INFORMATICS IN PRIMARY CARE

Research article

# The John Bryden memorial lecture: improving health with the community health index and developments in record linkage

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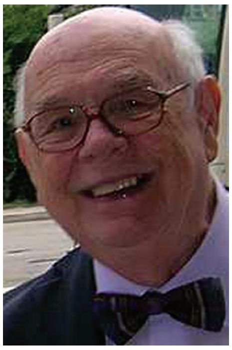
## ABSTRACT

Dr. John Bryden was the executive officer of European Federation for Medical Informatics for a decade between 1998 and 2008. When he retired from active work within the federation, he was awarded an honorary fellowship. In one of his early papers from the 1960s, he described how some relatively novel machines called computers might replace the punched cards that were being used at the time. He saw, before many others, that computers could be used for the care of individual patients and even more so for groups of patients. He implemented a unique patient identifier (community health index) which has enabled Scotland to link electronic medical record data for clinical management of chronic disease deterministically. An example was the development of the Glasgow Coma Scale. One benefit of demonstrating significant value in projects such as this at an early stage of record linkage was that the governance framework for the use of data became relatively permissive. Another major success was diabetes care; it became possible to apply insights from the aggregate data to improve services and make them more efficient. Scotland has developed safe havens for data where not only the physical environment but also the people, mechanisms and projects are all subject to control to ensure safety and confidentiality. Similar moves are under way in Europe. TRANSFoRm (www.transform-project.eu) led by King's college in London is mainly focused on primary care data. Excellence in medical informatics is possible as a result of the work of its pioneers, including John Bryden's first paper suggesting that computers might be useful.

## BACKGROUND

Dr. John Bryden was the executive officer of European Federation for Medical Informatics (EFMI) for a decade between1998 and 2008: a role which he performed with great distinction, including the chairmanship of several special topic conferences. When he retired from active work within the federation, he was awarded an honorary fellowship and continued to have an interest in its work. I first met John in the mid-1980s when I was a junior doctor working in the west of Scotland and he was a senior colleague. We were both interested in the problem of how to improve clinical care for chronic disease and wondered whether some of the new tools of medical informatics might contribute to managing patients better.



In the 1960s, when medical records were kept in unwieldy envelopes in the UK, John realised their potential power to improve health care. One of his early papers described how some relatively novel machines called computers might replace the punched cards that were being used at the time.[1] It may be difficult to recall now, but some of you will remember the moon landing in 1969. At that time, computers had about as much processing power as a washing machine has today.

John was one of the first people who could see that potential and was able to make real progress in Scotland and Europe. He saw that computers could be used for the care of individual patients and even more so for groups of patients.[2] The electronic medical record (EMR) and our increasing ability to link and share the information they contain would be a revolutionary change in medicine.[3]

During the rest of this lecture, I would like to talk about how his work on implementing a unique patient identifier or the community health index (CHI) number has enabled Scotland to link EMR data for clinical management of chronic disease, using diabetes mellitus as an example. I will then go on to describe how his work has also enabled contributions to developments in the UK and more widely in Europe by describing some projects I am working on.

## THE CHI

The CHI number is a 10-digit string comprising date of birth, the order of registration of an individual by birth or immigration, into Scotland for the first time, sex and a checksum to prevent computer users making up a number.[4] Its use has gradually spread and is now applied to 99.8% of health care events in Scotland. His early work with the CHI in Scotland enabled data from multiple sources to be linked together in a deterministic manner rather than having to rely upon probabilistic methods.[5] This has gradually been developed over the years to allow linkage from before birth until death which allows a range of uses from clinical care to service management and research (Figure 1).

An early use of record linkage which John was involved in was the development of the Glasgow Coma Scale.[6,7] This is one of my Glasgow's most famous exports thanks to hospital dramas like ER. The serious point is that better use of data on patient outcomes allowed studies to track patients after hospital discharge and correlate detailed clinical information on eye opening, motor and verbal responses to longer term recovery. This demonstrated 'proof of concept' for a methodology that has since been applied more widely.

One benefit of demonstrating significant value at an early stage of record linkage was that the ethical and legal framework for the use of data in medical research became relatively permissive.[8] The use of anonymous data was lightly regulated and only when information was needed to contact patients was permission more onerous. The health service sought to inform and reassure patients about the use of their data in leaflets and posters.

