g. Erasmus) whose life was recorded in great detail or because they stood out as medical curiosities (the unexplained death of a Norwegian family in the 1950s. It is only through finding a pattern of immune system breakdown—that is to say by recording all contributing causes even when it is at the current state of knowledge “obvious” what the patients died of—that there can be any hope of tracking such diseases through time.

Thus the reason for the ‘open past’ as told from within the history of medicine. But taking this tack one misses the commonalities with many other disciplines and professions that have adopted new information infrastructures. In order to tell this story, we can turn to the history of information technology this century—and the ways in which technological constraints and information processing developments have shaped the ICD.

The ICD is at each point associated with a particular configuration of technology. Like much modern information technology it bears traces of its past. Computer screens tend to be 80 characters wide, an echo of the 80 columns of the preceding punch-card technology (Norman, 1988). Similarly the ICD bears traces of its technological base. For a long time it remained restricted to 200 headings: the number of lines that could fit on a standard folio sheet used by census offices.

Both the form and the implementation of the ICD have been influenced by development of information processing technology. For the former, Blois (1984, p. 124) remarks that the use of

numeric codes in the ICD was directly attached to the development of punch-card technology. As an example of the latter, we might note that in the United States, coding of more than the single underlying cause of death was a failure before 1968 despite repeated attempts; such coding became standard when an automated computerized system was implemented for the selection of the underlying cause of death (Israel *et al.*, 1986, p. 165).

Tracing the imbrication of the technological configuration and the form and use of the classification system, we will attach the history of the ICD directly to the development of information processing technology this century. The story begins in the nineteenth century, with the rise of large-scale bureaucracies. This development is still under-explored by historians, but one consensus that seems to be emerging is that the insurance companies, the banks, the railway companies and the government were at the heart of this development (Chandler, 1977; Yates, 1990; Campbell-Kelly, 1994; John, 1994). As companies began to operate distributed over a very large space (the railway companies simultaneously created that space and operated within it), there was a need to share information standardized form. A mechanical “punched-card” technology was developed for storing and sorting vast quantities of tabulated information. A hole punched on a certain row of a certain column of a card could mean whatever one wanted it to mean: and cards could be mechanically sorted. The first applications of this technology were the use of the Hollerith tabulators for the American census in 1890—the information gathered at this census would have taken longer than 10 years (the period between censuses) to sort using the old methods.

Information stored in this way could be retrieved much faster than information stored in, say, ledger books. However, it was difficult to implement the punchcard technology, which came into its own only for large scale statistical and accounting applications. It was expensive and cumbersome to go through huge numbers of cards—the cards themselves had to be printed on the finest quality material (Campbell-Kelly, 1989). In the case of the ICD, only certain centralized government bureaucracies could afford the necessary technology and personnel to successfully implement the new information processing possibilities. As a result some countries soon adopted this mode of information processing—others never did (the problem of divergent information technology resources has dogged the ICD to the present).

In the 1950s, electronic stored program computers began to appear. There was talk both in the popular press and in academic circles of creating an “electronic brain”. The dream in medical circles became the integration of all the various kinds of trace that were kept of medical encounters (Blois, 1984, p. 127). First there was the patient medical record: the hospital’s central account of what had happened to the patient. Then there were the local versions of that record stored and maintained by the various hospital departments. Then the notes kept by the doctor. Then the reports to health insurance companies. Then the reports to government statistical services. If a single standard language (e.g. in part the ICD) could be imposed on all these reports, then all the various services that needed information could draw it from a single central source. All relevant information would be preserved.

The most famous resultant record system, still operating today, was COSTAR: the Computer-Stored Ambulatory Record. This was developed at Massachusetts in the period from 1969, where it was first applied to a population of some 37,000 Harvard Health Care Plan patients. The record was to be used by researchers, doctors and government agencies. Its programming was written in a special interactive programming language called MUMPS (the Massachusetts General Hospital Utility Multi-Programming System) (Barnett, 1975, p. 4).

The central problem in the period 1950–1980 was that it was clear that the new information technology could provide integration, but it was not clear just what sort of integration was needed. For example, Berg (1996) has chronicled the debate about the various ways the new information technology could interact with medical practice. He discusses the project of making automatic medical diagnostic tools capable of making medical diagnoses. Thus the expert system MYCIN could outperform doctors in clinical tests. Paradoxically it was never actually adopted, since it tended to be very cumbersome and slow. This was pitted against the production of clinical decision support systems, which could advise the doctor not so much on the diagnosis as on the course of treatment to follow (since often the diagnosis itself is *ex post facto*—the treatment worked therefore the patient must have had such and such a disease).

