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# Ensuring Trust and Governance in E-Social Care

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**Abstract:** Social care informatics is a new but potentially very rapidly growing domain which compliments, but is very distinct from, e-health. Electronic social care records will perforce contain information about family members and others who have an interaction with the client service user, while the proportion of record users who are registered members of formal professions is much less than in health. As social care is not only an important adjunct to health care, but is an essential component of ensuring an individual citizen's health and well being if they have needs and dependencies, e-social care needs governance arrangements at least as stringent yet transparent as in health care. This paper identifies the issues, and proposes principles, components and a strategy for implementation for an e-social governance framework. In turn, this may form a useful blueprint for other sensitive service sectors such as Housing and Education, especially where they are delivered in a mixed economy.

**Keywords:** confidentiality; trust; e-working; social care; governance

## 1. Introduction – The Role of Social Care in Health

E-health is an important and developing aspect in the organisation and the delivery of health care. However, with its usual restriction to services directly provided by health professionals and health organisations, "e-health" is often too narrowly and restrictively defined. Given that "health" is a state of physical, mental, and social wellbeing and not merely the absence of disease or infirmity [1], it is clear that health involves far more than health care delivery by formal health agencies. Lifestyle, daily living skills, family interaction, and social context are all involved, and the totality of advice and support to sustain these aspects must therefore also be considered.

In particular, and in the important context of the ageing society, and of the survival for increasing years of persons with enduring or chronic illness, it is clear that healthcare delivery must take place in a context of other services. Vital and prominent amongst these is social care, namely the provision of practical support for daily living and social wellbeing. Different countries may have different boundaries between health and social care, and indeed the style of provision (ranging from public sector provision through to a fully mixed economy sector) may vary, but the core principles are clear. These are described more fully in an accompanying paper [2]. For these services as much as any other, e-records are important for efficiency and for informed delivery – and so is addressing the major e-challenges they raise. Indeed, E-Social Care is becoming an essential adjunct and partner to e-health.

The core issues of e-health are now becoming well known. Though often technology-led, serious consideration of e-health does increasingly recognise that issues of governance including confidentiality, security, and the careful control of essential data sharing must be addressed. Most European countries implementing e-health solutions are developing robust protocols – such as the English NHS Care Records Guarantee [3]. With the anticipated rise of e-social care similar governance issues must be addressed, and this paper describes an integrated approach. In turn, this may well also set precedents for records concerning other forms of personal support which interface with personal health, such as housing and some aspects of educational provision.

## 2. Addressing the Challenges of e-Social Care

### *2.1 Intrinsic Challenges based on Content*

Against this backdrop the challenges of e-social care are significant. As indicated elsewhere [2], e-social care records are potentially even more sensitive than e-health records. Whereas the clinical health record has considerable depth of clinical detail and terminology, but inclusion of information about other individuals is intentionally minimal beyond the identity of involved health professionals, by contrast e-social care records frequently describe the functioning context of the client's family and other informal carers – enabling care workers to be effective in supporting the individual at home. Consequently these records have to contain details of both the attitudes and contribution of family and carers to the client, the effect of caring upon them, as well as any data about how (whether unintentionally or intentionally) individuals may be compromising that well-being. Therefore social care records must by definition include sensitive details of other persons in the client's daily life. Where e-health records are deep but narrow, e-social care records are by comparison shallower but wider; hence the confidentiality and sensitivity issues of each are different in detailed aspects but similarly both vital and challenging.

### *2.2 Challenges of Defining and Controlling Content Sharing*

With health records, including those held in e-health systems, there are long established and strict constraints on revealing or sharing any of the contents to other parties. Not only must permission be given, as required under the Data Protection Act for any disclosure of information, but the disclosure must be in line with similar pre-existing ethical constraints for health records. Disclosure is normally restricted to specific items, and then only to a fellow health professional with a specified duty of care to the patient. Depending on the specific referral or treatment context, either the patients' explicit to consent to sharing of items is obtained, or such sharing is self-evidently ethically necessary as part of the referral process. Moreover, the sharing of such items in e-health records is further controlled and protected by three actions: first, professional practice sanctions whereby any health professional abusing confidential data can face malpractice charges which can result in loss of professional registration and thus of livelihood (with equivalent clauses in contracts of employment for non-professional staff); second, the criminal law; and thirdly the increasing interest in electronic "sealed envelopes" or similar means of keeping very sensitive data items even more strictly controlled.