## DIABETES CARE

One of the major successes was diabetes care where Tayside developed systems locally which once successful became adopted nationally and it became possible to apply insights from the aggregate data to improve services and make them more efficient. Everyone involved in managing a chronic disease like diabetes realises that they only have a partial view of the problem. The increasing availability of electronic records in Scotland and the ability to link the data using the CHI number meant that a complete picture could now be obtained. This is from a *BMJ* paper in 1998 describing the use of a capture/recapture technique to ensure that everyone with diabetes in our region was on the register to enable recall and regular review.[9]

Of course, it was not entirely accurate at first, and every Easter, we reported the resurrection rate for the first few years when people categorised as dead reappeared. After 5 years of feeding this information back to front-line staff, the problem ceased. Garbage in, garbage out may be true, but if clinicians perceive that they will get useful information out of their computer systems, then they will be happy to take the time and effort to provide higher quality data entry. This enabled first Tayside to develop a series of linkages to data from all the sources used by patients. Once the concept had been established, it became possible for the idea to be

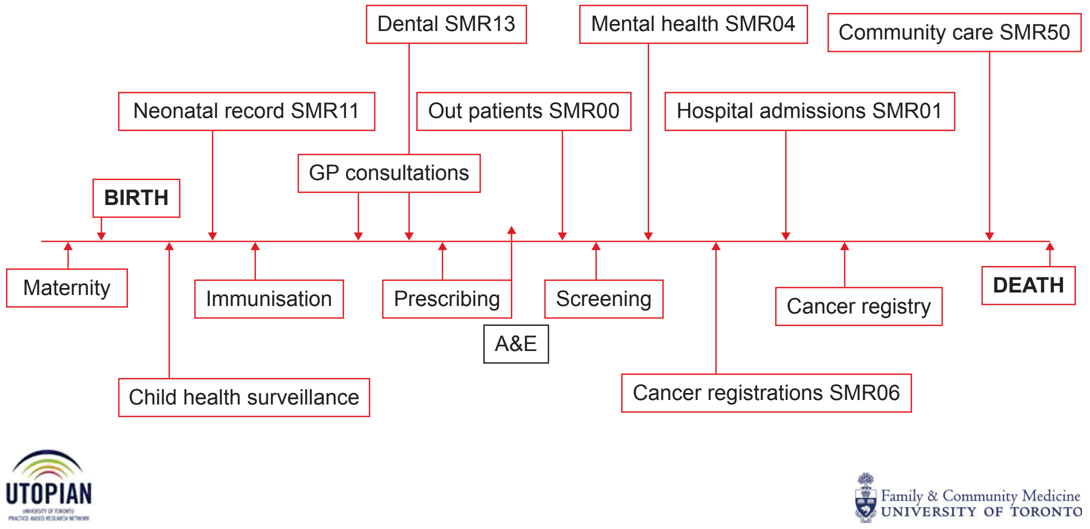


**Figure 1** **Scottish health records. Ref http://www.isdscotland.org/Products-and-Services/eDRIS/**

adopted nationally so that everyone with diabetes has shared records across the country.

Then, clinicians, academics and policy makers can start to address known but previously intractable problems like the rule of halves.[10] Where there seemed to be underdiagnosis, more intensive searches could be undertaken. Where patients had a diagnosis but were not on any treatment that could be rectified. And, where treated patients were poorly controlled measures could be put in place to deal with the system problems, which led to the difficulty identified in the data. Data showing the HbA1c levels of patients in all practices in Tayside identified one or two below the standards expected which could then be engaged in further discussions to identify the cause of the problem and, usually, rectify it.[11]

Data were even more important in addressing the widespread problem of the inverse care law 'The availability of good medical or social care tends to vary inversely with the need of the population served'.[12] Health services in many countries are designed for mobile, intelligent people who will attend for examinations when they are asked to do so. The problem it is older, less mobile people who have difficulty accessing or using services where the bulk of the problem lies. When a health service knows which diabetic patients have not had an annual foot examination and appropriate follow-up, then it can make new provision for the older, less mobile people who have difficulty accessing or using the mainstream services. This is what we have seen. Despite a quadrupling in the numbers of people known to have diabetes, there has been a significant reduction in the total numbers of lower limb amputations.[13]

Services can also be made more efficient by using real data and modelling as these graphs show. If patients with T1DM have had two normal examinations, then their next examination can safely be delayed for 2 years, whereas if an abnormality has been seen, then examinations need to be more frequent. So, even though some patients would be seen more often for review, overall resources could be saved.[14] In this case, around 40% fewer examinations would be needed. The final example from diabetes is opening up the patient's data for them to see for themselves what their lab values and examination results are. At the moment, the patients involved in this area a highly motivated, self-selected group, but it seems likely that their numbers will grow as the population becomes more tech-savvy and services are reconfigured to provide them their data when they need it.[15]

## HEALTH INFORMATICS INFRASTRUCTURE

Partly, as a result of success in these research activities in diabetes as well as other areas like pharmacoepidemiology, we embarked on the Wellcome trust funded €6M Scottish Health Informatics Programme (SHIP) to build up the Health Informatics infrastructure.[16] Developing safe havens for data was a key part of this with not only the physical environment, but the people, mechanisms and projects were all subject to control to ensure safety and confidentiality. Some of the key features of the information governance mechanisms are shown in the figure below, including centralised indexing for quality control and local access mechanisms.

