Disputes about data privacy

There is a dispute between the European Union and the USA over data privacy issues. The EU considers that data privacy is enshrined in human rights legislation and has been negotiating with USA to find a compromise to allow data transfers between the two areas, ensuring that continued protection of the individual is guaranteed. There is a feeling that, as the Clinton government comes to an end, the key staff are likely to move into the private sector. The USA wants to resolve the problem in the short term so that business in the USA is not disadvantaged.

Within the EU there are also problems because some member countries do not have workable legislation to conform to the strong EU position. The EU is to take France, Germany, Luxembourg, Ireland and the Netherlands to the European Court of Justice for failing to implement EU laws on the protection of personal data. If the judges find in favour of the EU then the member states will be forced to change their national legislation to comply with EU law.

Individuals who suffer damage as a result of individual member state's failure to implement the directive may be entitled to seek compensation before national courts. The EU laws are important to foster consumer confidence and minimise differences between the member state's data protection rules which should help the development of e-commerce.

European Computer Driving License scheme

The European computer driving license qualification is growing in strength. Over the first 18 months of the scheme more than 37,000 logbooks have been issued through 55 UK training and testing centres. More than 2,300 people have completed all seven modules of the scheme. An updated syllabus has been launched this year although those following the existing syllabus will be able to complete their qualification and have the necessary knowledge and skills. For more details phone 01793 417497 or look at http://www.bcs.org.uk/ecdl/

Was Y2K a non-event?

After all of the build up to the potential problems of the millennium bug it appears that there were no major problems after all. Debate has been raging about whether the whole thing was a total waste of money, or so well managed that all systems were fixed and did not have to cope with any problems. The likelihood is that the situation is somewhere in between!

There were some problems: safety systems in ten nuclear power stations did fail simultaneously across the world; electrocardiograph machines stopped working in
some places; the US's crucial defence intelligence satellites were out of action for hours.

What would have happened if all the preparation had not gone on beforehand? There is an argument that some countries did not spend very much on preparation (e.g. Italy and Russia) and they had no problems. However some of the costs spent by these countries have been hidden from official statistics and in other places organisations have found manual solutions to the problem. In many cases organisations simply put back the clocks on their computers to pre-2000 dates.

The problems may not yet be over - many IT directors and others are saying that only 5% of problems were expected to take place over the first few days of January. The rest will emerge over the course of the year at month ends, year ends and important dates such as 29th February and 1st March. Other problems may arise when date calculations are being made for the production of reports, month end or year end accounts etc., as the computer has to make calculations over the turn of the year.

A non-related benefit of much of the Y2K work has been that some organisations have analysed their IT systems in a systematic way for the first time and have used the opportunity to rationalise equipment and software. Many have comprehensive inventories which can be used for future planning and contingency plans documented for the first time. Organisations have also learned how to manage large, multi-disciplinary projects.

The National Audit Office has recommended that organisations consider the longer-term benefits of the Y2K activities. They are worried that many organisations may not learn from the experience if they see it as simply a struggle from one crisis to the next. The emergency, major incident, business continuity and contingency plans should now be integrated and regularly reviewed.

**GP access to NHSnet**

Around-the-clock access to the NHSnet will now be made available to GP practices at no local cost. This move has been welcomed by GPs but there are worries about the reliability, performance and security of the NHSnet. Improvement plans have been agreed with NHSnet and BT Syntegra and Cable & Wireless to ensure that performance problems are resolved.

The Department of Health and the BMA are considering ways to make contractors more directly accountable to users if problems do occur with NHSnet. The BMA have welcomed the concept of a free service but want details of how quality and performance are going to be policed. There is no point in having a free service if it does not deliver what is expected of it.

**Paperless hospital?**

Plymouth Hospital NHS Trust is updating its patient information system so that 2,500 hospital staff can access patient records and administrative staff can book patient appointments. A wireless local area network and hand held computers are to be used to provide ward staff with a replacement for their clipboards and notebooks. In the second stage the hospital plans to use the terminals to access online prescriptions and manage patient records.
The hospital has also been involved in a pilot study which will deliver electronic picture archives, such as x-ray images, directly to the computer screens in the intensive care department.

**Reducing procurement times**

NHS framework contracts can cut the network procurement times from a year to a few weeks according to Lincolnshire and Leicestershire health authorities. These two authorities have signed deals to provide local and wide area networks to GP surgeries with a company, Cable & Wireless, who had been awarded a framework agreement by the NHS Supplies Authority.

Under this agreement any NHS organisation can purchase networking services without the need for long procurement processes. In addition there is now a single point of accountability if something goes wrong, even if the problem does not come from the company itself.