By contrast social care records need in certain aspects to be much more widely shared, yet the range of sanctions available is not as strong as in the health sector. Because social care support frequently involves support to daily living tasks, which is frequently provided in the domestic context to compliment or take account of family and other informal support, the carer or team of carers needs to know more than simply the nature of the specific care tasks they have been commissioned to undertake. Even the simple task of assisting the client to prepare a meal may require an understanding of the social dynamics and relationships of household members and others having regular access to the household. Whilst the level of detail available to any particular record user needs to be restricted to that needed for the performance of defined tasks - for example the data needed by a provider of meals, or a person assisting with washing and dressing, will be significantly less than that required by a social worker - nevertheless the totality of the information shared from within the record is significant. Thus the issues are very different from a health record, both to the client and to other persons referred to within it. This means that without adequate, conspicuous, convincing and firmly implemented governance arrangements the effective use of e-social care records could be severely compromised by anxiety and mistrust.

At the same time, the availability of sanctions is significantly less, at least at the present time. A high proportion of essential social care support is given by persons who do not have a professional qualification and consequently the controls of a professional code of conduct, and the potential sanction of de-registration and thus loss of livelihood. Further, as described in a partner paper [2], social care is frequently provided from a mixed economy of many independent small providers, with no over-arching controlling or cooperation layer or indeed strong trade association. For e-social care records data protection legislation will apply, but legislation does not have the detailed guidance of regulation, and resort to criminal prosecution is a blunt and cumbersome instrument which should only be considered in the last resort.

## 3. The Need and Opportunity for an Integrated e-Social Care Governance Model

To address and guide the challenges facing e-social care and the controlled but essential sharing of individual record items on a case of need basis, while overall guaranteeing the sanctity of the client's confidentiality and privacy, needs a comprehensive approach. Indeed, the current absence of consistent guidance and sanctions provides the opportunity for a "clean sheet" and integrated approach which does have its own advantages. There are strong arguments for designing an integrated approach as part of one blueprint, and then completing the detail in stages.

This paper reports such a comprehensive approach being developed by the social care sector in England. This consists of principles, components, and an implementation strategy.

## 4. Principles

Any system of governance, or indeed regulation, needs to be based on firm principles. These should provide the beacon which identifies the direction of travel, whilst underpinning the detail. In cases of debate or disagreement, referral back to core principles should facilitate identification of the specific solution.

For e-social care governance, none of the proposed principles are new, but rather are those enshrined in good social care practice, data protection legislation, respect for human rights and human autonomy, and governance of service providing market sectors. The principles that have illuminated the development of the concepts outlined in this paper are:

1. Protection of the privacy and confidentiality of the service user.
2. Facilitation of the provision of a safe and effective service to the service user.
3. Protection of the confidentiality of third parties commensurate with providing adequate support to dependent or vulnerable service users.
4. Protection of the rights of staff and other individuals who provide care to maintain their own safety, and to deliver effective care and support.
5. Acknowledgement of the needs of service commissioning and service providing organisations to operate efficiently and effectively.
6. Acknowledgement of the societal interest in the provision of accessible, trusted, and effective social care services.

However, whilst principles are important, particularly for those devising and operating governance systems, they have little accessibility or meaning to the citizen when presented in stark simplicity. Thus it is anticipated that the principles will be the basis of three related forms of articulation.

### *4.1 Articulation of e-Social Care Governments Principles*

Three separate manifestations are anticipated, of increasing depth and technicality. These span from the simple but clear public document to the operational regulations covering all eventualities. The first is covered by a Charter to reassure the citizen without their needing to study large volumes of small print. However, that small print is needed, to cover all situation, as well as the introduction process, and constitutes a Regulatory Framework. Linking them is a Social Care Record Guarantee, which provides a framework of promises and sanctions.

