

Establishing and maintaining the Consumer Health Informatics Network for Scotland (CHINS)

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Abstract

The Public Health Institute of Scotland funded a Scottish-wide network of people working in consumer health informatics. Aims of the network included encouraging technology transfer and cross-sectoral synergy. An initial conference (October 2001) with participation from academia, NHS, local government, media, and industry raised issues including lack of infrastructure for the transfer of ideas. The network was subsequently expanded from 123 to 147 individuals with better representation across all sectors. Members requested information about new developments, seminars, conferences, and an on-line register of members' interests on a dedicated website. A workshop was held in April 2003 to discuss policy and funding, partnership and collaboration and the maintenance and development of the network. Many issues remained the same as in 2001, including no obvious funding for innovative development or for the transfer of successful projects into routine use. The network has enabled contacts between members, but has yet to influence national structures, policy or funding.

Introduction

Improved access to information for patients is a priority of the NHS in Scotland (NHSiS)¹. Research and development in the use of information and communication technologies to achieve this is starting to revolutionise the way health services are delivered, with computer-based consultations at home or in public locations helping to reduce travel to health centres and hospitals and providing support at a more appropriate time and place. There are many developments throughout the world which could, but as yet have not been, exploited in an integrated way to the benefit of patients and the public. There is also a danger that certain groups, such as the elderly or the poor, may become disenfranchised.

Patient education and information and health promotion activities are often dealt with separately. Health promotion is often perceived by members of the public not to be relevant to them. Personalised health promotion in which the information needs of patients and their families are used as an opening to encourage healthier lifestyles is probably more effective. Information and communication technologies offer the potential to personalise information (eg through the clinical record) but this also requires more collaboration between clinical services, public health and health promotion, and health informatics services.

The Public Health Institute of Scotland (PHIS) recognised the need to establish and manage networks of individuals and organisations working in all aspects of consumer health information (CHI) and in April 2001 funded work to set up a Scottish-wide network. The aim of the network was to; encourage technology transfer and the synergy of different developments at each centre in Scotland; develop cross-sector links and a better process of implementation and audit of research findings to benefit the public, patients and the health service; engage academics in computing science and related disciplines, local government, clinicians and other NHS staff to address the public health information needs of Scotland in their work. The overall task was to establish the network, to see the scope of CHI in Scotland; to identify the issues and problems restricting CHI and to develop a plan for the future to overcome such barriers.

Methods and results

The beginning

To realise the goal of a cross sector, Scottish wide network several methods were employed, such as organising a conference and workshop, making contacts by telephone, letter and email, and developing a website.

A conference was held in October 2001 in which those working in

CHI across Scotland and from academia, NHS, local government, media, and industry participated. The conference proceedings² provide documentation on the state of play in 2001. The main issues arising from the October 2001 conference were the lack of funding for sustained research and evaluation of CHI projects or an infrastructure in place for the effective transfer of ideas and projects. Systems developed in an academic environment were hindered in their implementation to routine practice by concerns over training staff, upgrading and maintenance of systems, funding and responsibility issues. These barriers were also encountered within institutions when attempting to adopt a system from a neighbouring department. The sheer volume and diversity of work presented at the conference highlighted areas of excellence and expertise, but also the lack of communication both between organisations and within institutions. The general consensus was a need for funding to evaluate and develop CHI. Although the debate of who had responsibility for funding the implementation was unresolved and continues still, PHIS agreed to further funding. A Network Facilitator was appointed for two years and the network was formed from delegates attending the conference.

Network maintenance

The next phase was to enlarge the network from its initial base of enthusiasts to include individuals from all sectors with an interest in the effective use of consumer health informatics across Scotland. In addition, decision-makers at various levels, eg policy makers, managers, practitioners, and researchers that were responsible for funding, research, development, and implementation of consumer health informatics in Scotland were to be identified. Recruitment to the network has been on-going. A snowball technique of requesting all CHINS members inform colleagues and potentially interested parties about the network was made and the Scottish Executive Health department, Health Boards and academic departments including Public Health, Computing, Nursing, Medical Informatics were contacted.

