

# **The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care:**

**Report of an ESF Exploratory Workshop held at Keele University on 21-23 July 2010**

**and Declaration drafted by Workshop Members**

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## Workshop Report

(Explanatory Note: The Workshop operated under the Chatham House convention, whereby initial presentations were attributed, but subsequent discussion was open and unattributed. No major division of view or dissent emerged, and the final Declaration was agreed unanimously.)

### Main Objectives of the Workshop

The background setting to the Workshop was the premise that social care is an essential partner to healthcare so, ideally, electronic health and social care records should be synergistic, given that electronic health records are becoming well developed. However, a number of largely unresearched problems arise – services are different; record content has a different construct; content includes information about third parties. Frail clients are unfamiliar with electronic systems, yet their rights – to care, to confidentiality, to coordination - must not be diminished.

Despite its potential importance, Social Care informatics does not yet have an identity, an organization, or a champion – by examining the issues this workshop will seek to form a platform for action. The Workshop was intended to identify the key issues, the main aspects needing further study and action, and potential means of progressing initiatives. It was also intended to provide analysis, illumination, and advocacy for the development of ethically and scientifically underpinned action.

### Additional background

As further background, it is important to be aware that in Europe the ageing of the population, and the attendant increasing demands on society and services, are acknowledged as important issues. Moreover, consumer awareness rightly leads to higher expectations of both the range and efficiency of services, particularly in terms of personalization and tailoring of care and the right to have an input into overall care and health management. Electronic record systems in social care are emerging as an important tool, but they raise new and serious issues of content, meaning, and ethical exchange of data with partner agencies, especially health. They also raise major challenges of balancing confidentiality of the individual with coordination of a holistic service, and create privacy tensions between the interests of the client and those of family and other informal carers whose needs (and autonomy) must also be taken into account.

Currently there is no forum for considering these issues, no focus of learning, no organizational locus of interest, and no coordination of the major research issues. Thus workshop was designed with the aim of identifying and exploring these research issues, and of creating an impetus and potentially a vehicle for following them though. This is a new field with little research and a range of serious issues to be faced, as highlighted below

## Outstanding Issues

The first is that social care is usually **organised and managed separately from healthcare**, through different legal entities. The nature of the services is very different, and while healthcare is increasingly centralised in health facilities for many reasons, social care is provided in the home or in the nearby locality.

Second, **social care records are very different from health records**. Healthcare records are deep but narrow, with a wealth of technical and biomedical detail on the history of the individual creating depth. However, intentionally there is little information about third parties, creating the narrowness of the health record, which is very much about the individual, making it difficult to record the impact of an illness or treatment regime on a third party such as a spouse. In contrast, social care records contain information on context as well as conditions. Moreover, planning and delivery of social care requires an understanding – and thus a recording – of the citizen's personal circumstances, including their interactions with and contributions from family and neighbours.

Third, there are very **different attitudes to sharing elements of records** in the two domains. Social care records need in certain aspects to be much more widely shared, yet the range of sanctions available to control abuse is not as strong as in the health sector.

Fourthly, social care records have **little tradition of structured recording and coding** to call upon. Rather, records contain a high level of descriptive narrative, reflecting the client's voice and perspective as well as that of the practitioner.

Finally, and important both for the citizen and for service efficiency, **new paradigms of coordination of scheduling between agencies, services, clients and informal carers** are needed not only to ensure a smooth service delivery (for instance avoiding clashing of appointments in different localities, or bunching of all appointments on one day of the week).



(photo: J Hofdijk)

### The Workshop Facilitation Team

*M Rigby, P Hill, D Keeling, S Koch*

## Scene Setting

### Introduction to the Topic and its Challenges

*Michael Rigby*

#### A New Topic in an Under-Valued Sector

Health is a personal state, both physical and perceived. It is much more than Health Care (which in fact largely consists of illness services). Social care is needed as a key support to health of many individuals, and in the need for efficiency and effectiveness modern information technology has a vital role to play. Paper records and telephone calls alone are not the best way to responsive services and cross-agency coordination.

#### What is Health and how is it Supported? An Introduction

Health is defined by the World Health Organisation as being “A state of physical, mental, and social wellbeing, and not merely the absence of disease”. This therefore includes being able to achieve normal living, though this may be facilitated by family, friends, or formal services. Independent healthy living can (and should) be achieved in adult life, but in the early stages of life, and often in the very later years, persons need assistance in order to achieve wellbeing and health; this is also the case for anyone with an illness or disability which compromises their self-maintenance ability. Quite separate from clinical health services, a number of functions are essential to maintaining health, and these can include nutrition, personal hygiene, toileting functions, and mobility.

Thus formal services to maintain health may include provision of meals, personal hygiene support, mobility, and enabling activities such as shopping for food and other essentials – these are often referred to as Social Care. These are not traditional health services, but without them the health of the individual with particular needs would be compromised and then fail. But given the balance of needs and complexities of the life of a person with illness- or impairment-based needs, the services providing social care support must work in harmony with those providing health care. Provision of such support must also comprise a balance between formal services, family, and the local community or society.

Pressures for these social services in support of health are growing. There are demographic pressures of increased longevity, coupled with more people surviving serious illness, but often with increased dependency. This is compounded by societal pressures for more and better services for needy members of society. Coupled with this there are increased consumer expectations of service availability and quality based on more widespread consumer-orientated attitudes of commerce and society, coupled with increased awareness from what is often referred to as the Information Society. In turn the electronic services endemic in this Information Society raise expectations that such technologies will be harnessed in the provision of consumer-focussed care services.

However, acting counter to this set of expectations is the increasing specialism within both health services and social care services, as well as between one another, creating a tendency towards fragmentation of provision, and silos of specialist knowledge and detailed records. This specialism may have justification, but acts directly counter to the citizen-based aims of holism and of service coordination and integration.

Important and challenging also is the fact that there are major differences in record keeping between health and social care, whether paper-based or electronic. Health records are focussed

on one patient, with often considerable technical detail and depth. Social care records place the citizen in their home context of family and carers, including attitudes and effects, but have far less technical material.

A final challenge in most countries and systems is the lack of a level of coordination and ownership between health and social care. Though there are some important exceptions, in most countries the management and funding of health care are quite distinct from the management and funding of social care. Though they serve the same citizen, and each depends for its efficiency on the other, there is seldom a formal shared management structure.

### The Societal Context

Across Europe the societal effects are even deeper than the ageing of the population, the increase of survivors of chronic conditions, and increasing consumer expectations. However, while these factors alone increase pressures on services, simultaneously economies are pressured both by the change in ratio of earners and taxpayers to dependents, and by the economic downturn. Thus budgets stall or shrink as demands increase. Yet at the same time not just the public, but also politicians and policy makers, argue for and promise the twin goals of Personalised Care and Integrated Care. In many cases these are more a mantra than reality – and they are too often led by the health sector. This sector has a vital role in the care of health issues, but no monopoly in the overall concepts of care and support.

### Consumer Expectations

Citizens in Europe are increasingly sophisticated as consumers. And while many – especially the elderly and the socially disadvantaged - are not universally digitally literate, they almost universally have high consumer expectations. These can be highlighted as expectations of readily available and reliable services, with high efficiency and effectiveness. As part of this, there is strong frustration with dis-coordination, which may manifest in different aims and goals, different support approaches, or clashes in delivery schedules.

To counter this, the citizen (and their family and informal carers) expect modern approaches to coordination and management. But at the same time, while resenting having to repeat information, or advise one agency of the actions of another, citizens value highly their privacy. Linked to this, there is often a distrust of computer systems, and in particular of computerised databases and remote automated decisions, especially on personal matters.

### The Information Society

Yet the modern era has been dubbed the “Information Society”. Computers, and Information and Communications Technologies (ICTs), are ubiquitous. There is a public expectation that these technologies will be used for efficiency, yet citizens are cautious when their own services and records are involved. Similarly, there is professional ambiguity within the health and care sectors – the theoretical benefits are seen yet there is mistrust on the effects on personal practice.

Both at EU level, and in most nations, there are moves to further the benefits of the Information Society, though this is often run in line with major economy sectors such as banking, insurance, retailing, or air travel. Though citizen benefit is the aim, development is based on organisations. Health is seen as a potential beneficiary of ICT applications, though often in a naïve way, but there is far less focus on the social care sector despite its strategic societal importance.

### ICTs in Health and Care – Specialist Silos vs Holistic Integration

In turn, the health and social care sectors have their own discomforts and challenges. Health care has its own ethos, delivery, record keeping, and indeed its own specialisms within ICT application. In this, personal ‘Health’ is not the focus, but rather health services, though coordination is an aim.

By contrast, social care is more fragmented, with more models of provision. Within this sector service differences, and confidentiality, cause barriers and silos. The fact that social care operates within, and has a relationship with, family and society is a complication.

The citizen wants an ill-defined compromise - integration of support provision, but segmentation between and even within sectors. They do not want clashes of provision, but nor do they want personal details passed between players any more than absolutely necessary.

### Lack of Ownership and Coordination

There are also major challenges of ownership and coordination. These can be posed as a series of questions, to which there are different answers in different countries (or provinces). These include:

- Who coordinates care objectives and related records?
- Who coordinates care delivery at the policy level?
- Who coordinates delivery at Individual level? (by default this is usually left to the individual citizen or carer, though they are likely to be vulnerable and least empowered.)
- Who coordinates Informatics Systems, and policies?
- Who provides coordination at EU, Research, and Professional policy levels?

It is clear that much needs to be done to support effectively citizens’ health through modernisation of social care delivery, and coordination with the health sector to form an integrated holistic web of support.

### Workshop Aspirations

Whilst broad objectives had been established in advance, it was seen as important for the workshop to be clear in not just identifying issues, but in aspiring to lay some foundations for making progress. These were identified as:

- Agreement on a Vision
- Agreement on a Desirable Action Plan
- Identification of Tasks and Leaders
- Sources of Funding
- Ongoing Communication (agree leaders, members, means)
- Awareness Raising (agree messages, vehicles, leaders, funding)
- Mission Statement or declaration – if the workshop finds strong common ground

It is against the achievement of these aspirations that the success of the event, both immediately on exit, and in the medium term, should be judged.

## Essentials of Social Care Service Delivery

### *Penny Hill*

#### What is Social Care?

A number of attempts have been made to define social care. Three results are:

- Social work is a profession and a social science committed to the pursuit of social justice, to quality of life, and to the development of the full potential of each individual, group and community in a society. Social workers draw on the social sciences to solve social problems. (*en.wikipedia.org/wiki/Social\_care*)
- Care services which are provided by local authorities to their residents, or which are commissioned by local authorities (for example, from community and voluntary organisations and from independent providers). (*www.sath.nhs.uk/OurNHS/glossary.asp*)
- Organised effort to help individuals and families to adjust themselves to the community, as well as to adapt the community to the needs of such persons and families (*http://encyclopedia2.thefreedictionary.com/Social+care*)

#### The Range of Services – and Mix-and-Match Options

Social care can comprise a wide range of services. The core ones are:

- Mobility assistance
- Aids to daily living
- Assistive technologies
- Meals
- Social activities
- Supported learning and employment
- Home Help (domestic tasks)
- Personal care, personal assistants
- Night sitting, home nursing
- Respite care (including carers)
- Care and nursing homes

These may be provided singly, or more usually as part of a package of care. Each may be provided by a different provider, or organisations may supply a number of the services.

