References


The Cardiology Information System: the need for data standards for integration of systems for patient care, registries and guidelines for clinical practice

Introduction

The building blocks come together, finally! Already three decades ago we were dreaming of the complete Cardiology Information System. However, at that time the computer programmers explained that it was too early. In the subsequent year information technology (IT) specialists, replacing the programmers, gave similar messages. Business interests of medical equipment industries seemed not to support data exchange; however this has changed in recent years. Now, finally the pieces come together. The bricks have been laid, the blocks have been made, and the system can be built.

The dream

For patient care, teaching, research and management, information is needed about the patient, the investigations which we perform, procedures and outcome. Each view on these data (patient care, clinical research, teaching, management) has its specific requirements, although these do overlap significantly. In the past, and still in many hospitals in the year 2002, the information required for different purposes is collected independently, with much duplication of work and possible errors. Wouldn’t it be great if information collected for one purpose could be made available for all other tasks, such that additional information might be requested only when not yet available? Wouldn’t it be great if this were to apply to both administrative data (address, date of birth, etc.) but also to the history, diagnoses and procedures performed?

Cardiologists and other physicians base their patient management on knowledge obtained during their training. Since the knowledge expands rapidly continuing medical education (CME) is required and provided by many different organizations such as the European Society of Cardiology. Yet, it remains difficult to keep up-to-date with new research results as presented at congresses and published in the journals, text books, and other documents. The European Society of Cardiology, as well as other societies, offers a partial solution to this problem, through creation of guidelines for prevention, diagnosis and management of cardiovascular disease. Yet, these guidelines also become too elaborate to be remembered in detail. Wouldn’t it be great if, upon request, the appropriate guideline information, as well as background material (journals, text books) were immediately available at your desk or at the bedside when a specific patient problem is identified?

Outcome research requires specific information on large groups of patients, with different characteristics and managed with different treatment strategies. Furthermore, patient-related information may be

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required for specific national registries and for billing purposes with the diagnosis-related group system (DRG). Once more, this specific information can be collected and is often collected independent from other information systems. Again, a simplified approach may be envisaged.

Figure 1 illustrates the different sources of information and products (patient care, surveys or registries and the knowledge base) in an integrated manner. In this article we describe the different systems or building blocks, system integration, and the role of the European Society of Cardiology to promote development of data standards for information needed to achieve the required level of integration.

### Building block 1 / cardiology information systems

The information used by cardiologists for diagnosis and treatment of their patients varies from personal notes (history, physical examination), to signals (electrocardiograms), images (echocardiograms, angiograms, CT, MRI) and reports from investigations and from procedures. All this information can currently be provided in digital format (Fig. 1). For example, specific information systems have been developed for electrocardiography, Holter electrocardiography, exercise testing and electrocardiography, echocardiography, stress echocardiography, radiology, MRI and computer tomography, clinical electrophysiology, diagnostic cardiac catheterization and interventional cardiology, intensive care, coronary care and medium care monitoring. Also, systems have been developed for registration of patient-specific data as collected during interviews and physical examination\[^{1-3}\]. In the past an attempt has been made to collect all such information in a single large computer system. However, current networking technology allows a more simplified and practical approach. For each specific task, computer systems have been and will be developed by different vendors. For example, at the Thoraxcenter currently 16 different systems are in use, from 10 different providers including systems developed by local information specialists (Table 1). Through a network, information from different systems can be made available at a central viewer, when the proper connections are provided. Standards have been developed through collaboration by industries and medical/IT professionals such as DICOM and HL7. Some approaches have been restricted to the exchange of the reports of investigations and procedures, while other systems allow exchange of reports as well as a review of the original signals and images at many locations in the department of cardiology\[^{4-7}\].

We envisage that this development will continue at increasing speed. The manufacturers of specific systems for echocardiography, angiography and cardiac intervention, electrophysiology etc., will continue to develop more sophisticated systems for their specific purposes. The users (cardiologists, hospitals) will choose among vendors of different products, taking into account system specifications, options for table:

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<th>Patient care</th>
<th>Registries</th>
<th>Knowledge</th>
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Figure 1
integration and costs. The pressure coming from requests by the professionals (physicians, hospital directors, governments, insurance companies) to integrate information from different vendors in a simple system will, where still necessary, drive the manufacturers and vendors to offer integrated solutions. The European Society of Cardiology may play a role promoting further development of the necessary standards for data exchange to be implemented by the different vendors.

Building block 2 / the hospital information system

Cardiology is part of a larger hospital structure. Accordingly in the ideal world, the cardiology information system should be integrated with a full hospital information system. The latter may provide administrative information, billing services, access to the biochemistry and other laboratories, access to radiology (reports and PACS — picture archiving systems), and exchange of information with other departments. Most hospital information systems started as an administrative system, often in connection with the biochemistry laboratories. However, nowadays, a hospital information system should also be seen as a network of specific subsystems which are each tailored to specific tasks. Picture archiving systems for radiology, moving images obtained during endoscopic investigation, but also intensive care charting systems may be part of the larger hospital information system. Again, the vendors of these specific subsystems need to collaborate to allow optimal exchange of information as required. With the development of current hospital information systems, the building blocks on the left side of Figure 1 are all available, allowing access of all patient-specific information as required by the cardiologists/physician using a single viewing station.