Whatever the form of integration, more categories were needed in order to manage the range of uses the system would be put to, and over this period the ICD increased hugely in size. A sprawling set of modifications were produced for specific clinical and administrative purposes.

Thus ICD8 was modified by the U.S. Public Health Service to provide greater detail in certain disease categories and was published for use in the U.S. as the International Classification of Diseases—Adapted (ICDA), 1967. This in turn underwent further revision by the Commission on Professional and Hospital Activities (CPHA) for use in American hospitals, and was published in 1968 as the Hospital Adaptation of ICDA (H-ICDA). Later versions included that of the Royal College of General Practitioners (1972); the International Classification of Health Problems in Primary Care (1975); and the OXMIS Code of the Oxford Community Health Project (1975). Again this is the classic story of information processing at that period. Compare the history of computer languages: one hundred standard languages were created. Each of these standard languages spawned one hundred, often mutually incomprehensible, dialects. The World Health Organization tried to keep control of this process for the ICD by producing guidelines on how to modify the ICD for particular purposes—but these guidelines were themselves modified locally.

In the modern period, the resultant steely skyscraper of a Tower of Babel is not so different in kind from the Gothic brick construction of the 1890s—there were one thousand “controlled medical vocabularies” for one thousand purposes, each of them having embedded within them some version or other of the ICD. As one article put it: “We are often reminded that medical knowledge has grown to the point where we require the assistance of computers to manage it. One response has been the construction of controlled vocabularies to facilitate this process. We are now at the point where the vocabularies themselves have reached unmanageable proportions and must again call on computers for help” (Cimono *et al.*, 1979, p. 517). The call now is for a Unified Medical Language System (UMLS), that will provide for automatic, flexible communication between all authorized controlled medical vocabularies. Embedded within the UMLS will be the ICD. Embedded in the ICD will be flexible classifications that will, in principle, allow a reconfiguration of past records. Readers will recognize herein a familiar chapter in the history of expert systems, with the emphasis moving from faith in a unitary vision of the world as modelled in symbolic artificial intelligence to the management of multiplicity. By concentrating on the ICD and information technology, we are able to see the “open past”, described before in terms of the internal history of medicine as a development that can also be located in the history of information technology: and as such shared by a number of different disciplines and professions.

## CONCLUSION

In this paper, I have taken the position that a key outcome of the work of information scientists of all kinds is the design and implementation of information infrastructures. In looking at the case of the development of the International Classification of Diseases, we have seen a fundamental figure/ground problem emerge in the analysis of such infrastructures. In particular, we have seen that the medical classification system that underlies a large part of all medical bureaucracy is historically contingent both with respect to its political origins and technological underpinnings.

This is not of itself surprising. To classify is human and all cultures at all times have produced classification systems. Our own Western culture has perhaps produced more than most. It is often mistakenly asserted that Eskimos have 50 terms to describe snow; Arctic explorers have hundreds, scientifically laid out in expedition manuals (Pyne, 1986). A consistent finding of the history of science is that there is no such thing as a natural classification system (see, for example, Lakoff, 1986; Latour, 1987). Classifications that appear natural, eloquent and homogeneous within a given human context appear forced and heterogeneous outside of that context. Borges gives a wonderful invented list created by the Chinese emperor: “animals are

divided into: (a) belonging to the emperor, (b) embalmed, (c) tame, (d) sucking pigs, (e) sirens, (f) fabulous, (g) stray dogs, (h) included in the present classification, (i) frenzied, (j) innumerable, (k) drawn with a very fine camel hair brush, (l) *et cetera*, (m) having just broken the water pitcher, (n) that from a long way off look like flies” (cited in Foucault, 1970, p. 15). However, our own lists themselves can appear strange to outsiders. Thus supporters of the rival schools in modern biological classifications—cladistics and numerical taxonomy—each make rapprochements between species or splits between them that jar with “common sense” perceptions. The ICD as an information infrastructure is an invisible underpinning to medical practice. On close examination it constitutes a classification as strange as Borges’; but that is strikingly well-adapted—precisely because it developed integrally with the modern state and new information technology.

As for the ICD, we saw that one could foreground state interests, and see the developing ICD as reflecting and indeed partially determined by these interests. By this picture, the ID is a passive list, molded by outside forces. We saw that the ICD can, on the other hand, be brought into center stage as one of the mechanisms developed this century for producing and defining the modern state. According to this position, it is no happenstance that a series of universal classifications emerged in the late nineteenth century (classifications of work, of industrial equipment, of criminal physiognomies—Tort, 1989). Rather, the development and maintenance of such classifications by increasingly ramified bureaucracies changed what it was to be member of a given state by providing fundamental tools for communication and control.