#### Social Care Professional Services and Interventions

Alongside these support services, social care has its own professional services, especially:

- Assessment of need and/or risk
- Supported planning and review
- Care co-ordination
- Re-ablement
- Counselling
- Safeguarding
- Family support and interventions
- Fostering and adoption
- Advice, guidance and service brokerage

These will have both short-term (often crisis) aspects, and long-term planned ones, according to individual needs. The ideal outcome is individual independence and well being. The different immediacy effects are:

- Care services support at points of crisis:
  - Following an accident or unexpected illness
  - Safeguarding the vulnerable
  - End of life care
- Long term enablers
  - Disability support
  - Mitigating long term health conditions

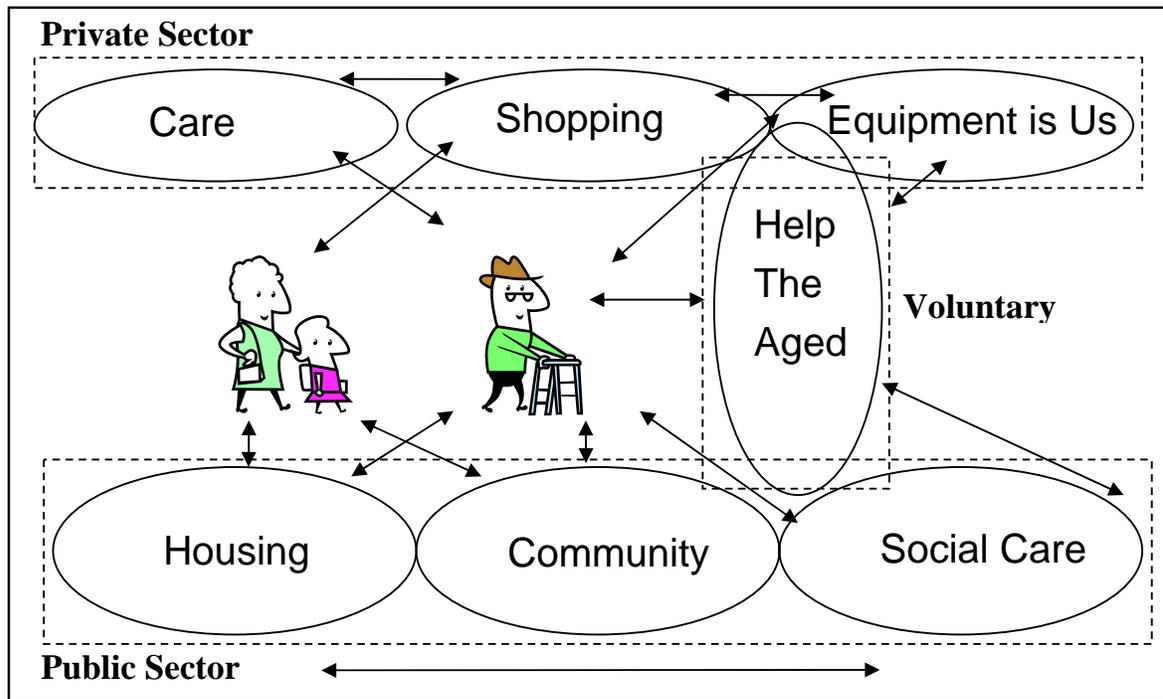
### Who Organises the Effort?

The pattern of provision is a mixed economy in the fullest sense of the term. Many players contribute, including:

- The family
  - The person themselves
  - Carers, relatives, neighbours
- The state
  - Public sector agencies
  - State funded services
- The voluntary sector
  - Charities
  - Self help groups
  - Advocates
- Private providers
  - Private practitioners/paid carers
  - Care Homes
  - Care Services

Health and Social care services should work in harmony to address the needs of each individual – the health sector combating ill health and limited functionality aspects of illness, ageing and disability, and social care combating the isolation, risk, and function compensating aspects, so that together they move the person from a poor and deteriorating quality of life to a good one.

The net result is a personal ‘pick-and-mix’ of services, as shown in Figure 1.



P Hill

**Figure 1. Pick and Mix – the Challenges of a Care Economy**

The Potential Role of Informatics in Social Care

In most settings, informatics is only slowly being brought in to help address the challenges of managing and delivering optimal social care, and harmonised with health care. Issues which informatics can help to address include:

- The need to better inform the public on what is available, what is effective, and how to identify what they need.
- The requirement to deliver quality services, working in partnership with individuals to enable them to achieve personal outcomes.
- The requirement to safeguard the vulnerable without unnecessary or intrusive intervention.
- The need to support and demonstrate the quality and effectiveness of services (clinical audit, research, prevention).
- The requirement to monitor public (and inform personal) spending, demonstrate value for money, evidence efficiency and effectiveness.
- The need to evidence pressures and manage service delivery within available resources.
- The need to monitor the implementation and appropriation of policy, with associated common indicators.
- The need to plan for future services linked to the needs of local communities.

- The need to manage markets and ensure that relevant services are available to respond to both community and individual need.
- The need to evidence compliance with regulation and legislation.
- The need to interface more closely health and care data to support seamless services.
- The need to respond to health models and map health data to care requirements.
- The need to support the workforce in developing skills for recording and analysis that meet the other agendas identified.

Clearly this is an extensive and potentially daunting agenda, but not one to be ignored. The urgency is to find means of tackling these issues in a structured and evidence-based way. And in moving forward, the responses to these challenges need to recognise, and balance, the following issues:

- The opportunities of and need for local flexibilities and local innovation.
- The opportunities arising from federated rather than monolithic approaches.
- The efficiencies (and challenges) of consortium and partnership developments.
- The benefits of sharing consistent, quality information (and therefore working to common core standards), reducing the need for citizens to repeat their story many times.
- The need for safe, secure environments and robust information governance arrangements to ensure public trust and confidence.
- The requirement to empower citizens to access and manage records that relate to them (their own, and those for whom they may act as carers or advocates).

## **Collaboration in Health and Social Care Electronic Records**

***Sabine Koch***

### Introductory Background

There is currently a lack of coordination between health care and social care providers. This leads to communication difficulties, especially limited access to information (which itself is currently a mix of electronic and paper documentation). This, coupled with the pressures caused by the increasing costs of health care, the shortage of staff resources, and the poor participation (or limited collaboration with) patients and relatives, is leading increasingly to an organizational centrality instead of the desirable patient-centricity. Clearly this is not an acceptable situation in the current context.

### The Aim of Electronic Record Collaboration

Collaboration in electronic records offers a much-needed solution. The aim must be immediate and ubiquitous access to patient-oriented data in specific work situations for different health and social care providers and for patients and their relatives. However, analysis shows that there are differences in the characteristics of social care records when compared with health records. Health records are clinical, narrow, mainly structured and often coded, and about the one individual. By

contrast, social care records are focussed on the social wellbeing of the individual, are broad, largely in narrative, and about not just the individual but also his or her familial and social environment.

Thus full integration is not a feasible immediate target. What is important as a way forward is to identify the intersection points. These will include

- initiation of patient-specific changes, sharing
- important patient-specific health events
- coordination of planned activities
- referrals
- delegations
- consultations

This list is not exhaustive, but a starting point. It identifies when there will be important issues of mutual interest between the health and social care teams supporting an individual. Also what will be important to resolve will be the issues of governance, including responsibility and accountability.

## The Current Situation in Europe

The current situation in Europe with regard to social care provision, the use of electronic records in social care, and patient-based integration, varies tremendously between Member States. To illustrate this variation, case studies on the current situation, issues and progress were presented by delegates from a sample of six countries.

### Denmark

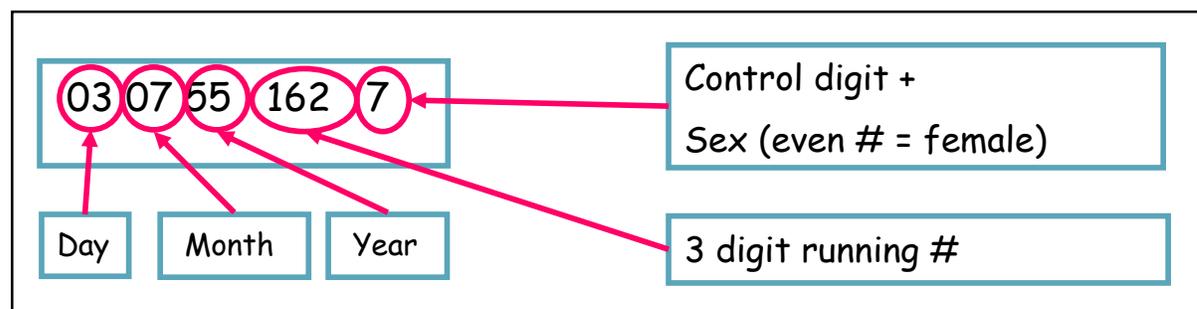
#### *Christian Nøhr*

With a population 5.4 million, and health care expenditures of US \$3,000 per inhabitant per year (8.5% of GNP), Denmark has 63 hospitals owned and run by 5 regions, and for which general practitioners act as gatekeepers, while long term and home care is run by 98 municipalities.

With regard to public services in Denmark, a particular asset is the system of unique identifiers at national level, of which there are three:

- Person identifiers - CPR
- Company identifiers - CVR
- Building identifiers - BBR

The relevant national registries are maintained by central authorities. The system has been in operation for more than 30 years, and there have been no scandals. Within this system, all citizens and residents have a unique personal identifying number (civil personal number), which is used for almost all interactions between individuals and government or public services. It is the key to all individual based documentation. Use of and access to the registers is regulated by law, and authorised cross-references are undertaken from different data sources. Figure 2 shows the open format of the personal number.



**Figure 2. The Structure of the Danish Civil Personal Number (CPR)**

There is a National Patient Registry which is based on the unique personal identifier. This contains information of all hospital visits since 1977, and all ambulatory visits since 1995. It is used by regions and municipalities for resource monitoring, for national health surveillance and research, and by all citizens to access their own data. The information content of the Registry comprises hospital and department admission and discharge dates, diagnoses, procedures (operations and radiology are mandatory), and waiting times.

Health and Care IT is well implemented in Denmark. 100% of GPs have EHR systems, and all communicate with other parties. 100% of pharmacies use IT, and these systems communicate with GPs and hospitals. 100% of hospitals have PAS, and these communicate with GPs (and other hospitals). But not everything is complete yet – only 50% of hospital beds are served by EHR systems, and there is sparse communication from these. Only 50% of municipalities have care systems, and these are starting to communicate.

Electronic data interchange (EDI) is strong in Denmark, via the MedCom Health Data Network. All of the 2120 general practitioners, 322 pharmacies, and 63 hospitals utilize EDI, as do 94% of the 765 specialists. Transactions in December 2008 were 1,389,203 prescriptions (84% of the national total), 1,131,750 discharge letters (94%), 988,151 laboratory reports (99%), 349,840 laboratory requests (95%), 177,525 referrals (65%), and 21,049 (99%) or reimbursements.

Denmark has an Internet public health portal ([www.sundhet.dk](http://www.sundhet.dk)), with service provision material for citizens and for health care providers. Services for the citizen include information about medicine, on-line purchase from pharmacies, information about hospitals (location, staff, services, waiting lists, and quality indicators), and personal health information (to access which they must log on) including medication prescribed by their GP, an “e-Record” of diagnosis and procedures, and GP consultation by E-mail.

Denmark has a range of telemedicine initiatives, comprising video conferencing (supervision and second opinion, psychiatric treatment, planning of operations such as between radiologist and surgeon, case conferences between hospital and home care, and education and training); image sharing (radiology, dermatology, wound assessment, ophthalmology and pathology); and home monitoring (assisted home monitoring, home hospitalization, and self monitoring).

The internal focus of health IT is on the clinical workplace and hospital efficiency, while the external focus is on connectivity, cooperation, and citizen empowerment. Quality is an overall linking theme.

## Finland

### *Hannele Hyppönen, (Martti Näveri), Persephone Doupi*

Finland has 5.3 million inhabitants spread over 338,000 square kilometers, with 23,000 doctors (232 inhabitants per doctor) and 70 hospitals. The national constitution states that public authorities shall guarantee for everyone adequate social, health and medical services and health promotion.

Health expenditure was 8.2% of GDP 2006 (which is below the OECD average), being €2,781 per inhabitant in 2007. Funding comes through municipal taxes, with the state paying a general subsidy to the municipalities, which was 33% of costs in 2008 – this subsidy depends on the age structure, unemployment rate, number of pensions for the disabled and the population density.

Municipalities have by law the primary responsibility for arranging social and health services (primary and secondary care) for their citizens. Services are provided by single municipalities (399 in 2008, in 229 health centres, giving a population median of 9,500 per health centre compared with

a target of 20,000). These services may be provided as joint services, or purchased from private or public providers.

