Co-operative Health Information Networks in Europe: Experiences from Greece and Scotland

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Abstract

Background Internet technology is transforming the general approach to communication and dissemination of information in the field of healthcare. However, it is also creating problems in terms of finding information and in knowing what credibility to place on the information found. The chaotic nature of the Web and the simplistic approach adopted by search engines can make the task of finding relevant information difficult and the user can waste considerable amounts of time in the process. Even when information is found, there is no general quality assurance process that can guarantee the credibility of the resulting information.

Objective The aim of this research was to develop an approach for establishing co-operative health information networks (CHINs) that can be used in different parts of Europe with different focuses. The resulting CHINs provide organised healthcare information and support comprehensive and integrated sets of healthcare telematic services for a broad range of users. Such developments reduce the difficulties in finding information and in knowing what credibility to ascribe to it.

Method A common approach has been developed based on drawing together contributions from the major healthcare service providers in the region. Standard structures are recommended so that information is presented in a uniform way. Appropriate mechanisms ensure adequate security and a level of quality assurance for the end-user.

Results Since 1996 CHINs have been developed in six European countries as part of an EU project. This paper presents the overall approach adopted and the achievements in two different regions of Europe (Greece and Scotland). Although the circumstances in these two regions are very different, in both cases the resulting CHIN has proved successful.

Conclusion CHINs offer a solution to the difficulty of finding relevant health information on the Internet and in guaranteeing its credibility. They can be used in different ways in different regions and have major benefits for both information providers and end-users.

Keywords: Community Health Services, Community Networks, Health Education, Health Information Network, Telemedicine, Greece, Scotland.

1. Introduction

Developments on the Internet have transformed our approach to communication and dissemination of information in a number of areas and this will continue to develop further as the dramatic growth in use of the Internet is maintained. It is particularly relevant in the area of healthcare where the way in which information is published and accessed could change radically over the next five to ten years with significant consequences for both medical practitioners and patients.

Co-operative health information networks (CHINs) represent one particular development of the technology in the area of healthcare, which holds considerable promise for the future. The CHIN project [1,2] is a European project that started in 1996 with the aim of creating organised health information networks in different European countries, which are linked together to support comprehensive and integrated sets of healthcare telematic services for a broad range of users. The countries involved are Finland, Germany, Greece, Spain (Catalonia), Sweden and UK (Scotland). Each region has different priorities and hence a different slant to the CHINs that have been developed in each case. This paper focuses on two of these regions and discusses the resulting developments.

In Greece the focus has been on establishing a CHIN to act as a resource directory for health related information in Greece and to provide health professionals with a number of telemedicine applications for remotely accessing multimedia patient records.

In Scotland the focus has been on developing a publicly accessible CHIN with comprehensive coverage of a range of healthcare services. This is matched with a protected version with more information on it, which can be accessed by healthcare professionals.

2. Methods

One of the overall aims of the CHIN project [1,2] was to develop a flexible approach to CHINs that could cater for a wide range of different requirements in different regions. In particular, an important distinction is drawn between on-line services that are intended primarily for health professionals and those that are intended primarily for public access – by patients and the general public (as well as by health professionals on occasion). In the former case an appropriate level of security is required whereas in the latter security is not an issue.

On-line services for professionals support various working scenarios between hospital staff and doctors in practices outside the hospitals, such as remote access to multimedia patient records, quality control for screening results, on-line patient referrals and resource planning. All of these require a relatively high degree of security. In addition, there are on-line services to support access to a range of information – including detailed information on local health services, professional education material, reference databases, statistical information and health data sets, etc. These require a lower level of security.

On-line services for public access include web-based regional healthcare resource directories (a presentation platform for regional healthcare service providers), on-line consultation, both patient education and public health education material, information on support groups and a wide range of information relating to healthcare services in the region.

Technically, the approaches adopted are based on standardised, open and scaleable solutions for computer and networking technologies, such as ISDN based Intranets and HTTP (Hypertext Transfer Protocol) as well as for medical applications, such as DICOM and HL7. Users access the resource directories and the patient records via a standard Web interface.