The Charter should be a plain language public statement about the core principles and sanctions which will be applied, clearly intelligible to the lay person, and readily available. The core purpose of the Charter will be to reassure service users and the public that strict governance principles are in place, in order to support their trust in the record system and its use.

The Social Care Record Guarantee is in already in draft as a statement for common readership between the public, representative organisations, and social care workers and organisations, declaiming the principles of confidentiality, security, and strictly qualified sharing of specific items, underpinned by effective governance and controls, which will apply to electronic social care records. This will be harmonised with the NHS Care Records Guarantee. The three key themes will be:

- Service user rights regarding records
- Organisational responsibilities
- Good practice by formal carers

These will manifest as twelve Commitments, on the following issues:

1. Record keeping and confidentiality principles.
2. Limited sharing for essential service delivery purposes.
3. Strict circumstances for sharing to third parties.
4. Controls for records of children or those not mentally competent.
5. User permission to be sought for sharing with a multi-agency care team.
6. Potential adverse effects of user refusing sharing.
7. Complaints procedures; redress for harm though inaccuracy.
8. Confirming accuracy of content.
9. Commitment to staff training in record systems and confidentiality.
10. Secure holding of records.
11. Listing of all who access a record.
12. Disciplinary or other action will be taken against perpetrators of misuse.

The Regulatory Framework will be aimed primarily at organisations (public, private, and NGO) within the social care sector, and will indicate the regulations and sanctions that will apply. It will be detailed, and contain much more technical content, and be linked in particular to professional practice regulations, and to contract requirements for commissioning social care services for service users.

The intention is thus to have clear public promises which are underpinned by guidelines and regulations; and conversely to have operational requirements and rules which are projected to the public in clear commitments.

## 5. Components

Promises and frameworks are laudable, but are of little benefit unless they are effectively implemented and monitored. The envisaged approach in England, with its mixed economy social care sector, is intended to include a number of complimentary components. These are still being discussed and developed, and the presentation will report on the latest status. The principal elements are:

- End user education and assessment – each end user will be offered training and assessment in understanding of handling of electronic social care records and ensuring their governance. An approach being discussed is to further harness the ECDL Health Module, which is already phrased in terms of "health and social care" [4]. This would complement the health-specific version already introduced by the NHS in England [5, 6]. At this stage a common sector-wide national training package is envisaged as being designed and made available, together with a user competence assessment in e-social care usage, though individual organisations may customise the detail of this material and of its provision according to their specific types of service provision and service provider.
- Professional education and registration – whilst much of overall social care support is provided by carers without formal qualifications, nevertheless the most significant elements are provided by members of professions such as social workers. Their basic professional education (currently provided by recognised higher education institutions) currently only tangentially (if at all) includes the issues of operating and maintaining electronic care records. The previously mentioned end user training should in the first instance be considered an essential adjunct or add-on to that professional education. However, the intention should be to migrate this to be included as a core part of the syllabus. Similarly, professional registration bodies should consider whether competence in e-social care elements should be a pre-requisite to future professional registrations.
- Corporate governance statements - each social care organisation will be expected to have a social care information governance strategy, available to the public, service users, and their representatives, and including identification of an information governance officer, and provision for appropriate e-social care end user training.
- Social care information governance officer - each social care organisation must have a named individual responsible for overseeing governance of care records in that organisation and for monitoring both principles and practice, as well as being the contact point for public enquiries.
- Inspectorate criterion - all social care organisations in England are subject to governmental inspection. Implementation of, and adherence to, the principles of social care information governance should be a clear criterion included in any inspection.
- Contract provision pre-requisite requirement - from a date as early as is feasible in the implementation process, adherence to the social care governance guarantee (including adequate implementation of training of end users) should be a pre-requisite before a social care provider can be recognised by a social care purchaser, authorised to provide services to the public, or contracted by the public sector to provide services to an individual.