Specialised care is arranged by federations of municipalities in 20 hospital districts (16 central hospitals and 40 smaller specialised hospitals), while tertiary care is provided in 5 university hospitals. Municipalities have a strong decision making power in arranging services (including eHealth). Regional differences exist, and these are worse in primary care.

The citizens contribute 7.4% of the healthcare budget in the form of client fees:

- Doctor visits in health centre at €27 per year or €13 per visit for the first 3 visits
- Secondary care €27 per visit, day surgery €89 per event
- Short term institutional care €15 per day (psychiatry), €32 per day (other short term care), day care €23-€54 per month
- There is a €633 per year maximum fee which includes all social and health care

Key health care performance indicators are good, deaths for heart attacks and strokes have dropped, and there are good screening rates for cancer, etc.. However, there are problems, particularly inequalities in to access services, shortage of personnel, waiting times to see a doctor at a health centre, and long waiting lists for elective surgery. Reforms of the system are tackling these issues – for example, reform of access to non-urgent treatment has shortened the waiting lists for secondary care from 66,000 patients to 4,600 between 2002 and 2008. The PARAS reform focuses on collaboration and merger of municipalities to ensure a sound structural and financial basis for municipal services in order to secure their provision into the future.

The state of the art of public services is progressive. In particular, eTaxation, social security services, employment services, and eID are already well established. Use of common support services such as eID and eForms has increased., but the use of e-payment in public sector services is still minimal. The degree of interactivity and the number of channels in services has grown gradually, for instance the verification of personal details and notifications supplied by e-mail. For eID, the net bank ID system has been adopted in the public sector at present.

National eHealth (<https://www.kanta.fi/web/en/frontpage>), and eWelfare ([www.tikesos.fi](http://www.tikesos.fi), [www.sosiaaliportti.fi](http://www.sosiaaliportti.fi)) developments have generated readiness for social and health care e-services. There is a Finnish National Patient Information System (KanTa), which includes an electronic prescribing system and an electronic patient record archive which the patient can access for their personal record – these are run by the Social Insurance Institute (Kela).

Challenges for the future are that Finland's traditional Nordic model of services is under pressure, requiring further collaboration of public administrations across sectors and levels. The current set of public administration reforms in Finland is comprehensive and ambitious. To sustain the current structure for public services, Finland may need to be even bolder and to go further in its reforms in order to achieve the strategic agility to respond to the current and future needs of its people. Shifting the current paradigm could be achieved by turning the public administration on its head, by changing its focus from better connecting ministerial stovepipes and local government boundaries to focusing work around the needs of its citizens and businesses. There is a need to strengthen e-government leadership and coordination in setting standards and assuring interoperability, and in creating an enabling environment with technical and ICT assistance in order to improve implementation.

A new eGovernment, eServices and eDemocracy program (SADe, 2009–2014), intends to ensure that Government services are available through multiple channels, easily found and support the life situations of the citizens or enterprises. Customers should see public administration as a coherent entity. e-Services will be available for citizens and enterprises in all key areas of service by the end of the year 2013 – this will include common public infrastructure projects and sector-specific projects in different administrative areas. These public infrastructure projects will include:

1. Common Architecture
2. Electronic services platform
3. Common document management, collaboration tools and archiving
  - (VALDA – Administrative Documents,
  - KanTa – eHealth documents archive, prescriptions database, eViewing
  - KanSa – eWelfare documents archive, eViewing
4. National portals - Suomi.fi and YritysSuomi.fi
5. Citizen's Account
6. National contact centre for customers

E-Service entities will include:

- Students eServices
- Citizen participation
- **pHealth and selfcare**
- **eHealth and eWelfare services**
- Built environment and living
- Employer services
- Entrepreneur services

Within this programme, planned national (shown as N) and distributed (shown as D) pHealth and eHealth services are:

- General information on health, illnesses, their care and medication (N)
- Personal health record (D, with N standards)
  - Storing and managing personal health data
    - Self provided data
    - data from measuring devices
    - data from EHR, including care plans
- Self-assessment of care need (N)
  - Risk tests
  - income support calculator
  - IADL evaluation
- Anonymous and personalised urgent and non-urgent advice service (N, D)
- Service provider information (for selecting suitable care provider) (N)
- eApplication (e.g. income support, day care, elderly care) (N)
- eAppointments (D)
- Electronic care diary (N)
- eCommunication services (lab results, care adjustments etc.) (N)
- Telecare services, e.g. interpreter services (N, D)
- Electronic feedback services

This comprehensive programme will be accomplished mainly through work done in separate local projects, pilots and existing solutions.

For the first time, there is a common political vision across sectors and a mechanism to create legally, organisationally, semantically and technically interoperable, citizen-centred public eServices in Finland. Volume services (e.g. citizen's income support application exploiting the individual's population and tax register data) are foreseen as the starting point, with client centredness and needs, productivity gains and cross-sectoral collaboration as key requirements set for the development. Collaboration with the Chronic Care Model (CCM) implementers and citizens is being established to ensure co-construction of eServices and technology. Strong municipal autonomy coupled with the need for municipal service integration, fitting of common tools for different types of clientele, services and record contents, defining access to third parties and ethical considerations and using research for informed decisions throughout development are just some of the challenges for the work.

## Germany

### *Sonja Müller*

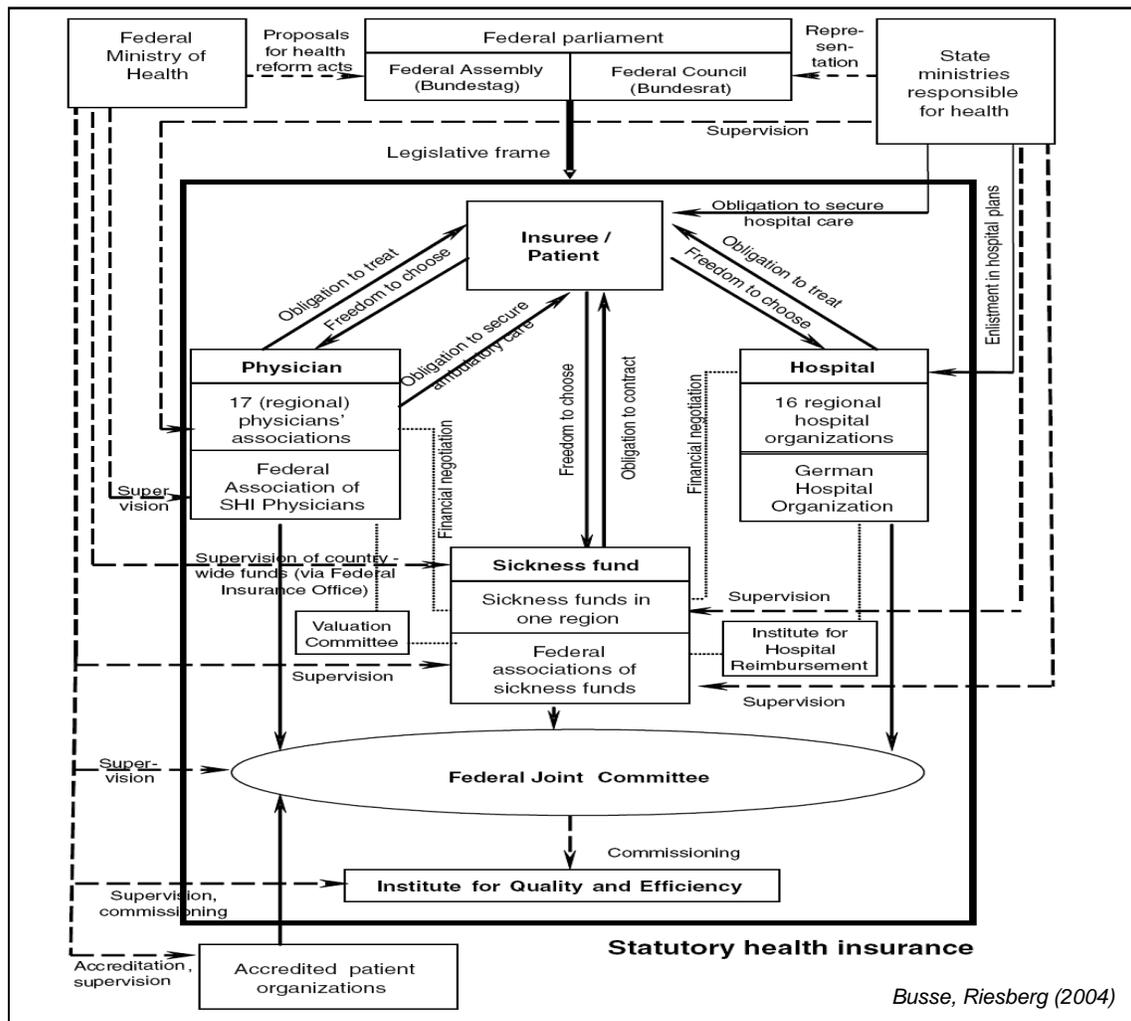
The German healthcare and social care systems are largely separated. Both are regulated in state (Land) legislation (Social Code Book) but there are also responsibilities at the federal state level. The systems are complex, involving a wide range of different stakeholders, and the reimbursement schemes are similarly complex. Figure 3 shows the health care scenario. Noteworthy too is Germany's complex data protection environment.

Germany's long-term care system is regulated in Social Code Book, as a tax funded universal insurance system. However, service provision financed through statutory long-term care insurance funds was introduced in the mid 1990s. Service providers negotiate with insurance funds and conclude supply contracts. Assessment of level of support needed is undertaken by MDK. Care provision is through providers of homecare, residential care, day and night care, etc..

On the subject of electronic records, documentation of care is regulated by national law, but is different for social care and healthcare. Electronic care documentation is most widely spread in the healthcare sector (hospitals, GP systems). The health insurance card is widely used, and contains basic information - introduction of an electronic health card has been regulated for but not yet implemented although planned for 2006.

Social care documentation is varied. In residential care home there are sometimes ICT supported systems, whereas in the home care sector documentation is written manually and needs to be stored in the home of the patient.

The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care



**Figure 3. The German Healthcare Structure**

Challenges and issues centre round the fact that health care and social care provision are largely separate (reimbursement schemes, legislation, assessment procedures, education and training, players, etc.). There is lack of communication between health and social care providers, often leading to inefficiency of services. Complex and strict data protection rules (federal data protection act, medical devices act, charter on patient rights) lead to intensive discussions in relation to introduction of health records. The use of ICT is rather limited, especially in the social care sector.

## The Netherlands

### *Jacob Hofdijk*

The Netherlands is implementing a patient centred, value based, health reform. The initiation of health as a science by Hippocrates led ultimately to ethical principles, the concept of ‘cases’, lump sum funding, and personal clinical responsibility.

The objective should be to keep people healthy and active. In the Netherlands the health reforms of 1994 were designed to meet a set of perceived needs. There were seen to be two contra-productive business models, whereby the hospital tried to keep within budget, but the physician benefited from fee for service. The involvement of Government was seen as too restrictive, and there were growing costs but no metrics of the outcome. Thus the 1994 Biesheuvel Report on Modernising Curative Care marked the start of the paradigm shift from supply- to demand orientation.

There is a move from budgets to contracting, from budget parameters to a focus on healthcare products focused on health issues of patients, with accompanying transparency. The first stage of the reforms was the reform of secondary care, based on the progression of Health Issue → intake → > diagnostics → diagnosis → therapy → restored health. This has led to a health issue based medical record, and open processes including patient choice.

The second stage of the reforms has brought in integrated disease management, recognizing that in the United States Kaiser Permanente found that while the healthiest 70% of people consume just 10% of healthcare cost, the 1% with the most expensive conditions consume 30% of total cost; the balance of 29% of persons with exponentially increasingly expensive chronic conditions take up the 60% of costs. To address this, the Netherlands has developed a series of disease-specific care standards. These are unique in that they have been developed jointly by care providers and patients. They are based on guidelines / protocols / lifestyle, and define what good chronic care is for patients, rather than who should perform what. They combine prevention and care, and define quality performance indicators. They form a base for task substitution, and for involvement of the patient. This approach requires collaboration between the patient, primary care practitioner, and secondary care provider.