Problems in identifying who has responsibility for funding CHI developments

Initial investigations to locate who was responsible at a local, health board, or government level for making decisions on the implementation and funding of projects was carried out by telephone, e-mail, letter and investigating organisational websites. Identifying decision-makers was difficult. Cold contacting people who are not familiar with the terminology (especially when they realise you want them to admit some responsibility, be it in changes or clarification in policy or in the scope of their research funding or new initiatives budget) was difficult.

Consumer health informatics did not fit neatly into Government strategies, funding and initiatives. Some projects would be included within the remit of IM&T, whereas other projects had aspects that overlapped work from the Patient Focus and Public Involvement Team within the Scottish Executive. Any mention of funding for research, development and implementation resulted in being re-directed to the Chief Scientist Office (CSO) of the Scottish Executive. However, the CSO only fund evaluation and not development or implementation. Although this process resulted in new key members being asked to join the network no NHS or government body or person could be found that would take responsibility for consumer health informatics policy.

Introductory survey of network member

An e-mail survey was distributed to find out what the members from this diverse cross-sector group wanted from a network and in what form. Members requested information about new developments, seminars, conferences, an on-line register of member's research interests for collaboration and contact information of network members. A virtual network, using e-mail or the Internet was the preferred method of operating the network. Members were keen to have occasional meetings, with the assurance of different locations, to ease travel across Scotland. Members requested information to be available on a dedicated consumer health informatics network website, including a message or bulletin board, a register of current or planned projects in non-research organisations and links to policy decision makers and funding.

Website

A key task early on was to have some form of communication between members. The proposed web-space for CHINS as hosted by PHIS had limited interactivity. As a short-term solution CHINS adopted use of the JISCmail bulletin board FISHI (Focal Institute of Scottish Health Information). This system allows an individual to post a message to the group by e-mail and the message remains on the board archive. As the host restricted space for CHINS to four pages of scrolling text with links to word and PDF files the process highlighted the need for a searchable, interactive site for the network to operate effectively. This was frustrating as a database of current and planned projects was initiated and there was no facility for members to directly search or add to the database via the site. An alternative host (University of Glasgow) was sought to provide space for a new interactive site³ for the exclusive use of the CHINS network. Concurrently, a workshop was organised in conjunction with the British Computer Society Health Informatics Scotland Group to discuss a plan to move CHI forward.

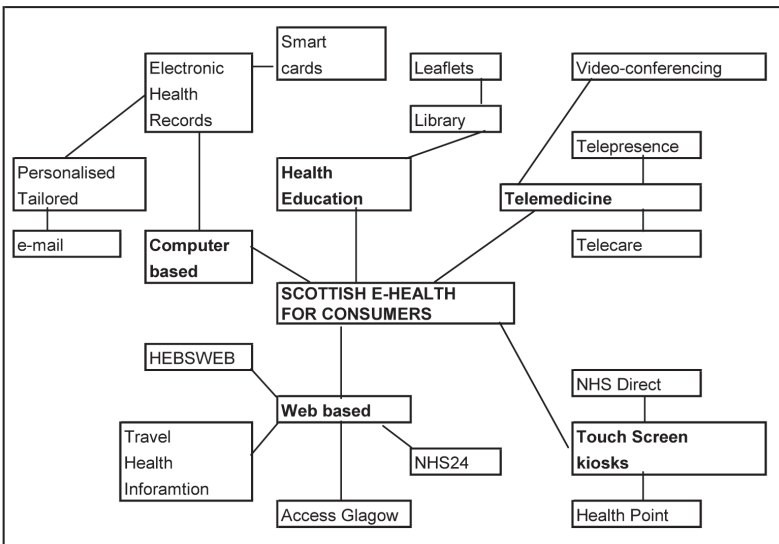
Workshop – April 2003 in Stirling

The aim of the workshop was to encourage active discussion of problems and issues raised at the October 2001 conference and to form a plan to ensure CHI in Scotland is successful. Following presentations from health board, academic and consumer representatives⁴, there was discussion on policy and funding, partnership and collaboration and of the make-up, value and future funding of the network itself.

Members

Based on the initial contact information from the October 2001 conference and results from the introductory survey a map of network member’s interests was outlined, Figure 1.

