Structured electronic health records

Despite clearly defined political goals for electronic interaction between hospitals and national health registries, little has happened in Norway. Proposals for structured data entry in electronic health records and automatic transfer from the records to quality registries have not been followed up. In this article we describe how Ontario, Canada has succeeded in establishing a province-wide system for structured electronic cancer pathology reporting.

Since politicians, public administrative bodies and medical professions all agree on such specific objectives, what stops them from being implemented in practice? In this article we will first summarise our own experience with structured electronic health records and then describe how a project for structured electronic pathology data has been successfully undertaken in Ontario, Canada. Finally, we will discuss the reasons for the success in Ontario and what can be done to achieve the same in Norway.

In August 2013, an article in Dagens Medicin argued that primary entry of patient data in electronic health records should be made in a structured format, and that the aggregated data should be fed back to the medical profession, so that the data could be used for purposes of continuous quality improvement purposes (1). In a feature article in the subsequent issue, the director of the Cancer Registry vented her frustration regarding how clinical cancer reports are sent to the registry on paper, and not in an electronic format. This entails a duplication of effort for the doctors, who need to register the same data in the health records and in the Cancer Registry’s forms. Moreover, the director resented the fact that most pathology reports on cancer arrive in an unstructured format on paper, meaning that all coding must be done manually at the Cancer Registry. The effect of this is that the data from the Cancer Registry are more than 18 months old at the time of their publication (2).

This issue is not of recent origin, and it has been discussed in a number of government reports (3–5). On assignment from the Ministry of Health and Care Services in 2005, the then Directorate of Health and Social Affairs conducted a major study of national medical quality registries. Among its recommendations, the study proposed that all registration of information intended for national medical quality registries should be undertaken as an integral part of local medical treatment processes, that the primary registration should be done in a structured format in the electronic health records, and that the transfer from the health record systems to the quality registries should be done in a standard electronic exchange format (6).

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In the period 2003–06, the Norwegian Society of Pathology collaborated with the Norwegian Cancer Registry on establishing structured electronic histopathology reporting of colorectal cancer. The project was initiated on the basis of a start-up grant provided by the then Norwegian Directorate of Health and Social Affairs to encourage use of the Norwegian Health Network. The electronic template that was developed was subsequently implemented in the two pathology systems used by all departments of pathology in Norway at the time (7). The project was halted, since the grant from the directorate was for one year only.

A nationwide study undertaken in the autumn of 2007 showed that use of the structured electronic template resulted in better reporting of pathology findings than traditional free-text reporting, but that the use of the template varied significantly from one pathology department to another (8). The departments of pathology at Akershus, Haukeland and Stavanger University Hospitals are some of those that have used the template for routine reporting. Data from these departments show that the template has been used for more than 90% of all cancer reports during the 4–5 years when such use has been registered (9, our own unpublished data).

In 2012, four departments of pathology and the Norwegian Cancer Registry took a new initiative for development of structured electronic pathology reporting (10). As part of this study, two of the authors visited Cancer Care Ontario in Canada. This is the organisation that coordinated a successful implementation of structured electronic pathology reporting in the province of Ontario (11).

Structured pathology reporting in Ontario, Canada

Ontario is one of Canada’s ten provinces and has 13.5 million inhabitants. Its health services are mainly public. The Ministry of Health and Long Term Care fills approximately the same administrative role as the Norwegian Ministry of Health and Care Services. Cancer Care Ontario is a subordinate agency, which since 2004 has been responsible for general planning and follow-up of the cancer care in the province. The provincial cancer registry is part of the agency. Ontario’s multi-year cancer plans are prepared by Cancer Care Ontario in a formal collaboration with the province’s 14 health regions. Management by well-defined objectives and systematic quality improvement of the province’s cancer care services have served as key principles for the agency’s modus operandi (12).

The province’s cancer plan for the period 2005–08 explicitly described structured electronic pathology reporting as one of its objectives (13), and a dedicated programme was in operation until 2012. During the years 2005–08, background data were collected, contacts with pathology departments were established, infrastructure was put in place and pilot projects were implemented. During the period 2008–12, structured electronic reporting was systematically implemented in all of the more than 50 pathology departments in the province. During phase 1 (2008–10), the target was that > 90% of all pathology reports for the five most common forms of cancer should be reported in this way, and during phase 2 (2010–12), the target was that > 90% of all pathology cancer reports should be reported with the aid of structured electronic templates (14). Data from the Ontario Cancer Registry are now available no more than 30 days after the date of reporting.
The project in Ontario has been so successful (15, 16) that a pan-Canadian initiative for electronic pathology reporting of cancer was launched in 2012 (17).