Looking at the ICD and information processing, we saw that one could tell the story of the history of medical classification internally from within the history of medicine as the story of the development of better and better classifications in tune with the development of medical knowledge. We also saw that the information technology associated with the ICD could be brought into the foreground. Thus the ICD can be understood as one of many classification systems this century that have changed in tune with the development of computing technology: the storage and retrieval devices involved played a large part in shaping the nature and form of the classification system.

Given Star and Ruhleder’s definition of infrastructures, such figure/ground switches are to be expected. Information infrastructures like classification systems are embedded both in work practice and in technological media. Their history cannot be told independently of the work practice that they constitute or the media that they are inscribed in. In the case of the ID, the former link the history of the ICD to the history of a set of classificatory practices that define the modern state; the latter link the history of the ICD to a set of classificatory principles associated with a particular technological base.

Information infrastructures force us to pay close attention to the unit of historical analysis. To bring these two switches together, one might say that typically an historian seeks to examine the change in an historical entity over time—a person as she or he gets older, a state as it goes to war, an idea as it is born, developed and superseded. In these standard cases one assumes—rightly or wrongly—that what it is to be a person a state or an idea does not change in the course of the historical treatment; in other words that there is a passive backdrop against which the historical drama is played out. Information infrastructures are constitutive of that backdrop; when they are foregrounded the historian’s standard categories are rendered contingent, they become objects of historical examination.

This kind of shift can be dubbed an “infrastructural inversion” (Bowker, 1994). It provides a framework within which one can consider the filiation between information processing practices in a range of arenas. The problems faced by the ICD and its solutions have as much in common with the history of the Dewey classification system in libraries (and industry!) as with the history of medicine before the ICD. In order to do historical justice to the development of information infrastructures, one must move between stories that historians traditionally tell of people and places and things and stories that are generally left untold of the woof and warp of the canvas on which historical dramas are painted.

