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Interview with David Ingram, Director, CHIME

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Please Tell Us a Little Bit About Chime. What are Your Current Top 3 Research Priorities?

CHIME, situated at the Whittington Hospital Campus of the Medical School of UCL in North-Central London, is founded on the principle that close contact with real health care requirements and services must underpin its research and teaching. CHIME enjoys a strong track record in national (Department of Health) and international research (EU Framework Programme), as well as in international standards activities for the field (CEN, ISO, HL7, openEHR). Our work is also grounded in innovation and the implementation of practical information systems and services required for health care and for the education, quality and governance frameworks within which these operate.

Our current research priorities include:

+devising a sustainable personal health record architecture (MRC CLEF project) that can be implemented;

+representation and management of patients' access to knowledge on inherited genetic disorders (ApoGI and Pegasus projects within CHIME WHO Collaborating Centre in Community Genetics), and

+evaluating the evidence base of current e-health services and their organisational development (Department of Health Projects).

What is the UK Connecting for Health Programme (CfH) and What Role does Chime Play in its Development?

CfH is an agency of the Department of Health, charged with the specification, commissioning and delivery of a strategy for a health care information infrastructure for the National Health Service in England. The Programme, first called the National programme for IT (NPfIT), arose from a government White Paper published in the late nineties, entitled "Information for Health." This paper set out a strategic case that the management of a modern health service is now critically dependent on good quality information services. It concluded that harmonisation of key clinical, managerial and technical systems and standards was necessary and that this required national mandate and coordination.

CHIME, as such, is not a contracted part of the programme, although it has many working connections with different aspects of its work. CHIME is seeking to make indirect contributions, in building human expertise and communities and creating the longer term underpinning health informatics discipline required to enable any health care information infrastructure to become a rigorous and sustainable entity, fit for purpose in the rapidly changing worlds of medicine and health care, internationally.

Areas of CHIME's work relevant to and contributing indirectly into CfH are:

+its teaching programmes, such as the graduate programmes in health informatics and risk management;

+its participation in health and bioinformatics research programmes of the national Science Research Councils, the Department of Health, the EU and the national eScience programme, and

+its leadership roles in international standards (CEN, ISO) and open source software initiatives (openEHR).

To Date, What Have Been the Biggest Success of the Connecting for Health Programme?

The programme is envisioned on a very large scale and is sometimes described as the largest IT programme in the world. It has pioneered new government contracting arrangements for the procurement of major national IT systems and services. These contracts have been constructed and implemented at great speed and have been influential in Whitehall’s efforts to improve its effectiveness and achievement of value for money in the commissioning and delivery of government ITbased services, generally.

At this stage, CfHis engaged in innovation on a wide canvas, working for example withMicrosoft on defining a common clinical user interface and with BT on implementing a core electronic health record for every citizen. It is implementing a major new national broadband network and an electronic booking system, for use in clinical referrals among practitioners, to provide choice of the where, when and with whom, in selecting the investigation, treatment and care they need. On the clinical applications side, it has implemented a great deal of software and achieved some, albeit limited, operational successes, in areas such as PACS.

There are many problems, though, in sustaining legacy systems while introducing new standardised systems in many areas of care delivery across all provider organisations. For these purposes, the NHS has been divided into five national regions, each under contract from a major Local Service Provider (LSP), a large company able to take on projects on the scale of hundreds of millions of pounds and made responsible for leading a consortium to deliver the infrastructure in that area. The feasibility and willingness of large systems suppliers to align and harmonise products within a national framework of standards is being severely tested, on all sides.

Of course, CfH has multiple stakeholders and each has different perceptions and dependencies on IT. There is, in simple terms, a triangulation of clinical and health care, management and technical dimensions to the framing of the Programme. Working across these boundaries at a national level is a new territory for all the players, both within the service and in the industries and consultancies engaged in delivering the IT solutions. Amongst CfH’s more significant accomplishments has been the initiation of a major national experiment in this area, bringing to the fore, at a national level, often hitherto hidden issues about the nature of the disciplines of medicine and health care services and of how well they are represented and communicated, in terms of information. This is a complex and often chaotic and fraught process, notably, now, for the clinical and management communities - where learning a practical sense of what being a good customer who is able to use IT well, really means for them and their roles and responsibilities. As such, this is an important area of learning and culture and organisational change.