**New hospital gets new information system**

The new Royal Infirmary of Edinburgh will open with a new hospital information system provided by HBO. Doctors, nurses and laboratory staff were all involved in drawing up the original specification for the system. The clinicians felt that they owned the project. The team that developed the specification consulted widely with their colleagues and peers, so that input was obtained from about 400 people working in the hospital. The IT department was able to access opinions and views of staff they would never have found otherwise.

The deal, with HBO, ensures that they accept 80% of the risk for the implementation and they have to meet a range of benefits and end-user acceptance measures. Failure to do so means the trust can renegotiate payment and benefits of the £30M deal.

**Another database black hole**

The Medicines Control Agency (MCA) took control of some of the files from the Office for National Statistics recently. It now has to tackle a problem that vast amounts of data about possible side effects of drugs are being stored unanalysed because no system exists to read the data.

There are 5Gbytes of patient files that have been zipped up for storage which have to be verified and analysed. The data were sent to the Department of Health from GPs who are part of the scheme which seeks to draw inferences about possible health risks from different treatments and drugs by looking at patient records over a large area of population.

Data can be read easily from that supplied by GPs who collect data using the older 'flat file' version of the software. It is with the newer "Vision" windows-based system that was introduced in 1995 where the problems lie. This is because no funds had been allocated to build a system capable of reading the data.

Due to the large amount of data provided in the older version of the software, the data from it alone will provide much useful information. The value of the data set is
recognised world wide and a number of drugs have been withdrawn from world wide distribution as a result of the data collected.

The Medicines Control Agency has found some funds to pay Anderson Consulting to merge the two sets of data and to provide a new interface which will allow all of the data to be used by the MCA, academics, drug companies and any suitably qualified parties who can log on for a fee. It is estimated that the new database system will be complete by the end of September 2000. However some people are questioning whether this can actually be achieved.

Why, after all the experience of the last few decades, can systems still be developed to collect data without any thought about how to get it back out at the other end?

More on the Medicines Control Agency

The Cochrane Injuries group was investigating the use of human albumin in the treatment of burns victims. The group was undertaking a meta-analysis of published trials and reached the conclusion that it could be causing the deaths of thousands of people.

One of the members of the group, Dr I Roberts from the Institute for Child Health, wrote to the MCA asking them to release any data from unpublished trials, provided to them by pharmaceutical companies. The MCA wrote back refusing the request because of commercial confidentiality of data.

The report was published without the MCA data and it reports that patients treated with human albumin were six percent more likely to die than those not given the product. In light of these findings, the MCA has set up its own working group and has revised product information and issued warnings to doctors in August last year.

Data integration with XML

XML is a language that may be useful to allow users to exchange information between different systems in a seamless and automated way. It has been adopted as the proposed official standard by the world wide web consortium (W3C).

XML is based upon HTML, the language that allows web developers to produce web pages. HTML is based upon a series of predefined tags, or computer instructions, to indicate how things should be displayed on a web page. XML has been designed to provide developers with a more flexible tagging system, so that they can define their own tags that are appropriate for the type of data they are exchanging. For example there could be a tag that allows the blood pressure of a patient to be exchanged between different applications.

It is the different ways of designing the XML that are of interest - they are called document type definitions (DTDs). There is now a need for DTDs to be defined for different areas of work to ensure that data can be exchanged between users.

The exchange of information using XML provides high performance quality and it is cheaper than other methods, however it is not widely used at the moment, is slower and is technically inefficient.
This is an area of growth at the moment and there will be many developments before any standards are finalised and users can see real, widespread benefit.

**Primary care groups and trusts must get IM&T support**

The Government has said that it is determined that primary care groups and trusts are included in the national IM&T strategy, Information for Health. All short term IM&T requirements for primary care groups and trusts have to be developed and implemented in tune with the strategy.

Health authorities are required to co-ordinate the production of local implementation strategies (LISs) by the end of March 2000; and these are expected to address requirements for information systems across the local health community for the five year period to 2005. These LISs must include the primary care groups and trusts and be endorsed by their boards.

A database of information about primary care groups and trusts will be developed and sited on NHSnet, which will allow primary care groups and trust to communicate directly with one another and hopefully learn from each other.

**Requirements for GP computer systems**

In the light of Information for Health new accreditation requirements RFA99, have been developed in partnership between the NHSE, GPs, health authorities and suppliers. The existing requirements have been updated to include any new legislation and other instructions in the areas of privacy and security, prescribing, registration, screening etc. The requirements also now include sections on training and support, MIQUEST and PRODIGY.

**NHS Direct remit may widen**

A pilot project run by NHS Direct Essex and Essex social services is looking into the possibility of increasing the scope of NHS Direct to include pharmacy and social services.