Building block 3 / journals, textbooks, guidelines and educational material, the knowledge base

The information in current text books and journals is available from publishers in digital format. Much of this information is nowadays available on diskettes, CD-ROMs, and also on the web through libraries (Science Direct, Ideal, other providers) or through personal subscriptions. Some journals even provide part of their information on the web only, such as Circulation’s electronic pages. The information is accessible through keyword searches or other search systems at relatively low cost.

Guidelines for prevention, detection and management of cardiovascular disease are being developed through professional organizations such as the European Society of Cardiology, in collaboration with national societies and working groups. The national societies of cardiology endorse these
Building block 4 / cardiology news, selection and authority

News services, often sponsored by the pharmaceutical and device industry, but also provided by independent organizations such as the ESC, cover the major congresses, recent clinical trials etc. Some of these services are integrated in the society web pages, while others require independent registration or subscription. Apart from the services mentioned above, information on cardiovascular diseases, cardiology, cardiothoracic surgery and related topics can be found on many places on the web. Some information is objective and valuable to cardiologists and/or patients while the quality of other information may be questioned. Yet, cardiologists and the lay public do access such information regularly. Authorization of news services by the ESC, by heart foundations or other organizations seems appropriate. Indeed, a professional organization such as the European Society of Cardiology is uniquely positioned to provide the necessary quality control and authority to identify and select appropriate information for cardiologists and other physicians. Guidelines are developed through an extensive system of multiple experts and peer review; the journals are also peer reviewed. Similarly a peer review system may be set up for news services and other information as available on the web. Furthermore, the Society may help to develop medical standards and patient profiles to implement efficient search engines for cardiology information systems, for example by selecting the appropriate search topics and links.

Building block 5 / registries and surveys

Systematic registration of patient-related information is required for reimbursement, particularly when diagnosis-related groups (DRG) are used. In some European countries, more detailed information is collected systematically to assess the use of facilities and procedures (quality assurance) and/or the need for such (waiting lists).

Independently, the European Society of Cardiology has created the Euro Heart Survey programme in order to verify the application of guidelines in clinical practice, the applicability of evidence-based medicine (particularly clinical trials) and to assess the outcome of different patient management strategies. For similar reasons, registries and surveys are conducted by different national organizations throughout Europe including the ALKK in Germany (Arbeitsgemeinschaft Leitende Kardiologische Kliniken), the Swedish Registry of Coronary Care Units, and national registries in Spain, in Italy and in other countries. Most registries and surveys require specific data collection and data entry, although some are already integrated in daily medical practice. Systematic data collection for registries and surveys would be facilitated in a major way if data collected for patient care (blocks 1 and 2) could be uploaded to the registry system upon request from the responsible physician. Furthermore, for educational purposes, but also for patient-specific decisions, it would be very useful if registry/survey information might be accessible by individual cardiologists. Of course, the information must be provided in a neutral way, protecting the individual patients and hospitals.

From building blocks to an integrated system

The current information technology allows the integration of the different blocks (systems) as presented above, through local, national or international networks. It would be great indeed, if the physician could access all patient-related information, and for specific difficult patient problems could access the knowledge base related to his specific problem (what would be the appropriate course of action) as well as registry/survey/information (what do my colleagues do in practice). Similar questions could be asked for education purposes: what are the patient data, what are the recommendations and the underlying theory (knowledge base), and what is clinical practice (registries, surveys).

The different ‘building blocks’ have been developed and are ‘owned’ by different organizations. In particular, the ‘knowledge base’ is owned by publishers (books, journals), but also in part by Societies (guidelines, journals). The cardiology-related systems are owned by medical technology and information
technology suppliers, and sometimes by universities, while the registries and surveys are usually owned by professional societies or governmental organizations. The European Society of Cardiology, through its network of 35,000 cardiologists from 47 countries, and its 27 working groups, may provide the link between the different building blocks or system components. The Society can bring together the industrial developers and vendors from different backgrounds, including the medical–technical, pharmaceutical and information industry, publishers and other knowledge providers and university/hospital information technology specialists. The needs of the different groups can be identified and exchanged through the Society, while maintaining the independent position of each provider. Together the industries, health care providers and medical professional organizations can develop data standards to be collected/registered for patient care as well as the standards for access to the knowledge base and registries. Data linking may then be provided upon request, using existing technical solutions for data exchange such as XML, HL7 and DICOM. In order to develop the required collaboration among different medical and information technology industries, publishers, authorities and universities, the European Society of Cardiology has initiated preliminary discussions with these partners. The dream which some of us had 30 years ago can now be realized. Let us join forces to provide the optimal cardiology information system for cardiologists throughout Europe and abroad.

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