This gaining of new insight is, though, extraordinarily hard to accomplish alongside all the other daily pressures of sustaining health care. Many senior people still hope to be able to look the other way and leave the challenge to someone else. CfH is now of such national priority and focus that this is less an option, and that is progress of a kind, too! It is arguable that without a CfH-like initiative - leaving aside issues of cost – the health care information infrastructure would have continued to fester and deteriorate. But CfH is a very high-risk strategy and urgently needs balancing, now, with a more bottom-up driven, iterative process of evolution of systems, anchored on meeting local needs and developing local practical capacities.

From a Clinical Research Perspective, What Have Been the Biggest Implementation Barriers of the Connecting for Health Programme?

The barriers relate to data standards, security and confidentiality and multiple competing systems developments which lack coordination. There is a great keenness in the research community to have an interface to the national health care information infrastructure. The focus for CfH is very much upon the implementation of systems and services for health care delivery. Important though research is to the scientific evidence base and quality improvement of services, these have taken a back seat. A secondary uses service is currently under development, whereby it is expected that researchers will, within nationally determined governance, have access to operational clinical data collected by CfH.

Clearly, the provenance of this data makes it an attractive proposition for both clinical and pharmaceutical research, provided that acceptable and effective governance can be implemented and the concomitant risks of unintended disclosure and use can be managed acceptably. There are currently inadequate resources devoted to studying and building this research interface, but new initiatives such as the national Clinical Research Collaboration (CRC), which will oversee clinical trials and research within the NHS and its relationships with academic, industry and patient groups, is expected to play a leading role here.

In the Development of any Healthcare Initiative, A Primary Concern is That of Ensuring the Quality OF Information and Information Services for Patients. In What Ways is this Being Addressed the Initiatives in the UK?

There are multiple initiatives within the NHS. Through telephone and web-based services, such as NHS Direct Online, citizens can gain advice on a variety of health problems. Through the National Electronic Library for Health, which is mainly focused on professionals, there is an intention to provide and update reviewed sources of useful knowledge about health and health care. Developments in knowledge discovery services go far beyond health, of course, and getting answers to many questions asked will involve using these wider resources. There is, however, a danger in health putting too much resource into developing its domain and not enough into aligning it with wider initiatives in data curation and knowledgemanagement.

An emerging concern is that the rhetoric and the reality of government information services for citizens are too far apart, as pioneering initiatives such as Starthere, focused on bringing together information resources across the voluntary sector and all media of dissemination, have shown. A more bottom-up driven approach to information services is needed, locally contextualized and built around what people actually ask about and the problems they experience in gaining help. Different services provided by different agencies across government are often very far from joined up, in terms of cover, consistency and coherence. More worryingly, the will to partner all stakeholders, including those across the voluntary sector, to tackle these problems in a cost-effective manner, seems, too often, to lose out to self-protecting agendas of one group or another to control information tightly. Seeking progress in isolation, or on one's own terms, is neither effective nor sustainable - but vested interests are powerful.

In Developing a Health Care Information Infrastructure, What are the Biggest Areas for Potential Mistakes?

The task of creating and sustaining a health care information infrastructure is one of the class now known as wicked problems, characterised, amongst other things, by never being completely solved, and by not having clear ownership of the problem, permission to experiment or right to judge. Such problems require innovative, iterative experimental approaches because their true nature is not understood until they are tackled and, in any case, change over time.

There are not right and wrong answers to such problems and solutions to them require change in human behaviour. There are multiple stakeholder perspectives and governments are notoriously ineffective and wasteful in tackling them since, almost by definition in politics, getting such things wrong is not an option!

On the other hand, top-down coordination and resources are essential for a problem of this scale within a national service. We know that good practice can evolve from the bottom up, in well-defined and bounded practical contexts. However, it does not, typically, disseminate and generalise, in terms of interoperability and acceptable governance, from the bottom up alone.

The CfH Programme has to build an organisational culture that can combine top down with bottom up; in situ innovation with national commercial contract, and national standards with the local custom and practice needed to meet local need.

Many of the issues of the health care information infrastructure are international. Achieving international coordination, focused on implementation effectiveness and what matters to patients and not on abstract and lengthy argumentation about the vested interests of the many stakeholders in the enterprise, is both the greatest challenge and the greatest risk.

What is the Emerging Scope of the UK Health Care Information Infrastructure?

From my perspective as an interested observer, loyal to the goals of the programme, but not in any sense as a spokesman for it, I see the emerging scope to include: a life-long and evolving electronic health record for every citizen, and the capture and communication of information needed at all levels of health care and service delivery, such that it is trusted, accurate, relevant, timely, safe, accessible, securely and confidentially managed, sustainable and affordable.

Quite a challenge.

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