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 <u>Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data,</u> recognising the rights
  - o of subject access not just to recorded historic data but also including access to dynamic data such as forward schedules;
  - o to express and record their own views and preferences;
  - o to record observations on their own health, functioning, and needs;
  - o to decide personal directions on individualised rules for information sharing to formal and informal third parties involved in care or family support;
  - o and explicitly qualified rights of defined appointed representatives and agents.
- Eliciting and defining the <u>Range of User Needs</u> 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 <u>Community of Practice</u> 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 <u>Ontology and Meta-Taxonomies for Social Care linked also to Health Care</u> 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 <u>Models of Information System Custodianship</u>, 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 <u>Rights to Data Access</u>, 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 <u>Rules for Urgent Sharing of Information</u>, 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 <u>Needs for Access to Information</u> 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 <u>Research and Development of Leading Edge ICT Innovation and Appropriate Application</u>, 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;

- o technology assisted scheduling, resource management, request handling, and negotiation;
- o near real time delivery monitoring;
- o integration of user messaging into scheduling systems;
- o planning tools to enable citizens as well as formal carers to build packages of care within personal need, resource and policy constraints;
- o assessment and decision support tools that assist both citizens and professionals when profiling needs or identifying risks;
- o 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 <u>Education Programmes</u> 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

Professor Michael Rigby
Emeritus Professor of Health Information Strategy, Keele University, Keele, United Kingdom

Penny Hill
NHS Information Centre for Health and Social Care, Leeds, United Kingdom

Dr Debbie Keeling
Lecturer, Manchester Business School, Manchester, United Kingdom

Professor Sabine Koch
Director, Health Informatics Centre, Karolinska Institute, Stockholm, Sweden

Dr Albert Alonso
Fundació Clínic per a la Recerca Biomèdica, Barcelona, Spain

Professor Elske Ammenwerth
UMIT - University for Health Sciences, Hall in Tyrol, Austria

Walter Atzori
Assistant Programme Officer, European Patients' Forum, Brussels

Professor Bernd Blobel
Head, eHealth Competence Center, University of Regensburg Medical Center, Regensburg, Germany

Professor Luca Buccoliero
Department of Marketing - CSS Lab, Bocconi University, Milan, Italy

Dr Persephone Doupi
National Institute for Health and Welfare, Helsinki, Finland

Valgerdur Gunnarsdottir
Directorate of Health Policy and Health Services, Ministry of Health, Reykjavík, Iceland

Jacob Hofdijk
Vice-President, European Federation for Medical Informatics, Oegstgeest, The Netherlands

Dr Hannele Hyppönen
National Institute for Health and Welfare, Helsinki, Finland

Dr Els Maeckelberghe
Expert Center for Ethics in Care, University Medical Center Groningen, The Netherlands

Professor John Mantas
Department of Nursing, University of Athens; Athens, Greece
(President, European Federation for Medical Informatics)

Dr Reli Mechtler
Head, Department of Health System Research, University of Linz, Linz, Austria

Dr François Mennerat
Health Informatics Consultant, Rix-Trébief, France

Professor George Mihalas
Department for Medical Informatics and Biophysics, Victor Babes University of Medicine and Pharmacy, Timisoara, Romania

Sonja Müller
Empirica Gesellschaft für Kommunikations- und Technologieforschung mbH
Bonn, Germany

Professor Christian Nøhr
Department of Development and Planning, Aalborg University, Aalborg, Denmark

Dr Angelo Rossi Mori
eHealth Unit, Institute for Biomedical Technologies, Italian National Research Council
Rome, Italy

Professor Elisabeth Rynning
Department of Law, Uppsala University, Uppsala, Sweden

Professor Peter Wells CBE FRS
Distinguished Research Professor, Cardiff University, Cardiff, United Kingdom