## 6. Implementation Strategy

E-social care systems are being introduced rapidly but in a piecemeal way. The introduction of an appropriate governance framework is therefore urgently necessary, but will itself comprise a radically new departure - both by its own nature and content, and because it is intended to be introduced across a total mixed economy social care sector. It will therefore require an initial major national roll out, followed by an ongoing operational provision to support the developments, new staff, and the continued deepening of e-social care applications and interlinkages. The coordination of this implementation would fall under the aegis of the existing Electronic Social Care Record Implementation Board, with support from the National Information Governance Board for Health and Social Care, which is a recognised national body. The following are considered the necessary elements for an effective implementation strategy:

- National endorsement – the Charter, the social care records guarantee, and all the other components should be formally recognised as national policies and standards by the national board. Similarly, this board would provide the final sign off for all the other components.
- Implementation group – a dedicated group drawn from representatives of social care sector, academia, and training and assessment organisations will be needed to provide leadership and coordination of the operational components.
- Training and assessment development - the set of competences and knowledge considered essential for end-user staff will need to be agreed and formalised. Based on this, full training programme contents, and competence assessment criteria will need to be developed and agreed.
- Interaction with professional education and registration – discussions will need to be held with recognised providers of basic professional education for social care professions, and with the registration bodies, to progress towards the inclusion of e-social care user skills and governance principles within basic professional education syllabi, and in professional registration and professional practice principles.
- Sector-wide awareness – the implementation strategy will need to include a phased awareness programme, introducing first the principles, and then the individual components, across the social care mixed economy sector. Some elements may be specific to types of provision or client group, and some elements will focus on those responsible for commissioning services, or those inspecting services, but the aim is an integrated ongoing awareness of the totality of programmes.
- Formulation of components – working synergistically with the awareness programme is the need to formulate each of the components identified above, such as model clauses for care commissioning contracts, or aspects and measures to be assessed by inspectorates. The implementation strategy should provide core components to be deployed by the individual organisations responsible, with customisation as appropriate. The national role will be to ensure harmonisation and to assess progress.
- Co-ordination and updating – whilst each of the stages and components is likely to be devised and launched sequentially, in the real and dynamic world new issues will arise, whilst organisations may also develop their own innovations and initiatives. An ongoing central programme is needed to identify and promote best practice, whilst ensuring a degree of continuing harmony adhering to the core principles.

## 7. Conclusions

Effective social care is an essential component of health services delivery to citizens, and maintenance of their health and well-being. However, whereas e-health is an established domain that has had chance to develop governance principles, e-social care is a new but rapidly developing domain. By virtue of the nature of the record containing sensitive information essential for care delivery, it is vitally important that governance principles be introduced from the early days. This does give the opportunity of an integrated comprehensive approach. This paper describes the foundation stage of such an approach within England, and the presentation will report on the latest progress.

Moreover, whilst social care is important and sensitive in its functions, its information, and the vulnerability of its clients, some other service sectors have similar generic characteristics, though with specific domain manifestations. Many vulnerable citizens benefit from special housing, where warden staff need to be aware of residents' special health and social needs, their other support mechanisms, and their family and social networks (or lack of), and to be able to interact with and discuss these as appropriate. Education up to and including secondary level is provided by organisations and staff (teaching and ancillary) who have a duty of care to children and young people, each with their own background and needs, some of which are formally designated as special needs for health, educational, or social reasons. These service sectors hold personal client records which contain very sensitive data, and would be more efficient with use of electronic systems. Each operates in a mixed economy which must nonetheless communicate across organisations (and sectors), with a variety of staff types, and each such service must be sensitive to confidentiality yet not blocked from effective communication about clients and users on a necessary and authorised basis.

Thus, though the case study in this paper is specific, the lessons should be much wider. In an emergent European Information Society, with eGovernment and eServices, the balance between confidentiality and control is crucial. Other than traditional data security – itself often managed badly as numerous publicised scandals have shown – little thought is being given to an integrated and managed approach to client personal electronic record governance. The approach in this paper, whilst focal and vital for social care, may also provide a blueprint for other sensitive service domains.

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