2.1. Approach in Greece

In Greece the development of a CHIN was aimed at providing healthcare-related on-line services for public access and for healthcare professionals.

On-line services for public access are provided through the development of a resource directory. Within the overall CHIN project a standard approach has been agreed for such a directory. The Greek resource directory was set up in accordance with this approach to provide a common platform for healthcare service providers to publish their content and for Internet users to search for it. In the case of Greece, the penetration of Internet use is currently very small (only 1% in July 1999 by comparison with other European Union countries where the average was 20% in July 1999); nevertheless, it is expected to grow to comparable levels in the future. Not surprisingly, the amount of Greek healthcare-related content that is published on the Internet is sparse and often limited to a few pages. An exception is MEDNET (www.mednet.gr), a project by the Athens Medical Society: however, this concentrates mainly on information for the healthcare professional. For this reason the resource directory in Greece was created to provide a focus and to motivate healthcare service providers to publish their content on the Internet in an integrated fashion.

In its current form [3], the Greek resource directory consists of the following sections:

- information on all hospitals in Greece,
- a detailed section on the National Health System (NHS),
- pilot presentation on one disease,
- a section on medicine,
- a presentation covering telemedicine activities in Greece and
- a section on the CHIN project.

All content (except for the NHS) is in both Greek and English, and the user can select the language of choice.

The information presented on hospitals includes the contact details of each hospital in Greece. In accordance with the general approach developed within the CHIN project, the lists provided contain links to the Web sites of all hospitals in Greece that have them (more than 15 in July 1999). In addition each hospital and healthcare center that does not have a Web site is provided with assistance to develop and publish its site on the CHIN server. For the information on hospitals, a Java program developed by the Scottish

group, termed CHINBuilder, was translated into Greek and used to assist in generating Web sites. One factor that has helped in achieving this is that all technical assistance and Internet costs are waived for public hospitals. During the last year four hospitals (Nikaia, KAT, Tzanneio, and Onassis Cardiochirurgical Center) used this service.

To the best of our knowledge the detailed section on the Greek NHS is the only one available on the Internet and contains extensive material on Health, Welfare and Public insurance.

A pilot presentation on diabetes was developed to demonstrate and assess the capabilities of the Web to provide health-related information to the Greek public. To this end information on diabetes was compiled and presented. A particular focus of the presentation was to provide educational material for children. Included in this are a tutorial and a comic strip, which were translated into Greek and incorporated into the presentation with due acknowledgements. It should be noted that with the exception of some presentations in the pages of MEDNET there is no similar information for patients available in Greek on the Internet.

The section on medicine provides a comprehensive list of related Web sites in Greece. For example, links are provided to the home pages of all medical departments of Greek universities. In this case, one of the initial objectives of CHIN in acting as a resource directory for legacy information sources has been realised.

The section on telemedicine provides a reference point for all telemedicine activities in Greece. As in the case of the NHS, content had to be developed due to the lack of published material on the Web about telemedicine in Greece.

In addition to these services for public access, two on-line services for professionals have been developed. The first is an application that runs on a network connecting a hospital with a healthcare center and allows the electronic exchange of medical results especially for patients with diabetes [4]. These two health institutions are connected through leased lines to ensure the security of transferred data. This network will be connected to the National Diabetes Network at a later stage (figure 1).

Insert Figure 1 about here

For the second on-line service for professionals, a Picture Archive and Communication System (PACS) and a Web-based application to access the stored images were installed in the General Hospital of Athens 'G. Genimatas'. The PACS installed was a product called DxMM and was provided by MedaSys. DxMM was installed at the Radiology department of the hospital. The architecture is illustrated in figure 2. Modalities are directly connected to Philips EasyVision, which also acts as a DICOM gateway. EasyVision is connected to DxMM and this is connected to WebMed [5], a Web-based application that allows all workstations in the hospital to access the data. WebMed was provided by GMD (Gesellschaft fur Medizinische Datenverarbeitung mbH), another partner in the CHIN project. It is noted that the hospital's network consists of fiber-optic cables between different buildings and 100 MB/sec Ethernet within buildings. The system aims to create a filmless hospital.