**Ontario’s success**
We believe that this success is attributable to a combination of various circumstances. The formulation of overall goals was undertaken jointly by Cancer Care Ontario and the health regions, and the decision was thus well embedded in the organisation «top-down». Furthermore, the project was ensured long-term funding from the Ministry of Health and Long Term Care. In our experience, several health-related information technology projects in Norway have been based on somewhat unstable grants allocated for one year at a time. This is inappropriate if general political goals at a high level of ambition are to be realised. Cancer Care Ontario coordinated the work throughout the entire period and had formalised agreements with all other key organisations. A project organisation was thereby established in which each organisation knew its role and was given defined areas of responsibility (Figure 1).

The quality-oriented mind-set that lies at the heart of Cancer Care Ontario’s work (12) implies that overall goals are translated into clear-cut objectives at an early stage of the planning process. Who will do what how and when, how will results be evaluated and what will be done if discrepancies are discovered? In this project, it was decided at an early stage that the pathologists («who») will report pre-defined variables («what») with the aid of electronic templates implemented in the hospitals’ ICT systems («how») in ongoing routine diagnostic work («when»). These data are transferred automatically in a standardised manner to the province’s cancer registry, which then sends reports on achievement of pre-defined targets («evaluation») back to the departments. Significant discrepancies may entail financial consequences for the health region involved.

Thus, all reporting to the province’s cancer registry happens exactly as recommended by the working group appointed by the Directorate of Health in 2005 (6).

**What can Norway learn from Canada?**
In Norway, the Ministry of Health and Care Services governs the regional health authorities and the Directorate of Health through annual assignment documents. However, there is no requirement for establishment of forums for joint preparation, implementation and evaluation of action plans. Thus, the Directorate of Health issues national professional guidelines, but these contain no specific information on how the hospitals should implement them in their daily operations or how compliance with them should be evaluated.

In November 2013, the Office of the Auditor General published an investigation of effectiveness and goal achievement in the Directorate of Health. The report pointed out that the Directorate fails to undertake sufficiently systematic efforts to implement its own guidelines and manuals, and that this reduces the normative effect these are intended to exert on practice in the health and care sector (18). In the Ministry of Health and Care Services’ national cancer strategy for 2013–2017, specific objectives for how national action plans should be implemented and their effects estimated are absent (19). In our opinion, the Ministry’s national cancer strategy ought to state that:

- The Directorate of Health and the regional health authorities should jointly prepare national professional guidelines that are relevant for the ongoing treatment of patients.
• The guidelines should be adapted to structured primary data entry in electronic health records.
• The regional health authorities are responsible for implementing national professional guidelines in their daily activities.
• The Directorate of Health and the regional health authorities have a shared responsibility for continuous evaluation of the application of national professional guidelines through the use of national quality registries linked to the Cancer Registry of Norway.

In our opinion, the example from Ontario, Canada, provides an excellent model for how this can be done.

The medical profession in Ontario (Ontario Association of Pathologists) had defined the pathology variables to be reported, and these had been accepted by Cancer Care Ontario. Thus, this decision was a consensual «bottom-up» decision. However, the medical profession had also undertaken another, quite unusual assessment. They had assessed the use of resources associated with the preparation and maintenance of the province’s quality indicators for histopathology cancer reporting. In the association’s opinion, it would be more appropriate to use equivalent indicators prepared by the College of American Pathologists. A professional collaboration was therefore launched to develop such indicators jointly. Cancer Care Ontario is granted free access to the electronic templates developed by the College of American Pathologists on an ongoing basis (20).

In Norway, the Norwegian Society of Pathology intermittently prepares professional guidelines (21). In parallel to this, the Directorate of Health produces similar national professional guidelines (22). These are not necessarily identical, and none of them are as specific and detailed as the electronic checklists produced by the College of American Pathologists.

Summary
In order to succeed in realising general health-policy goals for cancer care, they must be formulated as specific and realistic objectives. An administrative organ must be provided with the authority and funding needed to establish the technical solutions required. Reporting to national registries must take place automatically in electronic form, on the basis of ongoing structured reporting in the patient records.

In our opinion the Directorate of Health should enter into cooperation with the College of American Pathologists, with a view to integrating a Norwegian version of their electronic checklists for pathology reporting of cancer into the hospitals’ record systems.

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