

Some thoughts attached. I enjoyed the sessions of the UN Information Governance forum that I could attend. <https://intgovforum.org/en/dashboard/igf-2021>

## **The United Nations convention on the Rights of Persons with disabilities, the European Union general Data Protection and coding"**

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### *Abstract.*

This paper presents the case for a global patient centred ethical governance of health data processing and suggests standards of data processing that a United Nation body might in the future have some responsibility for overseeing, balancing the roles of industry, the State and the individual in the processing of personal health data. I hope to attract UN interest in personal health data governance lest we develop a global system of inequality of access to health data as has happened over millennia with petrol, gold, coal, pottery, bronze, iron, coffee, tea, weapons, drugs, spices, etc.

### I KEYWORDS

Electronic health records, patient, access, EU Legislation, Data protection, United Nations conventions on the Rights of Persons with Disabilities,

### II MAIN TEXT:

The current law covering data processing in Europe is the European Data Protection Directive 95/46/EC.<sup>1</sup> The European Commission at Brussels COM(2012) 11/4 has accepted a proposal for a regulation of the European parliament and of the Council

on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation [SEC(2012) 72] and [SEC(2012) 73] which comes into force in May 2018.

The United Nations Convention on the Rights of Persons with Disabilities declares:

“Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

“Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them,

“Recognizing the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,

“To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

“To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

“To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

### III OUR WORK ON CONSENT, PATIENT ACCESS, ALGORITHMS, CODING AND HEALTH DATA IN ENGLAND

“The Hadfield Medical Centre (HMC)<sup>1</sup> is recognised as an example of ‘good practice’ by the Department of Health (DoH)<sup>2</sup> as it is committed to enabling patient participation, by creating opportunities where patients may participate in issues related to and affecting their healthcare. Dr Richard Fitton, staff and patient volunteers at the HMC have worked hard to promote and to maintain the momentum of patient participation for over seven years.

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<sup>1</sup> For more details please see [www.nhs.uk/erdip/pages/news\\_items/demo\\_141100.asp](http://www.nhs.uk/erdip/pages/news_items/demo_141100.asp)

<sup>2</sup> [www.doh.gov.uk/pcharter/phctip3.htm](http://www.doh.gov.uk/pcharter/phctip3.htm) or Department of Health (1997), ‘Involving Patients – Examples of good practice, Crown copyright.

"The notion of patient participation was first recognised by the GP in 1993, at the time that he started working at the Hadfield practice. Time and experience led the GP to feel that there were large gaps in patients' knowledge regarding their healthcare and the activities of the National Health Service (NHS). The GP thought that patients were ill informed about their health and their rights and responsibilities as patients. The NHS Plan (2000)<sup>3</sup> stated that the NHS is a 1940s system of care that is in great need of modernisation. The plan devotes an entire chapter (chapter 10) to patients, and acknowledges that patients have a right to be better informed and have more choice regarding their healthcare. It suggests that patients need to be empowered, and planned to give all patients access to their health records electronically by 2004.

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**The importance of the relationship between patient and clinician.** (Ref Hannan and Webber Medical and Care Compunetics 4 L. Bos and B. Blobel (Eds.) IOS Press, 2007 pp. 108-116)

Dr Hannan and Fred Webber PhD "Shared decision making" may be regarded as an aspect of "patient centeredness" and can enhance patient autonomy as well as being associated with more positive consultations without increased anxiety [33].

"The clinician can bring to the consultation his or her experience and knowledge of the medical world whilst the patients can bring their experience of the symptoms of the disease and how it is affecting them. Together they can build a "partnership". But for this partnership to be beneficial, it needs to provide something for each party. Trust is that basic commodity. The clinician needs to trust the patient who is telling them all they can about their illness whilst recognising that patients have their own agendas and may only tell them what they feel comfortable with.

"Similarly the patient needs to trust the clinician hoping that they will be given all the relevant information about their illness in a form they can understand. By accessing the medical records, the clinician is in effect telling the patient what their understanding of their illness is and what the plan of action may be. The patient is able to access this information, agree with it or refute it or identify any mistakes that may co-exist and then respond by determining what course of action to take.

"The more information there is, the greater the trust this breeds between the two parties. Trust can be broken and partnerships can split but when a Partnership of Trust is formed, it can create a synergy that enables the clinician and the patient to feel more in control and more at ease with their disease and enables patients to feel less ill.

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**Record access in England** We contend that our work on record access has the potential to lead the way to a safer and more efficient system of health care that could be utilized globally but would require global governance that the United Nations might help to oversee to allow an equitable distribution of e-health care.