Insert Figure 2 about here

2.2. Approach in Scotland

The development of a CHIN for Scotland started with the idea of creating a publicly accessible CHIN that would bring together contributions from all major healthcare service providers in Scotland to create an integrated collection of material aimed at patients and the general public. At the time the thinking was that if it were successful, it would draw in an increasing number of organisations with a growing amount of material from each. As a result, it would rapidly become a local "reference library" on healthcare material, which was the obvious place for local citizens to refer to if they had an enquiry on healthcare matters. This would in turn increase the pressure on organisations to participate and to ensure that increasing amounts of information were published on it.

A major challenge of such a development is the organisation of information structure [6]. It is essential that information is structured in such a way that as the CHIN expands and increasing amounts of information become available through it, the user will still be able to find what he/she is seeking with as little effort as possible. Needless to say, the user should be able to do so without getting lost in the potentially vast sea of information that could accumulate.

The first focus of development was on hospital trusts and sought to establish agreement on the structuring of information provided by hospitals and on design guidelines that should be adopted in order to ensure consistency of presentation and a common "look and feel". Although such technical aspects are the province of IT staff within the hospitals, commitment at management level was required in order to proceed.

In parallel with this, a second focus of development was undertaken in the area of health education. This covered both public health education and patient education material. The Health Education Board for Scotland (HEBS) has been responsible for providing the general public with information on topics of general interest (such as AIDS, drugs, cancer, heart disease, etc.) as well as advice on healthy lifestyles. Initially, their developments focused on converting existing paper-based material to electronic form. For this they used a combination of static HTML (Hypertext Markup Language) pages and dynamic pages generated from databases. However, they rapidly moved on to multimedia presentations (including graphics, animations and even video) designed for the Web, which have greater appeal, especially with the younger generation. This has recently won them an award in the "Winners at the Web" competition in Scotland [7].

As the HEBS contribution has become established, other organisations have begun to provide information for patients on specific diseases (including particular types of cancer, asthma, diabetes, etc.)

A third focus of development was the area of general practice. However, here there

was much greater reluctance to participate. Initially, offers were made to general practitioners (GPs) both through local GP committees and through a GP newsletter to create individual sites for free – but this produced no response at all. Two successive versions of Web site generators were produced to enable general practitioners to create their own sites with a minimum of effort. These were based on a set of templates and a wizard application was used to lead the user through a sequence of steps to assemble and customise the templates to meet the user's requirements. However, this too met with little response. Finally, it has been agreed to generate Web entries for them by dynamic generation of Web pages from a database of the National Health Service in Scotland, containing basic administrative details of all general practices in Scotland.

In addition to these three main focuses there have been a large number of other health service providers that have added contributions, including:

(a) Professional information – this includes information on Y2K compliance and other reference material as well as direct links to databases such as the Travax database (providing up to date information on immunisations required for travel to every part of the world).

(b) Professional education – this includes a set of medical guidelines for professionals provided by Scottish Intercollegiate Guidelines Network (SIGN), laboratory handbooks for professionals, etc.

(c) Statistical data – the Information and Statistics Division (ISD) of the Common Services Agency has started to make its statistical data available through the CHIN.

The CHIN that has resulted from these developments is known as Scottish Health On the Web (SHOW) [8,9]. One of the objectives of SHOW is to maximise the benefits of individual contributors through integration. One aspect of this is to be able to move from one health service provider's contribution to that of another through the natural links in the system. This is clearly achievable through appropriate information structuring and indexing. A second aspect is that of encouraging contributors to make good use of cross-linkage between sites for the benefit of the user. A typical example is linkage between hospital or general practice sites and supporting public/patient

education material. This is a longer-term development.

Another important issue is that of quality assurance [10]. Since it is clearly impossible for any central organisation to maintain proper quality assurance of all information provided by all contributors and ensure that it remains up to date, this responsibility is left with the provider organisations to establish proper internal controls over the content. However, in order to ensure that this is taken seriously, the information providers are required to display their logo on each HTML page so that the user knows who is responsible for the information. This is achieved through a standard frame-based layout and information providers are offered support in producing this. The idea of including the logo of the providing organisation on each page acts as an incentive to the management of the organisation to ensure that proper quality assurance controls are in place. At the same time it provides an assurance to the user by clearly revealing the source of any information.