The resultant Dutch chronic care funding model sets a contract between a provider group and an insurer to provide Gold Standard quality care for a disease condition. Integrated Funding is now (in 2010) in place for three chronic conditions – diabetes, cardio-vascular risk management, and COPD, based on authorised care standards. These contracts set Price / Performance Indicators, with transparency via the Reporting Chronic Dataset. There is a focus on prevention, and the patient is part of the team – with the intention of effecting lifestyle changes.

Care and information are shared between patient, general practitioner, hospital specialist, pharmacist, dietitian, physiotherapist, podiatrist, home care team, laboratory and imaging department. The IT requirements are for multidisciplinary team of primary (GP’s, nurses, paramedical specialist) and secondary care (medical specialist), with the patient as part of the care team. There is an individual proactive treatment plan, using semantically interoperable data through a cross institutional solution. There is a patient-centric annual reporting dataset.

The resultant direction of the new health policy is thus to provide good care close to the citizen’s home, with a focus on integration of multidisciplinary services, and reorientation of the funding systems. This approach was been accepted well by the stakeholders, but the country is now waiting

now for a new government. What is absolutely clear is that it needs a reorientation of the IT to make the shift from disease to health.

However, this is entirely in line with European Federation of Medical Informatics (EFMI)'s Declaration of Reykjavik in 2010, to achieve seamless care for all by working together to define common definitions of data elements and how to collect them, joining forces and forgetting competition. What has been described by Rossi Mori as the Copernicus approach to IT systems would see proactive care based on good services, prevention and care. In the Netherlands this would link the defined parameters to evidence based clinical pathways. There is a strong argument for collaboration in doing this.

## Sweden

### *Sabine Koch*

Sweden has a population of 9 million inhabitants. Administratively, 21 self-governed regions/county councils have responsibility for hospital and primary care, while 290 self-governed local authorities have responsibility for healthcare of the elderly and functionally disabled and social services. Legislation on healthcare is at the national level, in the Parliament.

IT is an integrated part of the Swedish healthcare system. Electronic patient record systems are well established, with 100% of all documentation in primary care being electronic, 97% of documentation in hospitals, 96% in psychiatry, and 90% in ambulances (with direct communication to hospitals). 80% of all pharmaceutical prescriptions in Sweden are issued and transferred electronically. 56 national quality registries contain individual-level data on diagnoses, treatment interventions and outcomes, organized by condition. Additionally, telemedicine is important in sparsely populated areas.

Sweden adopted a National eHealth Strategy in 2006 which is updated annually. Current strategic issues at national level are

- Process-orientation and business development
- Citizen-centricity and personalised e-services
- Include social services to coordinate development within health and social care
- Secure continuity of care between different providers and take away organisational barriers
- Strengthen privacy of the individual

At Regional level the current strategic issues are:

- County councils/regions to integrate healthcare services between different providers; and offer e-services for citizens.
- Local authorities to partly use the same EHR system for healthcare documentation; offer e-services for citizens; develop own documentation for social services; and mobile tools for time planning.
- Integration between health care and social care documentation is far from being reality, but digital systems for e.g. discharge planning are implemented, as well as telemedical solutions for shared care planning in some places.

## United Kingdom (primarily England)

### *Penny Hill*

In England, health services are directly funded by national government, though with some user charges such as for prescriptions. Social care is planned and managed by autonomous local municipal authorities, who also manage a budget comprising a mix of local taxation, central government budget contribution, and user charges (usually related to client income). For policy purposes both services come under the Department of Health. Services in Scotland and Wales come under those devolved administrations, with broadly similar structures and patterns though there are some important differences (such as lower user charges in Scotland, and more health IT autonomy in Wales). In Northern Ireland health and social care are managerially integrated under the regional government. The balance of this section relates primarily to England, with some comments in major differences elsewhere.

England has a large NHS programme delivering England-wide health information services, including the Personal Demographics Service (managing the national NHS Number patient identifier), the Summary Care Record (linked to GP systems, Hospitals and local Community records), and Clinical systems (particularly PACS (picture archiving) and electronic prescribing). This ambitious national programme has been run by a government agency, NHS Connecting for Health, whose future is now uncertain though core services will continue.

Meanwhile, English Local authorities are developing independent social care systems. Adult and Children Services approaches are at risk of diverging, as adult services are responding to new policy initiatives to increase personal choice and control in social care (*personalisation*). There is a generalised expectation of closer integration with Health (and other services). Some projects have been funded to explore specific issues such as the Common Assessment Framework (CAF) and Intermediate Care. There is a national programme seeking to develop strategic direction.

Scotland has nationally shared health and care records, but developments in social care are still largely locally driven. Wales is supporting consortium approaches and encouraging local innovation.

2010 has seen the election of a new (coalition) government replacing the long-serving Labour administration. The new government's policy focus is now on *information*, not systems. A new strategy is being developed, based on greater emphasis on personal control and access. A key policy statement is:

*“Our aim is that people should be able to share their records with third parties, such as support groups for patients, who can help patients understand their records and manage their condition better. We will make it simple for a patient to download their record and pass it, in a standard format, to any organisation of their choice.”*

Major changes in the NHS have been announced, with a move towards local community control, with local authorities becoming engaged in public health and health service commissioning. The need for an integrated approach to records is increasing, but there is a risk of the health model becoming dominant. Developments will be challenged by limited (and reducing) resources – skills and knowledge as well as funding.

## Identifying the Issues

### 1. Identifying the Individual: approaches to Citizen ID

#### *Michael Rigby*

The citizen can be identified within electronic record systems by a number of different identifiers: National ID Identifier (as in Denmark), a Sector ID (e.g. the English NHS Number), or an organisational customer ID (such as a hospital number).

A national identity number works well where it is the national culture as in Denmark, while other countries have a Public Services number less robustly used (as in Ireland). Social care in many countries uses a different identifier to health, and an additional consideration is that not all social care (or health care) is publically provided. Many countries see a national ID as unacceptable (as being a ‘Big Brother’ approach). Thus in integrating health and social care, if there is a national ID number it is a sound approach, but it is not a solution generally available.,

By contrast, a sector-specific ID such as the English NHS Number provides linkage across providers within the sector, and thus should ensure coordination within the sector within the individual country. However, this approach works against cross-sector coordination, though by agreement each sector can record the identifier used by the other to provide a cross-linkage. A sector ID approach needs sector-specific registration (and enquiry) services; on the other hand, it can be seen to underpin confidentiality.

Organisation or customer numbers necessitate each organisational provider having its own ID system. This is a recipe for fragmentation - cross-recording is difficult, though there is no requirement for a central registry. Other solutions such as date of birth and address have major risks as not being unique, changing regularly, or being open to mis-recording.

Different issues are realised by consideration of the citizen as carer (as opposed to recipient of care) – informal carers are an important part of the care team, and formal providers may wish to brief them, train them, invite their input, compensate them, and also consider their own needs and capacity. If they can be identified within the client’s record their skills and competencies, as well as any needs or problems, can be recorded. At the same time such recording can be seen as intrusive, and making too formal a commitment. To achieve carer recording needs a unique identifier, and links with client’s record. It is difficult without a national ID number.

Distinct from the citizen as carer is the citizen as (usually involuntarily) affected person. Any client with needs affects the lives of others – such as spouse, children, parents, and possibly immediate neighbours. The health sector usually keeps this recording of needs quite separate from the core client’s record, whereas social care may look at interactions, effects, and dependencies. Issues of how to identify these affected persons are challenging. They may be recorded under their own ID, in a subset of the client record, or linked to the client record.

Quite separately, each professional will need their own professional ID for use when accessing a record or entering data, as well as when referrals are made to them. This might in some countries be by using their national ID. More frequently it will be through their (national) professional registration. Other solutions include employee ID, which may or may not link to profession and or

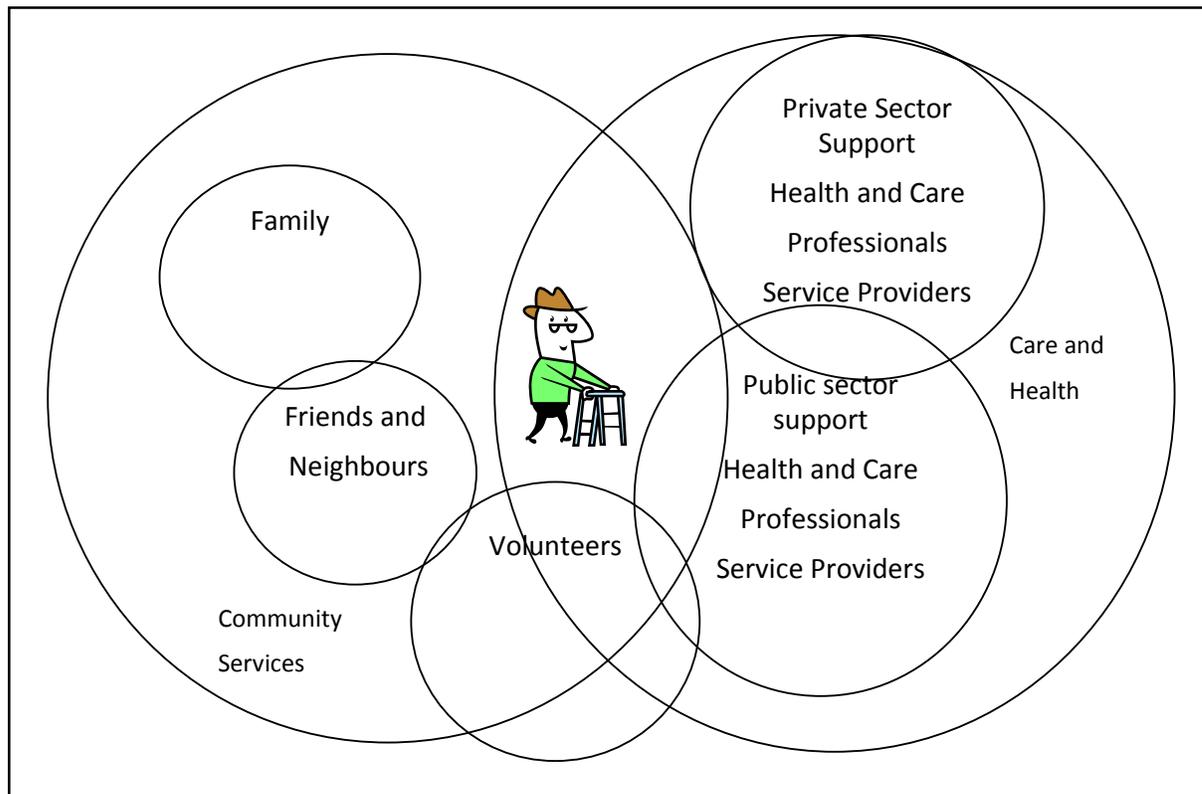
role (which is different). Role will change (sometimes frequently), and a person may hold more than one role, and role may be temporary.

Thus the recording of identity is a core issue for electronic records, and is significantly compounded with the many interactions within social care. One individual can have roles as client, carer, affected person, and professional. Identifiers must be unambiguous, reliable, and readily available when needed. National cultures and systems play a key role in determining what solutions are possible.

## 2. Identifying the Family and Care Network

### *Penny Hill*

No man (or woman) is an island; few people live in total isolation, and care giving certainly impacts on family and social networks. The majority of care providers are unpaid volunteers - family, friends and neighbours. Family context and circumstances are therefore a fundamental part of the care environment. Professional provided care often involves a team of practitioners - social workers, home carers, community health and others. There may also be a range of others involved in delivering care that are not part of the direct 'care team', such as financial advisors, service managers, and administrators. It is thus important to understand the Network of Care and Support. Figure 4 conceptualises this.