Researchers who want to use data have compulsory training in the legal and ethical issues, and they are assigned an experienced research coordinator who pilots them through the process. The linkage mechanisms may be familiar to some in the audience, but Figures 2 and 3 illustrate the idea. The first shows how patient identifiers are stripped off the 'payload data'. Both are then sent separately to an independent indexing service which returns the data to the data source with a study number.

In the second stage, the data sources can then send the anonymised, but linkable data to the safe haven for researchers to access. The indexing service has no data, and the safe haven has no way to identify the patients.

In addition to the technical progress, SHIP has made the assessment of applications to use data more proportionate.[17] Only the most restricted category requires researchers to go into a windowless room in a secure building and be checked for recording materials. SHIP has also involved a programme of research of the kind already mentioned in four broad categories.

One example of the power and efficiency of record linkage is the West of Scotland Coronary Prevention Study. The trial costs €30M over 5 years, but using record linkage for an

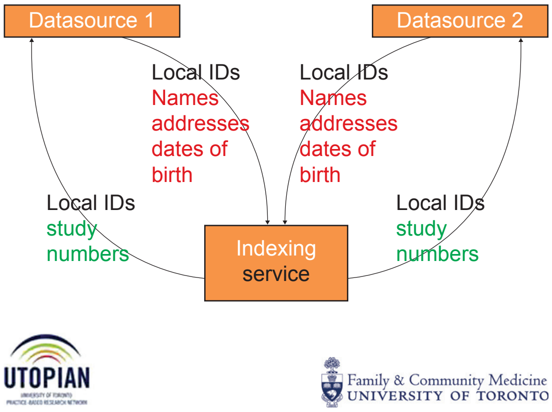


**Figure 2** **Linkage part 1**[22]

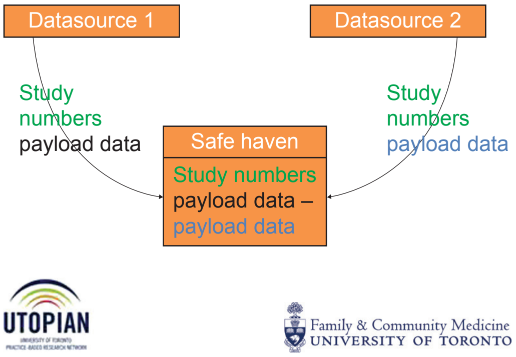


**Figure 3** **Linkage part 2**[22]

additional 10 years costs only €30K.[18] Success like that has encouraged the U.K. government to make further investments in a national network of centres to make greater use of linked health data for a range of purposes in the Farr Institute.[19] Of course, the architecture becomes more complex as the demands placed upon the system and more actors increase, but the essential principles of data governance remain the same. The source systems already exist, and they have evolved good systems to ensure privacy. Researchers have to prove that they can handle the data they are allowed to see in a confidential manner and the central area here are the informatics mechanisms to ensure that it all works.

## INTERNATIONAL PROJECTS

Similar moves are under way in Europe in two projects. The first, TRANSFORM led by King's college in London, is mainly focused on primary care data.[20] Like SHIP, it addresses a series of infrastructure and basic informatics issues as well as addressing research questions. As with all large projects, there are several work streams which draw upon the expertise, which is only found across a large number of collaborating groups. The work package led from Scotland focuses upon diabetes. The question links genetic data to primary care EMR data.

EHR4CR is an even more ambitious project with more academic partners and involving 11 pharmaceutical companies.[21] Some of this build upon work in TRANSFORM, and some are new. It has the ambition of ensuring that clinical data in EMRs and other sources can be used for research seamlessly, with no need for the current separation and loss of efficiency that entails.

## SUMMARY

There have been many successes in medical informatics since 1969 and John Bryden's first paper suggesting that computers might be useful. However, there are increasing challenges as well; patients move location and they need their medical information to follow them. Members of the EFMI are contributing to an ability to achieve this through action on a range of interlocking topics and projects.

I am sure that John would be pleased to see how things have developed, but he would also be encouraging us to even greater efforts to ensure that patients benefit from our work.

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