Most of the contributions are held on a small number of computers. There is tight control over these in order to maintain reasonable levels of security.

As SHOW grew, support for it was sought at higher levels, and the Management Executive of the National Health Service in Scotland (NHSiS) gave it its backing. This has resulted in its acceptance as part of the NHSiS strategy for the future and it has been mentioned in two government White Papers [11]. One consequence of this has been the development of two separate mirror sites, one public version accessible across the Internet and one version with more information on it, which can be accessed by healthcare professionals via a protected network, NHSNet.

Insert Figure 3 about here

3. Results

The Greek CHIN server is one of the largest health-related Web sites in Greece. The ultimate goal is to establish this site as the entry point for Internet users looking for health-related information in Greece. For this purpose, a number of activities have been initiated. For example, collaborations are being pursued with other health-care

related sites, such as the one developed by the Ministry of Health and Welfare. Web sites are being developed and included in the CHIN server free of charge for any Greek hospital and healthcare center that wishes to participate in this effort.

The Greek CHIN server has been recommended by a number of search engines and indexes in Greece. It is also the recommended health site by OTEnet, one of the biggest Internet Service Providers in Greece. The number of hits is growing and in June 1999 there were almost 11,000 page hits (i.e. instances when a page was downloaded). An on-line evaluation questionnaire, developed by the CHIN consortium, is being used to evaluate CHIN. This questionnaire includes sections on the site's layout and navigation as well as content's comprehensiveness and usefulness; it further asks users for comments. Although at this stage there are insufficient responses for a comprehensive evaluation, the feedback thus far has been very positive. The main request from users is for more information on specific diseases and emergency procedures. The acceptance of the CHIN is also evident from the large number of incoming e-mails from Greek hospitals asking for guidance to publish information on the Web as well as from professionals or medical students that are interested in the Greek healthcare system. Up to now, CHIN has assisted among others graduate students from Miami University (USA), a TV film producer (Sweden), postgraduate students at Exeter university (UK) and two European Union projects, namely multimedia health information for citizens (MELIC) and tele-healthcare European network (THEN). In summary, the Greek CHIN is trying to establish a service that is currently not offered by any other site is Greece, namely providing healthcare on-line information to the general public.

In terms of the on-line professional services, the initial goal was to familiarise health professionals with the new technology with a view to establishing an integrated information system in the longer term. In the latter case the objective is to establish a slide-less hospital, in which different information sources and databases containing images of patients from various modalities along with diagnostic reports would be integrated and made accessible to all departments within the hospital.

The Scottish CHIN, Scottish Health On the Web (SHOW), has as its overall goal the

creation of a virtual healthcare library for Scotland, which will become the primary reference site for healthcare information in Scotland. This will enable patients to take a more active role in their own healthcare and provide support for professionals in a variety of ways.

The current situation is that, of the 15 health boards in Scotland, all but the four smallest ones have developed or are in the process of developing sites for SHOW. Of the 47 hospital trusts in Scotland, more than half have fully operational sites integrated into SHOW or are preparing them [12]. All of the Headquarter organisations of the National Health Service in Scotland have SHOW sites that are fully operational or in preparation. In all, over 100 organisations now have fully operational SHOW sites. Yet others are still in a state of preparation.

The rate of access has grown steadily since the system first became operational and currently the hit rate is around 2 million page hits per month. Of this over 90% of the page requests come from within the UK - unfortunately, it is not feasible to separate the statistics for Scotland from those of the rest of the UK and thus we can take this no further at this stage. Assuming that this growth continues, the overall goal should soon be achieved.

