

EURIM Summary Report

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THE EUROPEAN
 INFORMATION
 SOCIETY GROUP

EURIM



Summary of a planning meeting of the Medical Records Subgroup held at 1 Abbey Garden, Westminster on Wednesday 19 June 2002; 1000 - 1200, chaired by Geoff Llewellyn (Schlumberger-Sema)

1. Objectives

- 1.1 The objectives of the meeting were to:
- appoint a Chair and fill other posts;
 - identify the main issues and define the scope, terms of reference and aims for the group;
 - determine the most appropriate forms of deliverables and identify targets;
 - establish a timetable for delivery;

2. Scope, terms of reference and issues

2.1 The group recognised that this was a huge, diffuse and diverse topic and challenge with which to grapple and make recommendations to Government. The group went on to consider aims, scope, and the issues it should be covering within the context of the PIU report on Privacy and Data Sharing, in a 'brainstorming session'.

2.2 It was felt that there was reasonable evidence to indicate that sharing clinical data between health care professionals can improve health care, but there were concerns too that data might be used inappropriately. Patients had rights to privacy and good health care.

2.3 Additional risk was attached to the increasing sophistication of medicine, which inevitable involved a greater number of professionals and therefore increased data transfer.

2.4 It would be impractical to discriminate between clinical and personal data – the old NHS distinctions were no longer relevant, especially in all-embracing Government agenda for health care information, and with the NHS and the private sector frequently sharing care management.

2.5 Conflict might arise between health care and retail business, e.g. in pharmacies; private care organisations which will want to reduce problems – it was suggested that some of these organisations might wish to join the group.

2.6 People seemed to be reasonably happy for their personal data to be transferred within the NHS, but this may not extend to other bodies, including social care. It might be useful to look at health services as being provided within a number of 'domains', it is at the edges of the domains that risks occur (such as commercial interests, insurance, genetic data, patient confidentiality, data content etc.).

2.7 In any new system the locus of care will migrate from secondary to primary and community levels. Systems for managing data must therefore be dynamic and flexible, with multi-levels of consent giving the individual access and control.

2.8 The DWP would probably want access to records, presenting a problem – patients might withhold information from medical professionals, in case it fell into other hands that might be detrimental to their interests. Such problems were difficult enough to manage in paper systems, let alone digital. Patients trusted that personal data held within the NHS was for their benefit, and this was supported by professional codes of ethics. **A crucial issue for the group to consider was how to regulate the transfer of data outside the medical precinct.**

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2.9 The example of a hospital-based social worker having access to a patients' clinical records and then 'parking' data with colleagues in another environment (e.g. local authority) accessible to other social workers was cited. The data may then be used in case-conferences and transferred again to other domains. This practice could affect the flow of data volunteered by individuals: the concept of 'informed consent' is not seen by the public as belonging outside the realm of clinical professionals.

2.10 Although privacy was a major concern, there was great concern in the public health service, from both the research and epidemiological perspectives, that the data must 'flow' for Government to plan and work efficiently. This meant that there must be a data-identifier, because e.g. a cancer patient with data in several different units must be identifiable as the person being treated, and because of public health and criminal behaviour concerns. **Truly anonymised data is not good enough; pseudo-anonymised identities allow linkage of databases.**

2.11 The twin objectives of health care efficiency and protection of privacy could best be achieved by:

- using the available data in the most efficient and effective way possible;
- the system not requiring personal data beyond what is necessary for efficient delivery of services;
- citizens being given the ability to manage use of their personal data records;
- maintaining a balance between an individual's rights and the public interest where data is used or shared without consent;
- regulating the transfer of data outside the medical precinct.

2.12 **The session concluded that:**

- **the Government policy of sharing medical databases would become a reality by 2005;**
- **present NHS practices are unsustainable in terms of cost and efficiency - new processes are needed to deliver high quality services, develop well-targeted policies and ensure efficient government;**
- **the group should therefore concentrate on the practicalities of 'how', not 'whether', change should be implemented;**
- **there was a need to balance the benefits of sharing medical databases against disadvantages of privacy considerations, and to mitigate risks;**
- **the objective of data sharing should be more effective health care and performance analysis;**
- **the group will collate inputs from a range of EURIM members invited to contribute to the debate;**

3. Technological issues

3.1 The medical records debate depends on the technological capability of IT systems, which have opened up many possibilities, with the promise of more in the future. The implication of this was codes of practice for professional bodies and possibly legislation, and we should structure our debate to anticipate developments.

3.2 Software now made it perfectly possible to transmit encrypted data across systems, for de-encryption by the recipient using the appropriate key, at reasonable cost.

3.3 Single databases were viewed as operationally efficient and made the business of Government cheaper, but the business drivers driving centralisation were actually the cause of many problems: we should advocate education for ensuring the right messages accompanied development.

3.4 IT enhances the ability to control and regulate, compared to paper systems. There were great benefits in health care where a doctor had access to a person's records held digitally on a central database and where authorisation provided a safeguard for data access. Evidence-based medicine was now coming on stream, and could have built-in protections for access.