## REFERENCES

- Abbott, A. (1988). *The system of professions: an essay on the division of expert labor*. Chicago: University of Chicago.
- Anderson, R. E. (1984). The autopsy as an instrument of quality assessment; Classification of premortem and postmortem diagnostic discrepancies. *Archives of Pathology and Laboratory Medicine*, 108, 490–493.
- Barnet, G. O. (1975). Director, Laboratory of Computer Science. *COSTAR computer-stored ambulatory record*. Boston, Mass.: Massachusetts General Hospital.
- Beniger, J. R. (1986). *The control revolution: Technological and economic origins of the information society*. Cambridge, Mass.: Harvard University Press.
- Berg, M. E. (1996). Formal tools and medical practices: Getting computer-based decision techniques to work. In G. C. Bowker, L. Gasser, S. L. Star, & W. Turner (Eds), *Social science, technical systems and cooperative work*. In preparation.
- Bertillon, J. (1990). *Sur une nomenclature uniforme des causes de décès*. Kristiania: Th. Steen
- Blois, M. (1984). *Information and medicine: The nature of medical descriptions*. Berkeley, Calif.: University of California Press.
- Bolter, J. D. (1991). *Writing space: The computer, hypertext, and the history of writing*. Hillsdale, N.J.: Erlbaum.
- Bowker, G. C. (1994). *Science on the run: Information management and industrial geophysics at Schlumberger, 1920–1940*. Cambridge, Mass.: MIT Press.
- Campbell-Kelly, M. (1989). *ICL: A business and technical history*. Oxford: Clarendon Press.
- Campbell-Kelly, M. (1994). The railway clearing house and Victorian data processing. In L. Bud-Frierman (Ed.), *Information acumen: The understanding and use of knowledge in modern business* (pp. 51–74). London: Routledge.
- Chandler, A. D., Jr (1977). *The visible hand: The managerial revolution in American business*. Cambridge, Mass.: Belknap Press
- Cimino, J. J., Hripcsak, G., Johnson, S. B., & Clayton, P. D. (1979). Center for Medical Informatics, Columbia University, Columbia-Presbyterian Medical Center. Designing and introspective, multipurpose, controlled medical vocabulary. In L. C. Kingsland III (Ed.), *Proceedings of the Thirteenth Annual Symposium on Computer Applications in Medical Care*, Washington, D. C., (pp. 513–523). IEEE Computer Society Press.
- Dagognet, F. (1970). *Le catalogue de la vie: Étude méthodologique sur la taxinomie*. Paris: Presses Universitaires de France.
- Desrosières, A. (1990). How to make things which hold together: Social science, statistics and the state. In P. Wagner, B. Wittorck, & R. Whitley (Eds), *Discourses on society: The shaping of the social science disciplines*. London: Kluwer.
- Desrosières, A. (1993). *La politique des grands nombres: Histoire de la raison statistique*. Paris: Editions La Découverte.
- Eisenstein, E. L. (1979). *The printing press as an agent of change: Communications and cultural transformations in early modern Europe*. Cambridge: Cambridge University Press.
- Ewald, F. (1986). *L'état providence*. Paris: Grasset.
- Fagot-Largeault, A. (1989). *Causes de la mort: Histoire naturelle et facteurs de risque*. Paris: Librairie Philosophique J. Vrin.
- Foucault, M. (1970). *The order of things: An archaeology of the human sciences*. London: Tavistock.
- Foucault, M. (1991). Governmentality. In G. Burchill, C. Gordon, & P. Miller (Eds), *The Foucault effect: Studies in governmentality*. Chicago, Ill.: University of Chicago.
- Grmek, M. (1989). *Histoire du sida: Debut et origine d'une pandémie actuelle*. Paris: Payot.
- Hacking, I. (1990). *The taming of chance*. Cambridge: Cambridge University Press.
- Hawking, S. W. (1980). *Is the end in sight for theoretical physics?: An inaugural lecture*. Cambridge: Cambridge University Press.
- Heidenstrom, P. N. (1985). Research Unit, Accident Compensation Corporation, Wellington, New Zealand. Accident statistics, coding systems, and the New Zealand experience. In R. A. Côté, D. J. Protti, & J. R. Scherrer (Eds), *Role of informatics in health data coding and classification systems* (pp. 69–80). Amsterdam: Elsevier.
- Israel, R. A., Rosenberg, H. M., & Curton, L. R. (1986). Analytical potential for multiple cause-of-death data. *American Journal of Epidemiology*, 124, 161–179.
- John, R. R. (1994). American historians and the concept of the communications revolution. In L. Bud-Frierman (Ed.), *Information acumen: The understanding and use of knowledge in modern business* (pp. 98–112). London: Routledge.
- Kirk, S., & Kutchins, H. (1992). *The selling of DSM: The rhetoric of science in psychiatry*. New York: Gruyter.
- Lakoff, G. (1987). *Women, fire, and dangerous things: What categories reveal about the mind*. Chicago: University of Chicago Press.
- Latour, B. (1987). *Science in action: How to follow scientists and engineers through society*. Cambridge, Mass.: Harvard University Press.
- League of Nations (1927). CH/Experts Stat/34 of 2 December 1927 (held in the League of Nations archives at the United Nations Library in Geneva). Report of the Committee of the Vial Statistics Section of the American Public Health Association on the accuracy of certified causes of death and its relation to mortality statistics and the international list.
- League of Nations (1938) League of Nations. *Bulletin of the Health Organisation*, VII, 944–987. International Lists of Causes of Death adopted by the Fifth International Conference for Revision, Paris.
- Lund, J. (1985). Nordic classification for accident monitoring, and its implementation in Norway. In R. A. Côté, D. J. Protti, & J. R. Scherrer (Eds), *Role of informatics in health data coding and classification systems* (pp. 81–87). Amsterdam: Elsevier.
- Norman, D. (1988). *The design of everyday things*. New York: Doubleday.
- Pyne, S. J. (1986). *The ice: A journey to Antarctica*. Iowa City: University of Iowa Press.
- Roth, J. A. (1963). *Timetables: Structuring the passage of time in hospital treatment and other careers*. Indianapolis: Bobbs-Merrill.

- Rothwell, D. J. (1985). Requirements of a national health information system. In R. A. Côté, D. J. Protti, & J. R. Scherrer (Eds), *Role of informatics in health data coding and classification systems* (pp. 169–178). Amsterdam: Elsevier.
- Ruhleder, K. (1995). Reconstructing artifacts, reconstructing work: From textual edition to on-line databank. *Science, Technology and Human Values*, 20, 39–64.
- Schaffer, S. (1989). Newton's prism. In D. Gooding, T. Pinch, & S. Schaffer (Eds), *The uses of experiment: Studies in the natural sciences*. Cambridge: Cambridge University Press.
- Serres, M. (1993). *Les origines de la géométrie*. Paris: Grasset.
- Star, S. L., & Ruhleder, K. (1996). Steps towards an ecology of infrastructure. *Information Systems Research*. Forthcoming.
- Stouman, K., & Falm, I. S. (1936). Health indices: A study of objective indices of health and relation to environment and sanitation. In League of Nations, *Quarterly Bulletin of the Health Organization*, V, 901–1081.
- Tort, P. (1989). *La raison classificatoire: Quinze études*. Paris: Aubier.
- Yates, J. (1989). *Control through communication: The rise of system in American management*. Baltimore: Johns Hopkins University Press.