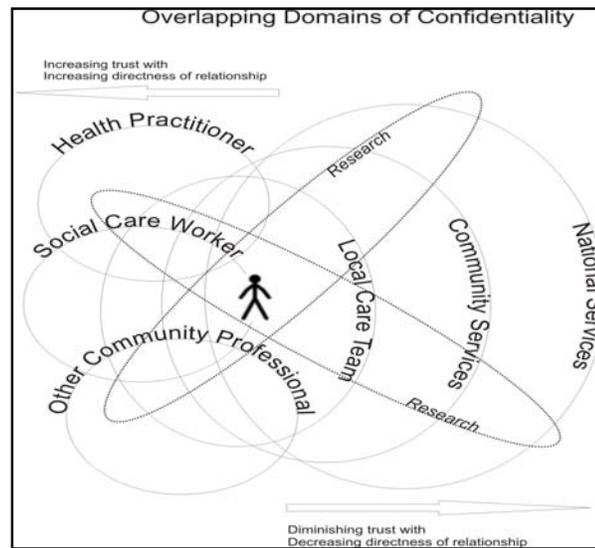


**Figure 4. The Network of Care**

*P Hill*

It is important that the client is seen as the centre of the network. However, far too frequently each of the organisations and individuals places themselves centrally, marginalising the client and making other providers causes of friction or even competitors.

However, position in a network raises issues of confidentiality, and of need to know (and understand). Thus this raises issues of access and control, as well as the need to manage care, and resources. Personal information (often highly sensitive) is involved. Figure 5 illustrates the issues.



**Figure 5. Overlapping Domains of Confidentiality**

### 3. The Privacy and Support Conundrum regarding Carers

#### *Michael Rigby*

The key issue is that the informal carer is a citizen with their own rights and needs. Additionally they have needs regarding the effect of caring for a person with needs. They also need personal consideration regarding their skills and abilities to care. Moreover, they have value as observers of the formal client's needs and changes.

Carers should therefore not be treated as 'add-ons' to the client's network of support, nor should they be regarded as a 'free good' in terms of expectations on them not having any effect or opportunity cost. This raises issues seldom addressed:

- Does there need to be a record of/for the Carer?
- How is it organised, stored and linked to the formal client?
- What are the Data Protection, Privacy, and Access, rights
- How much can or should the Client know about the effects on the carer?

Care organising bodies need to think carefully of the effect of informal care on the carer. The effects on family members may be different from those of neighbours and friends – for instance,

depression, or anger. The health sector will treat these carer issues as a separate clinical record, whereas social care may be more integrated, recognising the inter-linkage, and seek a balance or redress. But key issues are to find out how the effects are linked, who might legitimately see both record elements, and what is the client allowed to know?

At the same time, the carer with an acknowledged role is more than a passing amateur. They have a knowledge of the client, and see them in different situations and times of day. So when do their abilities become formalised, and is training offered (and recorded) - e.g. in lifting, special feeding, special dietary balance? Is this recorded as a 'quasi-employee' record? What about a record of what the carer 'cannot do', for whatever practical or psychological reason?

The potential of carers constructively to record and report the client's situation is also important. Carers are important as sources of warnings and alerts, and they may also be valuable as observers of causality or of change. Thus, should they record things about the client? If so, this should be open where possible and not surreptitious. But in turn this leaves a challenge as to how to record more personal or 'private' observations, such as "is drinking heavily" or "he hit me". Thus there are as yet unresolved issues about the balance of openness regarding the client, the value of the truth, and the (possibly conflicting) rights of both parties.

#### **4. Working to Budget Envelopes and Resource Constraints**

##### ***Penny Hill***

The cost of social care is not just cash. Carers' time has its own opportunity and personal costs as well as remunerative costs – this applies to both skilled and unskilled costs, and to both professional and informal carers. Additional to time, other costs are equipment and consumables, and client environmental adaptations. At organisational level there is the necessity of a supporting infrastructure, together with training, administration and research.

Sources of funding (with the balance varying between countries), are public sector provision (both health and care), and state benefits and allowances. Societal sources include charitable organisations and employer's schemes. Personal funding by the client or family will include insurance schemes, family resources, and personal savings and income.

These funding sources should have shared objectives for the individual client, but will have individual rules. The aim is holistic, seamless services, but there are limits to potential flexibility. There are constraints on service and skills availability, limits to poolable finance, different accounting rules and restrictions, and eligibility issues and constraints around use of resources. Commissioning, contracting, orders, invoices and payments all have their complexities, and mutual differences.

Effectiveness and accountability also must be considered. The client and carers, and providing organisations, need ways to identify and assess both individual outcomes (subjective and objective), but also community outcomes including compliance with policy and alignment with public perspectives and expectations. No party can avoid considering value for money – for individuals,

from providers, and regarding public sector spending and investment. Yet consideration of these needs both cost calculation and outcome measures.

Thus the financial, and budget related, aspects of record keeping, and care planning, are significantly complicated. In addressing the challenges of recording needs and provision, the financial and value-related aspects must not be overlooked as they are key to effective delivery.

## 5. Sharing Purpose and Mission in Care

### *Sabine Koch*

Given that no person lives and is supported on their own, and that no health or care agency works in isolation, forms of sharing – of purpose and of operational activity – are essential. The issue is What to share. Clearly important items are shared care plan and prescription list; patient history, current status, risk factors; calendar of activities; and to have an asynchronous communication facility.

Why should such sharing be necessary? The core purpose must be to achieve holistic care around the individual. And to achieve this, to coordinate care activities around the individual and plan and perform them more effectively, whilst at the same time enhancing patient safety.

Who should be involved in this sharing? Firstly, professional health and social care providers, whether public or private. Secondly, clients themselves; and then the client's network namely family carers, family members, neighbours, and friends. And in many settings, insurance based funders whether public or private.

How should this sharing be done? Naturally, with the individual's consent. In a format and method which is legally correct, timely, trustworthy, and secure.

## 6. Sharing Terms, Meaning and Language

### *Penny Hill*

Terms, meaning and language may not be issues which immediately raise interest, yet they are essential if communication is to be effective, and to share the same meaning. In any setting, there is a range of languages, and of perspectives. In this domain, these include the different Professional domains of Social Care practice, Clinical terminology, Informatics jargon, and Technological language. In the Community there is the vernacular of the general public, and the domain-developed terminology of support groups and advocates.

Rightly, in many areas of care, safety is a key issue now being recognised as needing management. But language safety is seldom considered – but it is key to knowing if What is said is What is meant – and to whether that is What is understood. Across sectors, the same term can have

different meaning to different groups. ‘General’ terms cover a range of meanings or intent. Everyone needs to understand:

- When language needs to be common/consistent
- Where difference is appropriate, and what level of meaning needs to be conveyed
- How to gauge understanding and support communication
- How to ensure clarity and precision while avoiding new ‘jargon.’
- Whether language can be ‘translated’ without loss of meaning

For instance, the term ‘assessment’ is commonly used throughout health and social care, but it may reference:

- Assessment of need
- Assessment of risk
- Assessment of functionality
- The business process that supports allocation of state funding to an individual
- Investigative practice undertaken by a social worker
- The use of a standardised ‘tool’ to score against a measurement scale.

Other examples can clearly be obtained from use of clinical or social work terms. Thus for safe and effective integrated care, a simple sharing of individual sector records is not enough- it may share words, but meanings may be different and thus and interpretations wildly divergent. More thought must be given to the sharing of meanings.

## 7. Empowerment and Communication

### *Michael Rigby*

Information in the patient and client record is crucial to good care. But hand in hand with that goes the situation that information becomes power – a power too often exercised by professionals, disempowering the client and their informal carers. It is instead valuable for the client to have access to their own records, and thus be empowered. However, some record elements are technical, and for this and other reasons such as literacy levels or reduced clarity of thinking due to illness or infirmity the client may need an ‘agent’ for effective access, understanding and interpretation. The electronic era should in many ways facilitate this record access, but on the other hand there is then the risk of digital disempowerment, as it is the older and the more vulnerable members of society who will have least IT connectivity and skills.

Regarding information access, the relationship with professionals may be difficult. Professionals have a tendency to hold back information, and also to express views as well as facts. For these reasons professionals may see client access as a threat, while a full open record may create tension. On the other hand, input from the client may be invaluable. A key factor should be the fact that it is the client’s life that is under consideration.

Communication with third parties raises further challenges. Access by family members and close informal carers may be helpful and empowering; it may also be threatening if individuals have vested interests or pre-set positions, not least with regard to avoiding personal caring responsibility

or gaining access to assets. At the same time identified third parties have their own rights, not least to privacy and to data protection and accuracy. The motivation of third parties – including at times professionals – should be considered to ensure that there are no risks of impartial judgements. Finally, but usually most common, third parties may supply valuable information about the client, their needs and their progress. The overall question, therefore, is how to balance privacy, openness, and honesty of motives.

Finally, it must be fully understood that there are other legitimate and important interests involved in running effective services, which need to draw on the immediacy of client-based data. These include supervision of staff, quality assurance of services, and training. The key processes of outcome measurement, charging and budgeting, and population-level care management and planning, need to draw from accurate client-level data. It is the use of this, and its anonymisation at the earliest point possible in each process, which must be emphasised.

## 8. Attitudes to and Personal Input to Electronic Systems

### *Debbie Keeling*

There are three levels of citizen attitude to personal electronic record systems which may prevail:

**Macro level:** Whose life is it anyway?

**Role:** That's your responsibility isn't it?

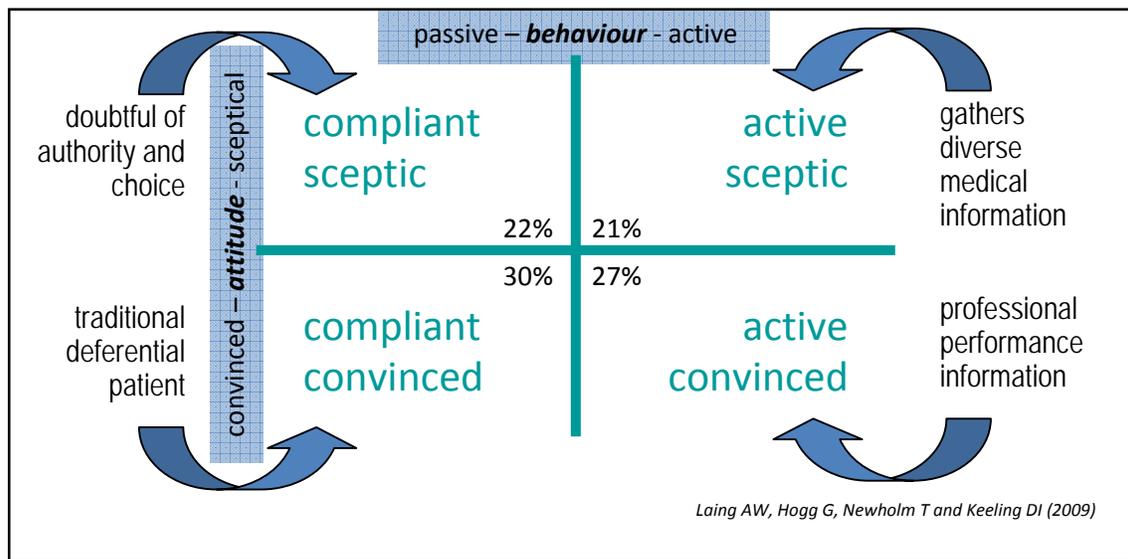
**Technical:** I don't know anything about that technical stuff!

The macro view involves a series of balances, as shown in Figure 6.

<b>Taking control</b>	<b>Accepting responsibility</b>	(see Elwyn et al. 1999)
<b>Acquiring information</b>	<b>Accepting uncertainty</b>	(see Elwyn et al. 1999)
<b>Allopathic medicine</b>	<b>Alternative therapy</b>	(see Cantillon 2004)
<b>Illness management</b>	<b>Health promotion</b>	(see Kravitz & Melnikow 2001)
<b>Abstemious health</b>	<b>Indulgent consumption</b>	(see Kravitz & Melnikow 2001)

**Figure 6. Balances in Personal Attitudes to Health Lifestyle Responsibility**

Whilst the macro view identifies the autonomous issues – those of the individual, the role view as shown in Figure 7 identifies issues of inter-relationships.



**Figure 7. Attitudes to Health Inter-relationship Responsibilities**

With regard to the third dimension – personal citizen attitudes to technology - there are a range of views, and they may or may not be related to the specific situation. Technology can variously be seen as:

- Enhancing information access, consumer knowledge, decision support;
- Having a transformational impact on social relationships; or
- A liberating mechanism to challenge the ‘establishment’

Yet the reality could be ...