3.5 Complications could occur, such as in the case of a chronically ill person with an EU 'Medicard', which guarantees the same level of care in any EU country. If an insurer ascertains possession of one, cover may be denied, even without detailed disclosure of medical conditions. There were also cases of discrimination

against individuals who have had blood test for HIV, regardless of the result. An individual should have some control over sharing such data.

3.6 Without defining a purpose, an IT system would still waste money. Doctors for example wanted quick access to data, and systems involving time-consuming complexity before release of data will deter use of the software. Also, operational and liability problems might arise if recorded data was stored but not seen e.g. by a doctor who subsequently prescribed or operated without such knowledge, to the detriment of the patient. Data sharing in such circumstances could become a liability. Trust was also an issue – clinicians in different hospitals may want different care-management pathways to an EPR system. Education was necessary to solve these problems, e.g. clinical assessment (to be driven by NSF).

3.8 The Prime Minister's stated objective is to have a shared electronic record by 100% available by 2005. This implies that consent is not an issue – the data will be available to authorised users at the point of care wherever that may be. **EURIM should attempt to**

- **provide a sensible definition of 'informed consent' – active, assumed and passive, -**
- **provide guidance on anonymization for research – it was technically easy to distinguish between true and pseudo- anonymisation.**

4. Outcomes

4.1 The debate identified both benefits and problems associated with a central database (Table 1).

Table 1

ISSUE - SHARING OF MEDICAL DATA		
<u>BENEFITS</u>	<u>RISKS</u>	<u>MITIGATION OF RISKS</u>
Efficiency	Snooping	Legislation
More effective health care	Patient privacy	Codes of best practice
Performance analysis	Multiple access complicates data transfer	Restrictions to access and use
Epidemiological research	Liability	
Resource planning		

The group decided that these issues should be more widely circulated within EURIM to canvass members' views and elicit contributions.

4.2 The group suggested that there was a range of targets for the group's communication, perhaps primarily ministers and Parliamentarians, for which EURIM could suggest the means for achieving ministerial objectives, e.g. through IT technology, roles and responsibilities, working practices etc. It was essential to install appropriate technological solutions, managerial practice and controls.

The group listed targets as:

- **Parliamentarians**
- **Media**
- **Professionals**
- **Top civil servants**
- **IT industry**
- **Public**

4.3 **A major output must be a document comprising:**

- **reasons for the EURIM exercise – to enable aspirations to be met;**
- **a set of contextual observations (referring to Government aspirations to modernise, technological capabilities etc), and an appreciation of what might prevent progress – e.g. public and media concerns;**
- **an exposition of the philosophical and ethical issues, e.g. informed consent;**
- **legislative issues, including shortcomings and loopholes, with proposed safeguards and solutions;**
- **technological issues, with recommendations regarding industry and procurement;**

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- **new roles and responsibilities for medics, legislators, administrators, the public etc. and the need for a changed approach.**

4.4 This list provided a framework for developing ideas and details: it may be better to point out for example that new technology, standards and capabilities may require new legislation, rather than adopt a broad 'catch-all' approach.

4.5 EURIM documents tended to be brief – we should therefore focus on perceived obstacles and risks to Government objectives, noting that the current NHS plan encompasses social care.

4.6 **The group could establish 'milestones' as visible markers of progress, including:**

- **a scoping or vision statement;**
- **definition of medical records, including operational boundaries and the purpose for which the database is to be used;**
- **definition of risks to peripheral boundaries between institutions;**
- **definition of informed consent;**
- **definitions of the roles of stakeholders**
- **definitions of restrictions on technological capabilities;**
- **definitions of codes of best practice for stakeholders.**

4.7 However, proposing boundaries for definitions may be a problem – we are not the legislators, and enabling powers will probably lead to legislation by statutory instrument. We urgently wanted answers from politicians to particular questions so that the industry could plan and progress.

4.7 The group should therefore structure its report in the assumption that Government will use enabling powers as widely as possible. **EURIM could identify barriers to progress and suggest sensible protections and solutions that lead civil servants may find useful, especially where an issue is likely to be sensitive in Parliament. Once this is done, technological solutions can be put in place.**

4.8 A technical model could be envisaged in which individuals could access their medical data using some kind of token, such as a smart card, for providing information to an authority. This may however lead to problems concerning the difference between informed consent and a National Identity Card – which in effect is what the smart card would be; authorisation would be necessary, perhaps using encryption. Ethical groups may nevertheless have serious concerns about the lack of control over medical data. The public needed to be aware of, and educated in, the capability and use of IT. **EURIM could therefore point out that technology can be helpful in certain areas, and the price of control over medical data, and the provision of its benefits, would be the use of authorisations, i.e. access needs to be justified. This could take the form of a flow chart showing database, access points and routes, with justifications and audit trails.**

5. Timetable

5.1 The group aims to produce a document to present to EURIM by mid-September, with a view to presenting a working document at the party conferences. In parallel with this, it was suggested that each member should work through a common agenda to influence the group's 'targets'. It was also proposed to stage some kind of event in London after the recall of Parliament.

6. Future meetings

6.1 A series of meetings is planned; the next will be held on July 15, at Westminster, 1500-1700.