As part of the CHIN project, CHINs have been developed in six regions within Europe and are in varying stages of development. They can be accessed at the following Web addresses:

- Scotland (http://www.show.scot.nhs.uk)
- Greece (http://www.nh.gr/CHIN/)
- Catalonia, Spain (http://www.chc.scs.es/chin/initial.htm)
- Brandenburg, Germany (http://www.ukrv.de/rv/str/chin)
- Umea/Norrland, Sweden (http://www.cs.umu.se/~chin/index.htm)
- Joensuu/North Karelia, Finland (http://www.pkshp.fi/english/eindex.htm)

The concept of Health Information Networks for Communities has been also addressed by a number of projects in the United States [13] and in Europe [14].

4. Discussion

In this paper, the concept of Co-operative Health Information Networks (CHINs) in Europe was presented. CHINs provide a common platform for healthcare providers to publish their content and for the general public to access it. In addition, CHINs provide a common platform for health professionals to support telemedicine applications.

The experiences from the development of CHINs in two parts of Europe, namely Scotland and Greece, were presented. The Scottish CHIN is recognised by the National Health Service in Scotland as the means by which to integrate information from most of the healthcare service providers in the region in order to provide the best service to users. The Greek CHIN started by producing content that was missing and is now trying to expand e.g. by developing free sites for all public hospitals and by introducing telemedicine applications.

Although developments in different regions may differ as they need to satisfy different needs and priorities, collaboration at a European level has been beneficial in establishing CHINs in different parts of Europe. For example, in Scotland the penetration of Internet use is much higher than in Greece and consequently there is more health-related content available on-line. This has allowed developers of the Scottish CHIN to concentrate on the integration of content; this knowledge was subsequently used by Greek developers. At the same time, the Greek site has developed content for the general public, e.g. for children with diabetes, which can be used by Scottish developers.

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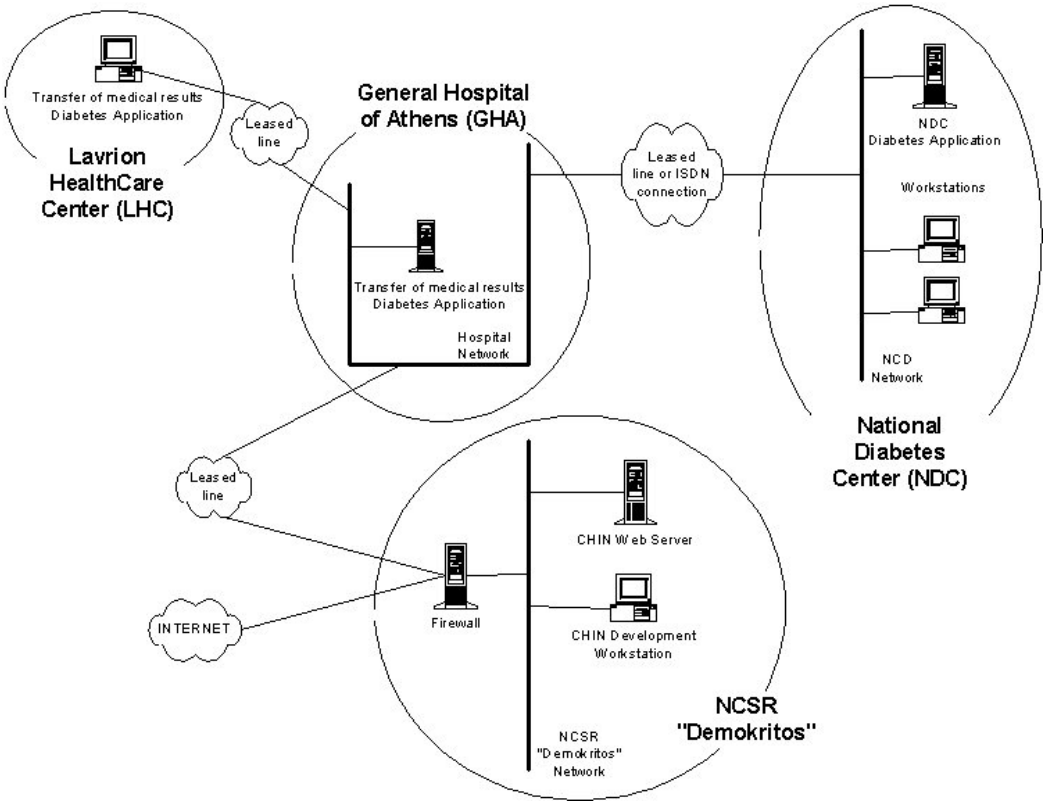
CAPTIONS FOR FIGURES

Figure 1. The diabetes application.