- An informational ‘Wild West’ of snake-oil salesmen seeking to hoodwink
- Demanding new skills and behaviours from consumers little able to respond
- Undermining consumer autonomy and creating new dependencies.

However, whatever the attitudes to technology, even when there is acceptance by the citizen they need to be able to gain access. This requires passing through a complex pathway of opportunities and barriers, both practical and cognitive, as shown in Figure 8.

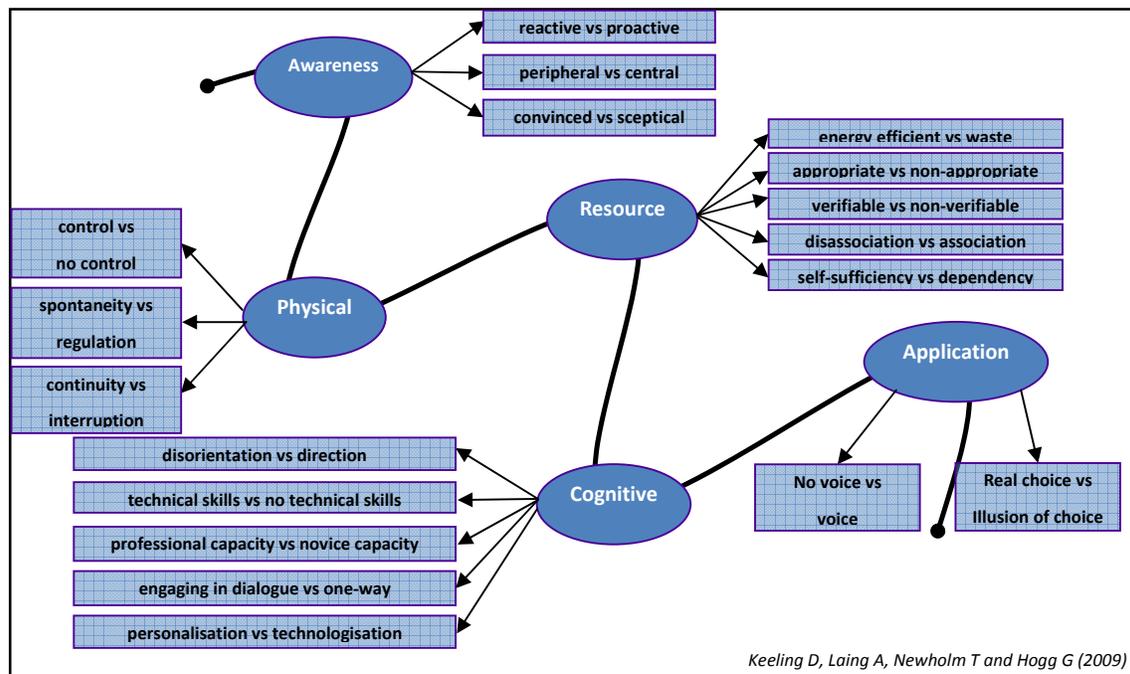


Figure 8. Pathways to Electronic Record Use

## Workshop Discussions

### Supporting the Citizen and their Carers

The Vision was seen to be:

**To offer an e-service that meets the extended needs of the individual (including carer(s)), taking into account diversity in need, ability and support, and as part of a wider health and social care toolkit, including informal e-support.**

To achieve this it was felt that there were a number of desirable actions and action points:

- At the level of the Unit of Care:
  - To conduct Feasibility studies
  - To develop Performance Indicators on impact not activity
- Aspects of the Service
  - Assess what can be learned from current practice?
  - To learn more about Integrated treatment
  - To consider Snowballing and staged or stratified approaches
- Aspects of Technology
  - To find solutions in response to the need
  - To match to the organisation of systems and associated responsibility
  - To ensure reciprocal relationship between organisation and ICT
  - To recognise and address conflicts of interest of ICT and efficiency versus quality of care.

E-services and electronic communications should not be the only channel into obtaining care support, but there should be alternatives. E-services should provide a set of tools for the consumer, but they can never completely replace the face to face services. It must be recognised that there are different types of citizen and client, and therefore that e-access as only one way of accessing services. Therefore we still need to see how we are going to identify the patients and carers in a way that is meaningful for the ultimate goal of offering a service that meets the needs of citizens and carers.

Often citizens have a specific need - a problem presentation or a risk - and in this they have an identity – they are a person with need. Then to meet that need there is a team set around them, and it is important to identify these people (informal and formal). Identification of people and achievement of the care goal are intricately linked. The risk is continuous, and it is the carers who take the 24 hour role.

Services are enhancing and the number of actors expanding, while information is the enabler. One can ask why we should differentiate in information and its access between the patient and professionals. It is important to think how can information be used for prevention, Informal support is an important element, as is peer education. It is also important to define the unit of care, focused on the client and their network.

Making a start will be difficult. Possibly identify the most at risk groups initially to build the system, working with small sets and a limited set of actors to work up the system identifying co-needs, using feasibility studies and possibly just one condition.

## **Understanding Terminology and Meaning**

Definition of Social Care was seen as: **The services that bring an individual up to a given level of social functionality.** There is then a need for terminology that defines the target levels of eligibility for care and enables the difference between target and actual to be measured. There is a need for consistency in this terminology to support transfer of care data within countries and between countries (supporting elderly choosing to retire to or to spend time in non-native locations, and enabling employment opportunities for individuals with disabilities). Common terminology is also needed to monitor and identify effectiveness of care services and practice and to compare approaches to service delivery.

The vision was of a **shared Ontology for Social Care that supports a range of core standards and terminologies and enables safe and consistent information sharing across Europe (and ultimately beyond). This should be supported by a Community of Practice that shares knowledge, innovation and good practice, enabling future learning and further development of terms and meaning.**

To achieve this, the following steps were recommended:

- Review existing work on standards and use of standards in the sector, and assess transferability of relevant standards from associated sectors (e.g. SNOMED, Classification of Interventions).
- Map current use of classifications/terminologies used in individual countries and identify commonalities.
- Explore the use of the ICF as a potential standard for profiling the functionality of individuals
- Compare commonly used social care tools (e.g. assessment tools) to map areas of potential standard development and create conceptual information models to begin informing Ontology development.

## **Who Should See and Share Records?**

If collaboration is wanted, record sharing is necessary. However, there is a prevailing attitude of “All want data but nobody wants to share”. Key issues are Trustworthiness, Purpose of use, and Access and control? Access to personal data needs to be on the basis of justifiable use.

The vision was of **policy-driven information access and sharing, shaping a system of trust where the patient is an active partner and policies are established considering all partners/interests, which would enable flexible access to all parties involved according to established policies.**

There are a number of actions necessary to achieve this, principal of which are:

- Gathering knowledge about justifiable access purpose
  - Supervision etc (indirect interest)
  - Benevolent family member
- Linking justifiable needs to authorisation
- Make people aware of responsibilities
- Policy establishment and negotiation
- Designing what information is relevant
- Minimum basic data set for social care
- Structured documentation and tagged narrative
- Education of patients and professionals

## The Potential Role and Challenges of Electronic Shared Care Records

### Record Sharing – share, view, or broker?

#### *Michael Rigby*

There are a number of different approaches to record sharing. Principal among these are:

- Common Record: Two or more agencies share a single record, for instance health and social care. This common record may have compartmentalised areas. His approach needs a higher degree of commonality, but should enable deeper collaboration.
- Record Viewing: Each agency's staff can access the other's records in read-only function. This retains the full autonomy of record holder. It needs common vocabularies and understanding, and full trust over use of information. Inter-professional communication about a client then has to be off-line in parallel.
- Broker: An electronic broker operates between autonomous provider record systems. It needs the prior establishment of a trusted community of sharing, but restricts access to specific information on a need-to-know basis, as requested by the user at the point of interrogation. The record holder determines the access rules, so still has control. A broker can operate either with a common terminology or with a built-in look up thesaurus. This approach is strong in commercial and consumer fields, such as airline booking (e.g. [www.travelocity.co.uk](http://www.travelocity.co.uk) which answers an overall journey enquiry by drilling into each airline's booking system in real time). The Canadian Health Infoway, among others, is adopting this approach.

### Privacy, Permissions, and Protection

#### *Debbie Keeling*

From the Consumer perspective it is necessary to resolve the 'Fact or Fiction?' questions:

- Is it safe to put sensitive information 'online'?
- Are data often misunderstood or distorted
- Is a paper-based system any safer?

However, these cannot be considered informedly without consideration of Access rules. Who has access? How is access controlled and qualified? Necessary preconditions for such informed consideration also include the perceived need for systems, and the level of trust in health and social care systems.

Information can of course be used for a variety of purposes. Diverse actors and systems are involved, while the consumer sometimes lacks understanding of these flows. However, it is the consumer who should give permission. There are a number of routes to disclosure, apart from

authorised disclosure for a specific action related to the data subject. Secondary use within organisation can be legitimate, while accidental disclosure within the organisation never can be. Accidental disclosure can also extend outside of the organisation.

There are recognised means of facilitating and protecting information flow. Methods include accountability (backed by audit trails), perimeter definition, role and need based access, controlled access, and restricted availability.

Consumers have specific rights, particularly to privacy by controlling who has access to personal items. Rights to confidentiality are protected not least by restrictions on the conditions under which information may be released. Security is protected by physical controls, and by gateway procedures to protect information integrity.

Overall, the issues of privacy and disclosure are a balancing act, with difficult trade-offs. Controlled access can yield functional benefits of better management and improved care, and there are cost dimensions related to finance, integration, management, user time, and user interfaces. Controlling the risk of inappropriate or malicious disclosure needs a realistic assessment of risk, which in turn raises the question of which (if any) health and social care information has intrinsic financial value.

Overall, this is both a people issue and a technology issue. The People issues must focus on ensuring that people protect confidentiality, and restrict use of data to the use intended. This requires an ethical framework, a supervisory mechanism, and a legal structure. At the same time, staff have to know and understand how to protect passwords.

## Ownership, Authorship, and Authenticity

### *Penny Hill*

In understanding the issues of ownership, it is necessary first to understand the viewpoints on this, namely whose record is it?

There are four perspectives of ownership:

- The **person** (the information is *about* them)
- The **practitioner** (evidence of their *personal practice*)
- The **agency/business** (records of *activity* and use of resources)
- The **carer** (and other third parties) who *supplied* the information

The concept of record ‘ownership’ is in order to fulfil a purpose or need, as indicated, and as there are multiple purposes this may imply multiple ‘owners’. A further consideration is as to whether shared records *co-produced* – for instance, in partnership between person and practitioner, or between agencies.

In order to consider authenticity, accuracy, and meaning it is important to understand authorship, and the reason for recording an item. Principal authors are:

- **The practitioner** – different purposes may be:
  - Their analysis or intervention on behalf of the person concerned
  - To evidence their own practice
  - To register issues or information for others working in the care team
  - As part of a business process
- **A carer**
  - Recording observations as requested by a practitioner
  - Evidencing activity (e.g. purchasing or recording delivery of a service)
  - To share concerns or their own issues
- **The individual themselves**
  - To formalise a contract
  - To inform their care team
- **An Administrator**
- **An auditor or regulator**
- **A combination of any of the above, with shared agreement to do so**

At the same time, it is necessary to validate the author's recorded information – are they who they say they are?, and Can you believe what they have entered? There are two elements to this, as provenance of information depends on two things:

- The level of confidence in the system to ensure the author's identity.
- The perceived trustworthiness of the author's accuracy

In the move towards shared records and federated systems, the first issue takes on greater significance. Authentication and security for a single system can be effectively governed by the owning agency, but a federated approaches require the establishment of trust between governing agencies, removing (or reducing) the need to re-authenticate. Thus access to and updating of records by the individual and their carers requires new approaches to Information Governance controls.

## Electronic Diaries

### *Michael Rigby*

There is a need for a patient diary approach to care delivery scheduling for a number of reasons: the need to integrate different providers and professions into a smooth and balanced regime; to fit in with patient preferences and lifestyle; and to fit in with informal carers, who have other lives and commitments.

