

Confidentiality Issues from the User Perspective – Lessons from Learning Disability Services

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Abstract. The e-social science learning disabilities project is seeking to explore the potential for semantic web technologies to enhance the care of people with learning disabilities. There are a number of distinctive issues with learning disabilities that make this a particularly relevant research topic. As care is managed by a disparate group of providers, from health through local authorities to the voluntary sector, there would seem to be considerable potential to provide 'joined up' data and information services. However for this to be effective many organisational and policy issues have to be addressed, not least amongst these is the concern of patient confidentiality. This is particularly pertinent as people with learning disabilities are least able to take informed decisions.

The approach that this paper will take is to review the policy and service scenarios that would benefit from 'joined up' data, examine the potential solutions and then review how concerns about confidentiality may, or may not, impinge upon these solutions. In other words we will examine confidentiality concerns from policy and service viewpoints, in order to gain a firmer perspective of the user gains and losses from effective data sharing strategies.

Distinctives of Learning Disabilities

People with Learning Disabilities are diagnosed as having the following:

1. evidence of early developmental delays
2. functional impairments (comparative lack of ability)
3. intellectual impairment (low IQ)

Of particular importance is that all three of these are necessary for diagnosis of learning disabilities. Of course it is apparent that judgement is involved and that the boundaries are not clear cut. There are issues with the sensitivity (the proportion of correct diagnoses among a population who do have Learning Disabilities) and specificity (the proportion of correct diagnoses amongst people who do not have Learning Disabilities) of the diagnosis.

Also important is that diagnosis itself is not a value free judgement and can lead to unhelpful stigmatisation that may be more harmful than the support that comes with a correct diagnosis.

As well as the difficulties with diagnosis, there are wider issues that arise from Learning Disabilities. It is noted that people with Learning Disabilities are a particularly vulnerable group, they are very heterogeneous, there is evidence of high physical co-morbidity, high service demand, and over-representation in prison.

Given the difficulties of caring successfully with a group whose problems can arise from genetic disorders or social and environmental conditions or any mix of these, it is self-evident that the more robust and usable is the evidence base, the better the potential service environment.

Stakeholders

Many individuals and organisations have a 'stake' in the care, policy and research of people with Learning Disabilities. These range from:

1. health service trusts, typically the Primary Care Trusts who may be operating as a provider or a purchaser of Learning Disabilities services.
2. local authorities via the social service department
3. a local Learning Disabilities partnership, typically the health and local authority
4. voluntary agencies
5. national support groups (for example the Down's Syndrome Association)
6. local groups (that may or may not be affiliated to a national organisation),

All of these organisations have an interest in the development of Learning Disabilities services or the specific care of individuals. As such they have a concern in the use and potential abuse of data and information.

Data developments

Within this wide landscape of interested parties, both the data and the technological environment are changing rapidly. The development of the National Programme for IT (NPfIT) promises to deliver an integrated patient care record which should make the provision of service much more straightforward. This will generate the Secondary Use Service (SUS), which will provide an anonymised subset of the full database (NPfIT, 2005). This subset has been designed to be used for performance management, but also offers a very effective source of information for policy research and public health surveillance.

On the technological level, the emergence of semantic web and GRID technologies (see Rector, 2004) enhances the possibility of creating virtual data environments in which the data is held by all the stakeholders but made available to trusted third parties. This contrasts with the current provision of a service in Essex based on the delivery of data via CD ROM to a central database (Essex County Council, 2004). The availability is best carried out by enabling intelligent access to the distributed servers assuming that the data is understandable. For this to happen, developments in ontologies and metadata are necessary (Pisanelli, 2004). There are well developed clinical and public health languages, (such as SNOMED-CT, 2005) and they may be developed for Learning Disabilities to the extent that more database structures are being shared (Emerson, 2003). Whether full ontologies can be developed for Learning Disabilities is part of the aim of the project and will be reported in due course.

The literature on integration between heterogeneous data sources includes a number of integration strategies: linguistic matching (via shared ontologies), structural matching (between nodes and attributes) and pattern recognition among data instances. The project will seek to identify the technologies that are most likely to be viable from a pragmatic point of view.

Confidentiality Issues

It can be seen that access to data is dependent on; the availability of the data themselves; the implementation of suitable semantic web technologies; and the right policy and organisation environment. The data confidentiality issues are discussed elsewhere (Elliot et al, 2004). It is the organisational issues that we will concentrate on in this paper. There are two elemental use cases that we will consider. The first is the policy scenario in which the user is concerned with examining the overall picture. The second is the service scenario in which an individual care programme is being managed.

Policy Scenarios

On one hand are those users who want to access the data as a whole in order to plan services, understand trends or research particular topics. These users are likely to be taking an overview and not be interested in individual cases, even if they wish to have access to the individual level data so as to have complete flexibility to test different hypotheses by carrying out detailed statistical analysis. For them the main concern is to have as much data access as possible so that the population can be served most effectively by well-researched, well-managed and well-monitored policy interventions. In other words the better the information, the better the service can be.

The down side is that the more unrestricted the information, the larger the risk on inappropriate disclosure of personal information. If data can be suitably anonymised or randomised, then some of these problems can be overcome. At the end of the day, the decision can be presented as a balance between two non-optimal solutions, poor information leading to poorer services but with reduced risk of inappropriate information disclosure against better information and services but with higher risk of inappropriate information disclosure. The better the tools and procedures for safe data access, the lower the risks become.

Service Scenarios

The other elemental use case is centred on the individual record. In this scenario the care provider is the user and, ideally, they will want access to data in such a way that efficient individual care strategies can be pursued. For example a patient might need residential care and the care worker will want to; identify available care provision; liaise with other agencies with an interest in the patient; liaise with parents or other guardians; and possibly link to support groups or other informal care networks. For this to happen, an integrated care record, probably based on the NHS number or other identifier, is required. This is not unproblematic. In practise there are many organisational as well as technical and legal barriers. Whilst at the practitioner level, there may be good care co-operation, at the organisational level there can be many obstacles and the Caldicott provisions even made it illegal to exchange data between organisations.

User Feedback

The project will be running a confidentiality workshop in May and the results of this will be fed into the presentation of this paper. The participants will include a selection of the stakeholders with an emphasis on the two broad scenarios outlined. A theoretical model of easy access to distributed data will be presented and a contextual inquiry approach will be used to identify and quality the obstacles in the way of delivering integrated and efficient yet professional and confidential care services (Gaffney, 2004).

Individual conversations with NPfIT staff suggest that the major barrier to the successful implementation of effective information systems is the fear of change (and related social and organisational issues). In this context we might ask whether confidentiality issues have become a useful scapegoat issue blocking change and preserving established work patterns and positions of influence. The case for integrating learning disabilities data is all the more complicated as it crosses organisations. However the fact the data is located across organisations may lead to learning disabilities being an early innovator of semantic web technologies as local control of interoperable data sources may well be the best way forward for delivering safe access to data for aggregate and individual purposes.

Conclusions

The paper seeks to develop the issues around the provision of care services to the Learning Disabilities population. The key issue is how to make sure that up to date and timely services can be developed and delivered without compromising patient confidentiality. The costs of this strategy are considerable as the benefits of patient confidentiality have to be weighed against the costs of creating barriers to the sharing of data and information for the delivery of care.

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