Patient Online ( <https://www.england.nhs.uk/ourwork/pe/patient-online/>) is an NHS England program designed to support GP\*\* practices to offer and provide online services to patients, including access to coded information in records, appointment booking and ordering of repeat prescriptions. The service is at an early stage of adoption and is available to 50 million patients in England. Patients may share their health data in this way with whoever they wish.

\*\* (Wikipedia – “In the medical profession, a general practitioner (GP) is a medical doctor who treats acute and chronic illnesses and provides preventive care and health education to patients”)

### **What algorithms and heuristics arose that involved coding?**

Medical records contain many data and there are logistical issues around how patients can select and mark which items they do not wish to share. We considered two strategies for patients to mark sensitive data that they wanted to be asked about before sharing. The first was a heuristic system in which the patients checked through every entry in their notes and mark the data that they do not want to share. The second was an algorithmic system that utilizes the intelligence of data that has already been collected, coded and sorted into its root classification to simplify the process for the patient.

A group of patients in an English General Practice were asked to examine their own complete medical record and to mark those parts of the record that they would not want to share with a national care record. As expected the patients chose parts of their records that had a social context as well as a health service context. These parts of the record were data about infectious diseases, drug and alcohol problems, mental and social health issues, sexuality – including pregnancy and contraception and genetics.

To facilitate automatic separation of these sets of sensitive coded data we used the following common coded ICD10 (International Classification of Diseases) roots from the GP record and produced a data engine that put them into unique folders. In the system data engines created specific views of the patients' data customized for each type of access. One engine displayed the codes to mirror the structure of the Read coding hierarchy. One engine created “folder” or chapter views of the patient Read codes and text. Each “folder” was populated by codes from its own Read code

chapter. Folders were designed to manage lifelong records and to aid sealed envelope use for purposes of confidentiality.

The patient then marked the folders that they did not want to share without consent at each attendance or health data interaction and those that they would share within a regulated health service environment.

### **Disease categories**

Infectious/parasitic diseases, Neoplasm, Endocrine/metabolic, Blood diseases, Mental disorders, Nervous systems/senses, Circulatory system, Respiratory system, Digestive system, Genitourinary system, pregnancy/childbirth/puerperium, Skin/subcutaneous tissue, Musculoskeletal, Congenital abnormalities, Peri-natal conditions, Symptoms, signs and ill defined conditions/working diagnoses, Injury/poisoning, causes of injury/poisoning

### **What are our suggested global standards for the processing of sensitive personal health data?**

In our patients' opinions at Hadfield Medical Centre in 2004:

- Data controllers (GPs in our particular case) should no longer be able to refuse online access to data subjects to all of their real time digital data if the technology can allow this access. (There is no section in the English current DPA that deals with immediate access to digital data)
- Data subjects should have the option of being part of a dynamic and ongoing process of deciding which parts of their data are sensitive and not to be shared without consent.
- Patient sensitive data (as defined by the patients as they view their data as it is being created with real time access to data that current technology allows– or later as they view it through their access rights) should be digitally coded and recorded at source as processing takes place.
- Data subjects should have an opportunity to be involved in the decisions that are made about the retention and destruction of their data. We believe that one option would be a statutory requirement for data controllers to approach data subjects say 6 months before they destroy the data to see if the data subjects would like to have the data retained or to have it processed at their own expense elsewhere. (Some patients wish their medical records to be detained for their families after their death. They already pass on their records

to family members when they have been given them in a hard or digital format.)

- Digital audit trails of access to personal data by third parties and professionals should be made available to the data subjects.
- Commercial and State data controllers should be under statutory obligation to publish on their public facing websites the information sharing contracts that they have made with other data controllers.
- Commercial and State data controllers should be obliged to publish the details of bulk transfers of personal data that they make from one data controller to another.

## **Discussion**

The State can legislate for professional ethical, clinical, technological, security, administrative, legal and information governance standards for data processing but it cannot legislate for each individual's moral choice of sensitive data.

## **Conclusions**

Twenty seven European countries are about to utilise laws that will support a better ethical and moral sharing of data for health care purposes. In the past professionally produced and stored data has been stored in paper or enclosed electronic silos. The introduction of technology security, information, clinical, moral, organisational and legal standards is presenting an opportunity for the re-cycling and sharing of personal health data with consent amongst professionals, researchers and patients.

Well established and developing coding and classification systems allied to patients' social definition of data may provide a way of adding a personal moral filter for each citizen to apply to his health data as his life and circumstances develop whatever the State or commercial organisation's default on sharing.

Electronic health record architecture will need to support and instantiate national and international legislation, human rights and the technological interface that allows patients and citizens to exercise their moral choices about who can see their data. We would suggest that the United Nations be asked to consider supervising standards to support citizens' rights and responsibilities within the processing of their own health data.

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