At the same time, both the social care and health sectors are bad at using resource and workflow management techniques. However new IT solutions are emerging, not least from commerce which is much better at this.

The current paradigm with regard to patient scheduling is organisation-centric. The over-stretched organisation has a multiplicity of clients, and fits them in as best it can. In so doing the patient

focus is lost. Looked at from the patient or client perspective, they have to deal with a number of providers and professionals, all with heavy workloads of which they are only a single element, and so it is they the client who has to negotiate clashing or inconvenient appointments – the small voice of the frail or ill person competing to be heard by the big organisation or the busy professional. The balance is totally the opposite of client-centric. Yet moving toward electronic scheduling and time management would put the citizen at the centre of their care world, as the client could input preferences and choices. Electronic resource management optimally fits plans to resource availability - only the possible is promised, while failure to deliver is immediately spotted, yet at the same time the client can notify planned absences on their part. Resource use is best matched to demand, and resource scheduling and the client diary interlink.

The benefits of electronic diaries and scheduling are multiple. Everyone knows why care is being delivered, and everyone knows their role. The client and (and their family with consent) can see what is planned when. The schedule can be balanced and co-ordinated, and skills and resources can be planned.

## Workshop Discussions

A generic point to emerge from the workshop and plenary discussions was that the concept of a 'record', as a flat and static electronic equivalent of a paper record, was inappropriate and outdated. Electronic data are held in systems which are dynamic, and data for an individual may be dispersed and only brought together when a specific view is needed. Such systems work interactively, and active aspects such as prioritising, scheduling, processing to add value, and determining decisions and actions are involved. Thus 'electronic personal data storage and processing system' is a more appropriate term. However, as many actors outside the Information System world are not yet fluent with these concepts, and for brevity, the term 'record' is used in this section to refer somewhat inaccurately to such systems. The need to promulgate and move to the dynamic data system concept is important. Further, when considering the use of records, workshop members found the French term '*usager*' to be very helpful as describing those benefit from the utilisation, rather than the more simplistic and less expressive or precise term 'user'.

## Electronic Record Provision and Custodianship

Issues to be addressed include

- Who provides the record?: the care domain commissioner funder; the care provider organisation; a specialist third party agency; or the commercial Sector (GoogleCare?)?
- Who 'owns' the data?: The Client (it is their life); the Author (it is their livelihood); the Funding body (the care is their purchase); or a Provider organisation (it is their business). Anyone on this list who is not identified as an 'owner' will thus become a disenfranchised stakeholders.

- Who is the best guardian of the record?: The record holder has a duty and responsibility to hold it on behalf of all interests, but this has to be categorised, and rules set. This specialist duty of record holding should be recognised.

Maybe the best approach is to add social care to the health domain rather than building a completely new area. At the same time, to move from a fragmented records system to an integrated system – where records are just one part of that. There are likely to be different perspectives: consumer, professional, technical, and managerial.

The vision is necessarily a research vision:

- To identify the appropriate requirements of custodians based on the principles of:
  - Knowledge of ‘what is going on’ – an understanding of the information/access flow
  - Build on trust as a fundamental building block of control – including all actors
- That a system is devised that takes into account:
  - That a custodian be in a single located, within a transparent system, (synchronised)
  - The kind of custodianship: recognition of responsibilities, set within the culture knowledge management, auditor – that this is a strategic role rather than a technical only role.
  - The citizen will not be the custodian. But actors should be able to have an expanded role as they want to.
- Not all groups have so far been considered, e.g. police, housing corporation, who contribute to the well-being but also may be first to be called to a crisis.
- Trigger situations – what information can the different parties get? What are the boundaries, the rules of interaction access, and the justifiable needs for information?

The action points could be summed up as:

#### At a macro level

- What are the tensions between health and social care ownership in managing such a system?
- What are the basic principles of provision and custodianship?
- The difference between the technical vs knowledge management aspects of this topic – the need for a mediator? The French concept of ‘*notaire*’ as an impartial official with legal standing but not directly part of the judicial process (rather as in other settings some countries have designated arbitrators) is valuable and worth exploring as to how it could be developed.
- Based on the integration principle there is a need for actor boundary research - the questions are not new, but the operational definitions may be different.
- Do we need a set new rules, e.g. access, privacy etc.?
- Justifiable needs for information of those ‘outside’ of the health and social care setting, e.g. police, housing.
- Research different scenarios and different settings, to identify what is appropriate.

#### At a National level

- What are the national competencies?
- What are the cultural aspects?
- The ground level practice needs to impact on the overall strategy.

## **Electronic Record Content and Constraints**

The care record contains six types of information – Identity; Relationships; Current Needs and Circumstances; Current Services; History of care; and Financial Matters. However, as indicated earlier, other than for past history these are dynamic information sets within information systems, not static files. All these record issues need developing along the lines raised in earlier sessions and discussions.

## **Electronic Record Linkages and Exchanges**

The vision emerging from this technical discussion was congruent with that emerging from other plenary and workshop discussions, and was framed as:

**To establish a framework to provide different stakeholders/users with context-relevant knowledge based on citizen-centred health and social care information as well as coordination activities/communication**

A number of actions were identified as necessary to achieve this:

- Define the specific requirements of social care and the intersections with healthcare
- Identify the network of actors
- Identify available information and communication needs related to different scenarios of use
- Identify mechanisms and set up rules that will enable governance and follow-up according to legislation, agreed policies etc.
- Develop and map ontologies, and standards for integration
- Run proofs-of-concept
- Investigate use of automatic/intelligent knowledge based and context-relevant services

## Action Planning and Consensus

### Principles

The final session of the workshop was, by consensus, in plenary. Members felt a strong unanimity on the core principle that social care informatics was important but that the over-riding priority was integration of service delivery round the citizen in holistic and integrated mode, to be aided by electronic data recording and processing systems. Electronic data management gave new opportunities to move back to the core vision of health as being person-based and holistic, rather than provider based and specialist. The challenges were great, including the fragmentation (in most European countries) of service delivery across different types of agency and funding system, yet citizens did not have fragmented lives, and it was the most vulnerable in society who had to seek to negotiate with provider organisations and professionals.

Europe was facing an ageing of the population, coupled with an increase of survivors of chronic conditions, and rising consumerist expectations of service responsiveness and quality. Health informatics and eHealth were being widely promoted as tools to facilitate handling the issues to be faced by health services, but despite the patient-focussed emphasis on aspects of this it did nothing to address social care as an essential component of maintaining health.

Participants were unanimous in believing that modern informatics systems, developed properly on a scientific basis, could be a major beneficial technology for enabling integration of health and social care support, and thus in truly addressing the support of citizen health (rather than patient care).

Much needed to be done, and urgently, to progress this agenda. The final session of the workshop was devoted to considering action to initiate and stimulate the first moves.

### The Research Agenda

Members felt that the workshop had been valuable in addressing the research agenda. The report highlights the main areas, which are about investing in research to support and develop social care informatics, not as a stand-alone sphere, but one which can simultaneously support the assessment and delivery of social care (with its special approaches and this data needs), and equally importantly the integration of assessment and delivery with that of health care so as to produce holistic citizen support, based not on a solely medical model but addressing the integrated needs – and preferences - of the citizen according to his or her own condition, circumstances, and lifestyle values. This will require a strong research programme, but to develop this will need advocacy to develop a programme of the same standing as components of the eHealth research agenda.

### The Awareness-raising Agenda

This followed on from the previous issue. Workshop participants felt that the issues raised at this workshop were not appreciated and did not have an adequate profile. While eHealth in terms of issues such as remote medical system inter-operability had a high profile, the growing issues of supporting the health of citizens though social care integrated with health care had no profile. Yet the needs were significant, the discordance of service delivery worryingly commonplace, and the potential for beneficial impact on a large number of dependent European citizens was high. Participants felt the need for advocacy though publications and scientific papers, through

professional bodies, and by lobbying governmental and research bodies over the issues, the potential informatics solutions, and the needs for urgent and adequately funded research.

## **Locus and Ownership of Action**

Participants welcomed the fact that the European Science Foundation had shown the understanding to fund this Exploratory Workshop. It was felt that it had achieved exactly that function – it had explored the issues, identified the research needed, and reached consensus and shared commitment. Members were strongly motivated to continue the work forward, as a group, through new linkages and collaborations, though professional channels, individually as opportunities emerged, and by lobbying. It was agreed that there was strong value in maintaining a group identity, though with recognition that this should not become a ‘closed’ community. There was an openness and trust that had developed amongst members which should be protected, but selected new contacts would be welcome.

## **Outcome Statement**

There are three elements to the outcome statement.

### ESF Opportunities

Members welcomed and appreciated the funding by the ESF – this had led to major progress in a very short and intensive workshop. However, despite full scrutiny of the other ESF funding opportunities, there was a shared view that none were suitable for the immediate needs. There was too little (indeed, virtually no) national research being funded currently, and thus any form of research network was not feasible. For the same reason, there was not enough scientific data to support a conference, though this could be a strong opportunity in a few years. Therefore there did not seem to be suitable ESF opportunities to support the immediate next stages of the work necessary.

### Workshop Declaration

Participants did feel strongly that they should make a unanimous statement, recognizing the standing of an ESF event, that they were united across all their disciplines and countries, and that there was united strength of feeling on the subject and the need for a proactive research and development agenda. Such a Declaration was drafted in the last afternoon of the workshop, and is appended to this report (though also available in free-standing format).

### Action and Lobbying

Participants felt it important to make progress according to opportunity and position, harmonised as necessary but tailored to situation. Thus it was felt that the Declaration, and this Workshop Report, should be passed to relevant research, policy, professional and selected governmental bodies. Above all, as indicated below, some immediate action was instigated.

## Action Plan

The following actions were agreed amongst participants, and by individuals, by the end of the workshop:

- Individuals present who were officials of the European Federation of Medical Informatics (EFMI) agreed to take to the Board a proposal to establish a new special group on social care informatics and holistic health support within EFMI.
- Opportunities would be sought to promote the issues at the International Network of Integrated Care INIC11 conference to be held in Odense in March/April 2011.
- A special conference strand would be sought at the Medical Informatics Europe conference to be held in Oslo in August 2011.
- Members agreed to look at all research funding calls to see which could be used for this purpose, and saw fellow participants as potential collaborators. European Commission programmes in particular were to be considered. It was strongly hoped that at least one European project could be submitted which would largely feature partners from this workshop.
- Several ideas for scientific papers emerged during the workshop, and specific members agreed to collaborate on these.
- A proposal to the ESF for a supported conference would be a strong possibility in some 2-3 years, if successful work could be initiated locally and nationally, sufficient to create a strong programme.

The workshop closed with a strong sense of commitment, enthusiasm, and collegiality.