Figure 1: Map of interests reported by network members in 2002



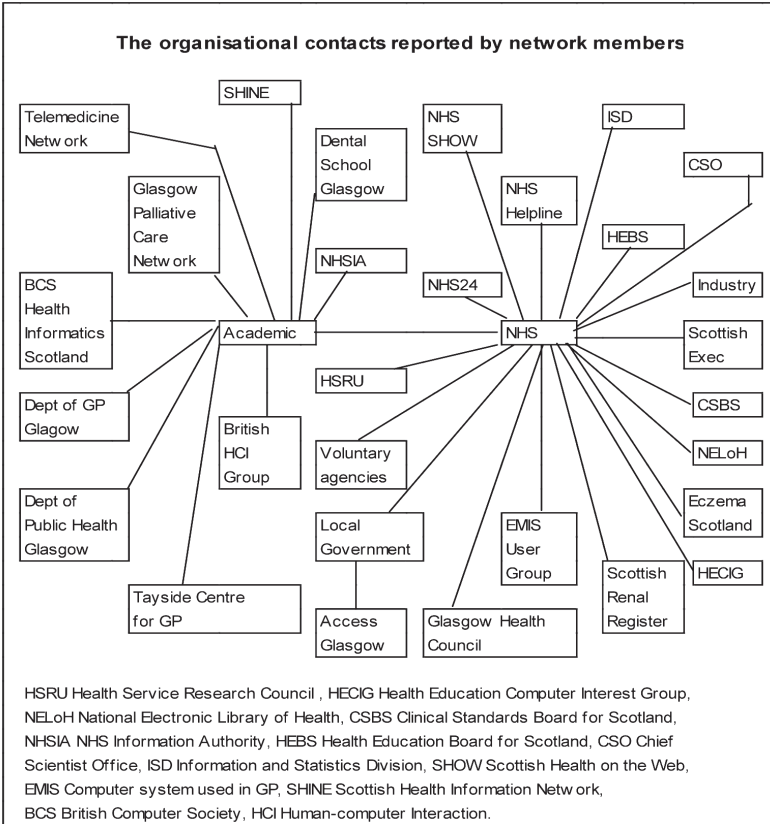
The map of consumer health interests was drawn up by allocating the reported interests into broad categories of methods such as telemedicine, computer or web based health education and touch-screen kiosks. Branching out from these categories are more specific interests.

Members sector and activity

Social network analysis is the study of the patterns of relationships among sets of people, within and between occupational groups, departments and organisations. The effect of the relationship patterns on individual member’s attitudes, behaviours and performance can be analysed. Using network analysis on a basic level we used a 2

dimensional sociogram, (this is a diagram that consists of nodes joined by lines) to display graphically the different sectors (nodes) from which members belong and of reported contact between the sectors (lines), Figure 2.

Figure 2: The reported contact between sectors by network members



The network, though rich with enthusiasts and expertise could be described as fragmented, with individuals or small groups often working in isolation. According to the reported contact the network had limited cross-sector communication, Figure 2.

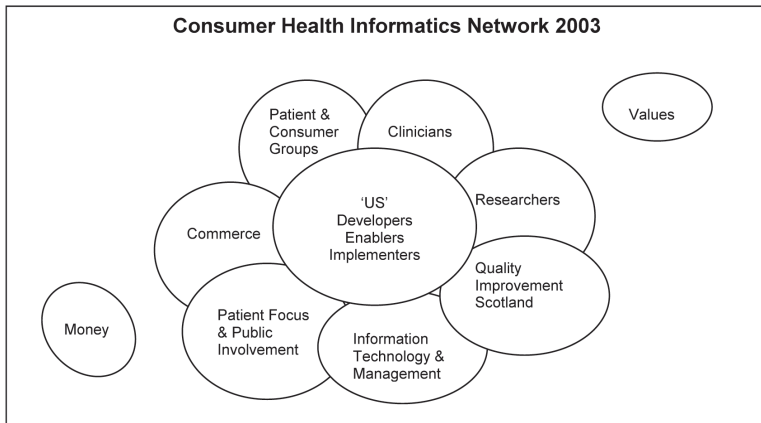
It is difficult to give a clear illustration of how members of the network use informatics within their roles as this is very specific to each individual. However, a summary of the roles within the network shows the breadth of membership within the network at all levels, Figure 3.