Callers in Essex can now access the social services out-of-hours team for advice and support on social welfare issues. From March, the pilot will be extended so that, if required, callers can be referred to a qualified community pharmacist for advice on the medicines they have.

Users of social services in the area have said that they want to speak to someone who can give them advice regardless of whether their needs relate to health or social services. It will be interesting to see the evaluation of the pilot project and to see if there are plans to role it out across the country.

Pharmacists have criticised NHS Direct about the software used in some sites, the way it has been established, the belief that pharmacists have been sidelined in the setting up of the new service and their potential role in giving advice to both the nurses and patients.

The software in use at many of the NHS Direct sites was developed in the USA. It has been criticised because it features many inappropriate medicine guidelines, uses US
drug brand names, rather than UK ones and often focuses on clinical issues more relevant to North America than Britain.

Hopefully the pilot study described above may go some way to allaying some of the criticisms.

**NHSIA Data Standards Board**

The NHSIA has set up a new Data Standards Board (DSB) which held its first meeting in October last year. The DSB has three main subsidiary boards, the Clinical Standards Board (CSB), a Technical Standards Board (TSB) and an Administrative Data Standards Board (ADSB). The latter, ADSB, will be set up sometime in the future. The chair of the Information Authority, Professor Alastair Bellingham, said that a data standards strategy has to be established as soon as possible. He said that there is an urgent need to get clinical data standards owned by the health care professions and to ensure that all clinical groups are represented on the boards.

The DSB is now in the process of contacting the relevant organisations to ensure wide representation.

**Cons and cons of prescribing**

A doctor and a pharmacist have both been fined almost half a million dollars in damages after the death of a patient caused by an illegible, hand-written prescription in Texas.

The pharmacist misread the prescription for Isordil, for the patients angina, for Plendil, a treatment for high blood pressure. The pharmacist had dispensed twice the daily recommended amount of Plendil. The patient subsequently had a heart attack and died and the family sued both the doctor and the pharmacist. The court found each equally culpable.

In Britain a spokesman for the Medical Defence Union has claimed that electronic prescribing system can give rise to errors in prescriptions. Where doctors are rushed they may click on an onscreen list of similar sounding drugs and chose the wrong one. If these are not queried by the pharmacist the wrong drugs can be dispensed as a result.

It appears you can not win either way!!

**Ethical standards for health-related websites**

The Internet Healthcare Coalition (IHC), at its meeting in Washington DC held on January 31- February 2, 2000, drafted a set of ethical principles for health-related websites, termed an International Code of Ethics for Internet healthcare. This will cover advertising practices, sponsored content, privacy and disclaimers.

A first draft of the Code was made available to the public on February 18, 2000. The Code will be launched in May 2000 at a reconvened, extended Summit, but prior to the May launch, the Code will undergo a rigorous review process, including public hearings, consultation, and the opportunity for people throughout the world to participate in the process via a Web site hosted by the Internet Healthcare Coalition.
The IHC, founded in 1997, represents professional and consumer organisations worldwide and aims to help health care consumers and professionals stay well informed about the evolving issues relating to the quality of internet health-related resources and information. They are confident that the principles will be available before the end of the year.

In the USA a consortium has been assembled by a former US Government Surgeon General, Dr Everett Koop, the Hi-Ethics alliance. They have initiated a programme of weekly discussions over five months to arrive at a consensus on policies for advertising, privacy and content. One of the areas that they are particularly interested in is the disclosure of sources of information, leading to an end to unattributed advice and claims on health and pharmaceutical websites.

International classification of functioning and disability (ICIDH-2)

The NHS Information Authority has taken a key role in co-ordinating the UK contribution to the production of the new version of the International classification of functioning and disability (ICIDH-2), previously known as the International Classification of Impairment, Disability and Handicap (ICIDH).

ICIDH was originally developed in 1980 and is being revised in response to changes in health care provision and a new social understanding about disability, to include physical, mental and social well being. The environment and how it affects the individual's ability to function at the level they wish to has been included.

The ICIDH-2 aims to:

- provide a scientific basis for understanding and studying the functional states associated with health conditions;
- establish a common language for describing functional states associated with health conditions in order to improve communications between health workers, other sectors and disabled people;
- permit comparison of data across countries, health care disciplines, services and time;
- provide a systematic coding scheme for health information systems.

The NHSIA, which is an official WHO collaborating centre for ICIDH-2, has been involved in extensive field testing of the new coding system including all stakeholders (disabled, health care professionals, social services etc.) to ensure that potential uses and issues in relation to its possible implementation are explored.

The NHSIA is also involved in looking at how ICIDH-2 integrates with existing coding systems.