*Photo: Anon. for M Rigby*

## The Workshop Participants

**Back Row:** A Rossi Mori, G Mihalas, J Hofdijk, C Nøhr, F Mennerat

**Standing:** A Alonso, E Ammenwerth, L Buccoliero, J Mantas, P Wells, B Blobel, M Rigby, E Maeckelberghe, H Hyppönen, R Mechtler, E Rynning

**Seated:** P Doupi, V Gunnarsdottir, S Koch, D Keeling, P Hill, S Müller

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## Appendix 3 – Workshop Programme

### Wednesday 21 July 2010

Afternoon	<i>Arrival</i>
19.30	Informal reception and dinner (optional), Hawthorns Restaurant

### Thursday 22 July 2010

09.00-09.30	<b>Welcome by Convenor; Mutual Introductions</b> <b>Prof. Michael Rigby</b> (Keele University, UK)
09.30-09.50	<b>Presentation of the European Science Foundation (ESF)</b> <b>Professor Bogdan Mach, Polish Academy of Sciences, Warsaw</b> (ESF Standing Committee for Social Sciences (SCSS)) <i>(presented on his behalf)</i>
<b>09.50-11.00</b>	<b>1<sup>st</sup>. Morning Session: Scene Setting</b>
09.50-10.10	<b>Introduction to the Topic and its Challenges</b> <b>Michael Rigby</b> (Keele University, UK)
10.10-10.35	<b>Essentials of Social Care Service Delivery</b> <b>Penny Hill</b> (NHS Information Centre, Leeds, UK)
10.35-10.50	<b>Collaboration in Health and Social Care Electronic Records</b> <b>Sabine Koch</b> (Karolinska Institute, SE)
10.50-11.00	<b>Initial Questions</b> <i>Coffee / Tea Break</i>
<b>11.20-12.45</b>	<b>2<sup>nd</sup>. Morning Session: The Current Situation in Europe</b>
11.20-12.20	<b>Overview of Awareness, Issues and Progress in Participants' Countries</b> <b>Presentations and situation assessments from delegates</b>
12.20-12.45	<b>Generic Questions</b>
12.45-14.00	<i>Lunch</i>
<b>14.00-18.00</b>	<b>Afternoon Session: Identifying the Issues</b>
14.00-14.15	<b>1. Identifying the Individual: approaches to Citizen ID</b> <b>Michael Rigby</b>
14.15-14.30	<b>2. Identifying the Family and Care Network</b> <b>Penny Hill</b>
14.30-14.45	<b>3. The Privacy and Support Conundrum regarding Carers</b> <b>Michael Rigby</b>
14.45-15.00	<b>4. Working to Budget Envelopes and Resource Constraints</b> <b>Penny Hill</b>
15.00-15.15	<i>Coffee / tea break and Workshop Sign-up</i>

15.15-15.30	<b>5. Sharing Purpose and Mission in Care</b> <b>Sabine Koch</b>
15.30-15.45	<b>6. Sharing Terms, Meaning and Language</b> <b>Penny Hill</b>
15.45-16.00	<b>7. Empowerment and Communication</b> <b>Michael Rigby</b>
16.00-16.15	<b>8. Attitudes to and Personal Input to Electronic Systems</b> <b>Debbie Keeling</b>
16.15-17.15	<b>Parallel Workshops:</b> A. Supporting the Citizen and their Carers – <b>Michael Rigby</b> B. Understanding Terminology and Meaning – <b>Penny Hill</b> C. Who should See and Share Records? – <b>Sabine Koch</b>
17.15-18.00	<b>Plenary Report-back – Agreements and Issues</b>
18.00	Break
19.30	<i>Workshop Dinner, Old Library, Keele Hall</i>

## Friday 23 July 2010

<b>09.00-12.45</b>	<b>Morning Session: <i>The Potential Role and Challenges of Electronic Shared Care Records</i></b>
09.00-09.20	<b>Record Sharing – share, view, or broker?</b> <b>Michael Rigby</b>
09.20-09.40	<b>Privacy, Permissions, and Protection</b> <b>Debbie Keeling</b>
09.40-10.00	<b>Ownership, Authorship, and Authenticity</b> <b>Penny Hill</b>
10.00-10.20	<b>Electronic Diaries</b> <b>Michael Rigby</b>
10.20-10.45	<i>Coffee / Tea Break and Workshop Sign-up; Vacate Rooms</i>
10.45-11.45	<b>Parallel Workshops:</b> C. Electronic Record Provision and Custodianship – <b>Michael Rigby</b> D. Electronic Record Content and Constraints – <b>Penny Hill</b> E. Electronic Record Linkages and Exchanges – <b>Sabine Koch</b>
11.45-12.15	<b>Plenary Report-back – Rappports, Research Needs, and Remaining Issues</b>
12.15-13.15	<i>Lunch</i>

<b>13.15-14.00</b>	<b>Afternoon Session: <i>Action Planning – Parallel Discussion and Consensus Sessions</i></b> <b>Parallel Workshops:</b> Technical Issues – <b>Sabine Koch</b> Citizen Issues – <b>Debbie Keeling</b> Professional Issue - <b>Penny Hill</b> Organizational Issues – <b>Michael Rigby</b>
14.00-14.30	<b>Report Back – Headlines</b> <ul style="list-style-type: none"><li>- Principles</li><li>- The Research Agenda</li><li>- The Awareness-raising Agenda</li><li>- Locus and Ownership of Action</li></ul>
<b>14.30-16.00</b>	<b>Concluding Action Plans for follow-up Research and Collaborative Activities</b> <ul style="list-style-type: none"><li>- Outcome Statement</li><li>- Action Plan</li></ul>
16.00	<i>Tea / Coffee</i>  <i>End of Workshop and departure</i>

## Appendix 4 - Bibliography

The following were identified in advance, or by workshop participants, as a selection of relevant current publications.

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## Appendix 5 – Immediate Post-Workshop Actions

Members of the Workshop committed to following up the issues discussed, calling on all opportunities from drafting scientific papers to seeking research funding. Even within the eight week period to 30 September, Members had initiated the following actions (over and above commitment to the Declaration reproduced in the workshop report):

### **European Federation of Medical Informatics (EFMI)**

The Board of EFMI has agreed to establish a Task Group on integrating Social Care Informatics into holistic patient-based information. This will link to many other existing EFMI specialist Working Groups. This process is in hand, with three members of the Workshop identified as coordinators.

### **International Medical Informatics Association (IMIA)** (the global body)

EFMI representatives reported to the 2010 General Assembly in Cape Town their action on this issue. IMIA decided to follow suit, and would try pioneering a method of sharing, with a Global working group linked to the EFMI group. There would be a rapporteur network, and volunteer members. Further, there was the aspiration that this would lead to an IMIA/EFMI White Paper on Social Care Informatics and Personal Health.

### **Medical Informatics Europe (MIE) 2011** (the annual European Scientific Conference)

MIE 2011 will be in Oslo in August, and the theme is already published as 'User Centred Networked Health Care'. The Local Organising Committee and Scientific Programme Committee have now agreed in principle that Social Care Informatics in Health will be a strong theme within this. In particular, it is proposed that there will be:

- A Keynote on Social Care and Health
- Dedicated conference strand
- Workshops and/or field activities.

### **International Network of Integrated care Conference INIC11**

This conference will be held in Odense in March and April 2011. Papers, and a specific workshop on social care informatics arising from the ESF Exploratory Workshop, have been accepted onto the programme

### **Scientific and Conference Papers**

A number of specific issues have been identified, and clusters of authors are now developing.

**Declaration by Members of the ESF Exploratory Workshop on Social Care Informatics and Holistic Health Care, Keele University UK, July 2010**

**Social Care Informatics meets Health Care Informatics –  
a Holistic Citizen-Centric Vision for Information and  
Communication Technologies to Support Personal Health**

The Members of this European Science Foundation Exploratory Workshop, held at Keele University, Staffordshire, United Kingdom

**Recognising**

- that Health is internationally defined as a state of physical, mental and social well-being and not merely the absence of disease;
- the essential nature of the Fundamental Human Right of every citizen to the highest attainable level of personal health;
- that to reach this maximum achievable state of health many European citizens require individual support with essential functions, which can include mobility, nutrition and feeding, personal hygiene, social and mental support and assistance with tasks of daily living, together with appropriate housing and financial stability;
- that whilst in an integrated society the prime sources of this support come naturally from family and community sources, nevertheless (and increasingly) many individuals need assistance from formal sources, predominantly social care services working in harmony with health services;
- that according to individual needs this support may be needed either to cover a short-term problem or may be needed sustainably in the longer term;
- that this health-enabling support should be provided with a philosophy of meaningful empowerment of the citizen, all having equal rights and individual expectations, as well as the right to respect for private life, with its implications for individual self-determination and other aspects of privacy;
- and believing that current and emergent Information and Communication Technologies can significantly facilitate the effective and individualised delivery of such services specific to personal needs and circumstances;

**Declare** the fundamental importance of

- providing harmonised health and social care services that meet the extended needs of the individual, taking into account diversity in need, preferences, ability and support; and also recognising the concurrent resultant rights and needs of informal carers as individual citizens;
- focussing these services on the individual citizen as the beneficiary, including the pattern of delivery they find most effective;
- and to this end, utilising modern Information and Communication Technologies as enabling services, as part of a wider health and social care toolkit;
- whilst recognising the importance of e-services being an appropriate enabling mechanism, and not an inappropriate replacement for necessary inter-personal interaction;
- and also recognising that citizens may move between European Union Member States (or indeed wider) during the period of need for support.

To this end, the Members of this European Science Foundation Exploratory Workshop **call on relevant authorities** to initiate and facilitate a programme of Research and Development to include:

- Drafting a Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data, recognising the rights
  - of subject access not just to recorded historic data but also including access to dynamic data such as forward schedules;
  - to express and record their own views and preferences;
  - to record observations on their own health, functioning, and needs;
  - to decide personal directions on individualised rules for information sharing to formal and informal third parties involved in care or family support;
  - and explicitly qualified rights of defined appointed representatives and agents.
- Eliciting and defining the Range of User Needs for an ICT-enabled supporting framework, to provide different users and stakeholders with context-relevant knowledge based on citizen-centred health and social care information as well as coordination and communication.
- Defining a Community of Practice that shares knowledge, innovation and good practice, enabling future learning and further development of terms and meaning, including definitions of membership and responsibilities. This should include consideration of the different approaches of the health and the social care domains,

and the areas of overlap between aspects of community nursing and aspects of social care.

- Developing a shared Ontology and Meta-Taxonomies for Social Care linked also to Health Care that supports a range of core standards and terminologies to underpin need assessment, service planning (both short-term, and to meet lifelong needs), service provision, and the monitoring of outcomes, and that enables safe and consistent information sharing across social care, health and other sectors around the citizen. Ensuring that this ontology relates appropriately to health care ontology, meets local and national needs, and is adequately harmonised across Europe (and beyond) to support the situation when the citizen moves.
- Developing suitable robust Models of Information System Custodianship, whereby ICT systems and the data they hold and process regarding social care and its integration with health care are provided by trusted parties accountable to, and monitored by, explicit and transparent standards.
- Developing models of Rights to Data Access, recognising and defining further the clear but distinct interests of the citizen as data subject, professionals involved in assessment and care delivery, named third parties, funding and monitoring organisations, and others to be defined; and also that ‘data’ will include *inter alia* contacts, activities, encounters, assessments, requests, goals and targets, mandates, and inter-agency liaison
- Developing clear and citizen-oriented Rules for Urgent Sharing of Information, accommodating in emergencies such as a change of personal condition (health or functioning), unexpected absence from home, and enquiries from police not least in cases of unusual or extreme behaviour.
- Identifying and codifying justifiable Needs for Access to Information other than immediate care delivery, with related authorisation and monitoring mechanisms – such reasons may include service delivery, quality and outcome monitoring, staff training and development, complaint investigation, and financial audit.
- Sponsoring Research and Development of Leading Edge ICT Innovation and Appropriate Application, including (but by no means restricted to)
  - controlled forms of information brokerage, cross-viewing, or record sharing between agencies and providers, as well as by citizens and their supporters;
  - the ethical, cultural, professional, legal and practical issues related to the joint management of health and social information and communication, and in particular to the generation and maintenance of a holistic synthesis of the health and social conditions of the subject of care;

The Challenges of Developing Social Care Informatics as an Essential Part of Holistic Health Care

- technology assisted scheduling, resource management, request handling, and negotiation;
  - near real time delivery monitoring;
  - integration of user messaging into scheduling systems;
  - planning tools to enable citizens as well as formal carers to build packages of care within personal need, resource and policy constraints;
  - assessment and decision support tools that assist both citizens and professionals when profiling needs or identifying risks;
  - trusted data stores with representation of service type, providers, and availability in social and related care; new concepts of user-friendly intuitive devices utilising technologies such as touch screen and drag-and-drop; knowledge management services to help inform citizens' and carers' choices.
- Development of Education Programmes for citizens, carers, and professionals related to ICTs in Social Care and integrated health and social care support to health;

and to achieve all these goals, to **identify European Organisational Focal Points** for coordination of research, policy development, and practice support in Social Care Informatics and the integration of holistic care individualised to the citizen.

Meanwhile we **welcome**, as an important initial move, the concomitant proposal of participating officers of the European Federation for Medical Informatics to establish a Social Care Informatics and Individualised Health Working Group as one means of facilitating debate and development as a means to assisting progress.

On this 23rd. Day of July 2010

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