Figure 2. Multimedia patient record application.

Figure 3. Public and private components of Scottish Health On the Web (SHOW).


Transfer of medical results
Diabetes Application
Lavrion
HealthCare
Center (LHC)
Leased
line
General Hospital
of Athens (GHA)
Transfer of medical results
Diabetes Application
Hospital
Network
Leased
line or ISDN
connection
NDC
Diabetes Application
Workstations
NCD
Network
National
Diabetes
Center (NDC)
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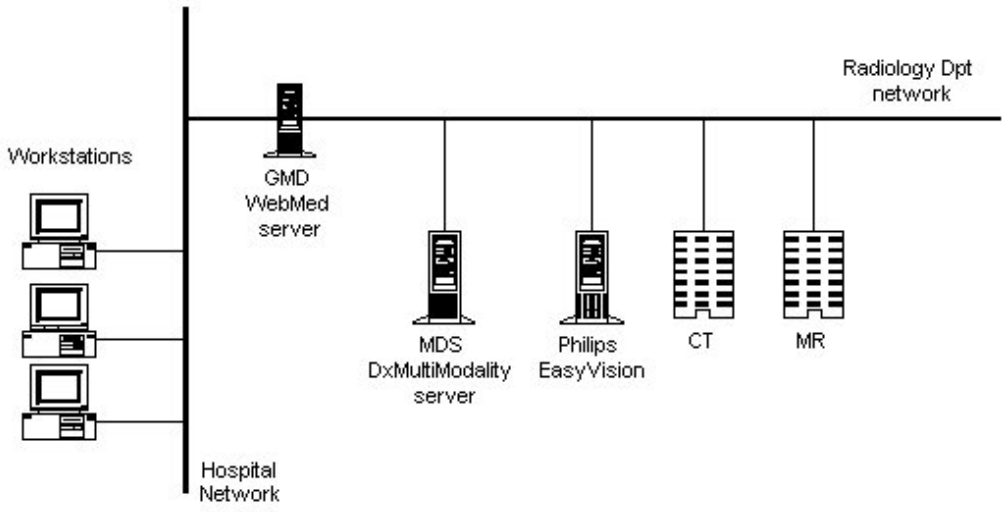
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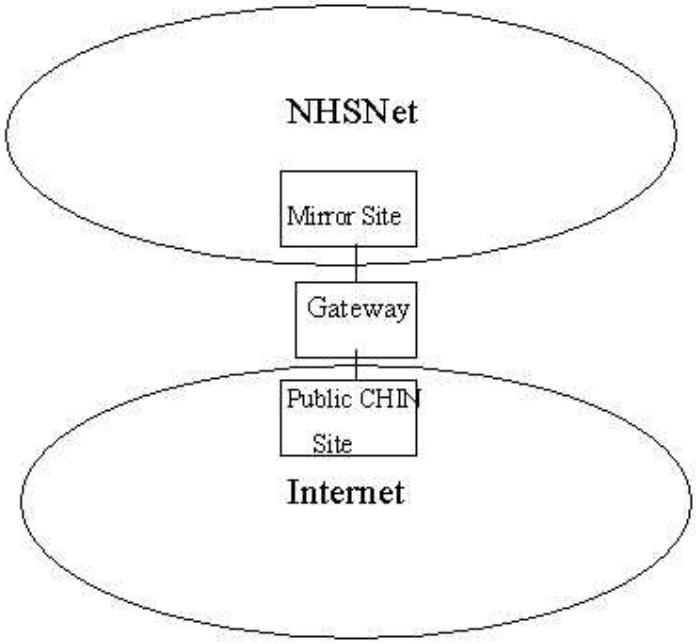
Network


NHSNet
Mirror Site
Gateway
Public CHIN
Site
Internet