Figure 3: Roles within the network

Roles within CHINS	Use of informatics within role
Academics including Directors, Professors, Lecturers, Research Assistants, Research Fellows and Students	Development and evaluation of informatics systems, users, software/web developers
NHS including Directors, Consultants, Managers, Project Co-ordinators, G.P.s Data Protection Officers, Health Promotion Pharmacist, Nursing, Information and IT Managers and Librarians	Users, planning and management of informatics.
Local Government and Consumer Representatives including Patient helpline Co-ordinators and IT Managers	Users of informatics
Commercial and Industry including Managing Directors, Software/web developers and marketing representatives	Software development of packages for health promotion and education. Suppliers of chips used in cards in health information projects. Design and build interactive terminals for consumer use.

During the April 2003 workshop sectors and organisations that have an interest in the network were identified through discussion. Figure 4 was a product of the debate held at the end of the workshop.

Figure 4: Sectors and organisations with an interest in the Network



Network membership

In 2001 the network consisted of 123 individuals, made up of 49% NHS, 37% academic and 14% from commerce and other sectors. By 2003 network membership had risen to 147 with 48 new members and 24 lost, often due to changes in e-mail address, (50% NHS, 32% academic and 19% from commerce and other sectors).

Identification of issues and problems

The themes of policy, funding and the need to improve communication across sectors to enhance partnership and collaboration were raised and discussed at both meeting of the network. It was made clear that policies directing research in consumer health informatics must be backed up with funding. One problem with funding is the short-term time scales available, usually 4 years or less and this creates limitations on the planning, implementing and evaluating of CHI projects. As a result there is limited evidence-based practice using CHI. There is the added difficulty of carrying out evaluation studies when the technology base changes so quickly. This limited evidence in itself makes it difficult to put forward a case for more funding, as those giving the money want positive results ahead of time. Ironically funding for evaluation of projects is available, but there is no obvious funding for research and development of projects in the early stages or for the transfer of successful projects into routine use. The issue of whether money should come from a national or local level is open for debate. If funding decisions are taken at a local level the size and sustainability of projects may be limited. One barrier to funding projects is the need to work with more than one organisation, institution or sector; as such funding departments at a local level will be reluctant to proceed if a proposal suggests money goes outside their remit. Policy and funding at a national level remains an unknown quantity as Scottish Executive representatives vetoed the opportunity to attend and present at the April 2003 workshop.

The process of creating the network has highlighted the desire for, yet lack of sufficient collaboration and partnership on consumer health informatics projects. Currently projects operate in isolation in part due to a lack of communication and co-ordination between sectors. A major problem is that of identifying potential partners with similar interests and different expertise. Within academic circles the issue of ownership of ideas (and the pressure to publish) is a barrier to recruiting partners to new projects, for fear of ideas being stolen. Better cross-sector communication will allow those on the front-line, using health information with the public and patients, to inform researchers which problems need resolving ie, needs lead as opposed to the technophiles trying to find a use for some new concept.

As mentioned, the ambiguity of whom is responsible for funding, training staff and the maintenance or updating of systems is a problem for the implementation or transfer of projects and identifies a need for a clear framework, preferably outlined at a government level. There is a need for training for health professionals to make more effective use of health informatics and evidence of such use. Broader issues such as equity of access to information and problems of information overload, information quality and the need to tailor information are additional

barriers. Overall a greater recognition and awareness of consumer health informatics as an area of interest distinct from medical informatics, which are both subsets of health informatics is required.

The future

We are now working on widening the research agenda and producing a report with policy recommendations to benefit research, implementation, evaluation and use of CHI across Scotland. This will provide a framework of what is needed locally, nationally and internationally and identify who is responsible for what at each level. Recent merging of organisations creates a danger of CHINS being lost as no funding is in place beyond 2004 to maintain the network. However, we anticipate that the report will help to raise the profile of the network and influence health policy in the future.

Conclusion

In developing the network, a map of e-health in Scotland is starting to emerge. The major issues, barriers and problems that presently restrict the research, implementation and evaluation and use of consumer health informatics have been identified. We have a growing virtual network that enjoys peer support and access to contacts from all sectors.

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References

1. www.scotland.gov.uk/library/documents1/care-00.htm
2. www.show.scot.nhs.uk/chinconference/
3. www.gla.ac.uk:443/departments/dph/chins-index.html
4. www.gla.ac.uk:443/departments/dph/stirling.html