Paediatric Respiratory Reviews 20S (2016) 8–11

Contents lists available at ScienceDirect

Paediatric Respiratory Reviews

Review

Electronic patient records, past, present and future

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ARTICLE INFO

Keywords:
Cystic Fibrosis
Electronic Patient Record
Online Access

SUMMARY

The health informatics revolution was spear-headed in the 1980s by pioneers in primary care who worked in an opportune environment and were able to successfully implement electronic patient records (EPR) as far back as the 1990s. Although the ambitious and costly National Programme for IT failed to deliver an integrated EPR, the project achieved the creation of the Spine, the N3 Network, choose and book, picture archiving, communication systems and standards which have allowed integration. Real change is taking place within the NHS with the launch of exciting new projects focusing on true integration and secure data flows across primary, community and secondary care. These changes have been brought about by the realisation that linking "best in class" is more likely to secure a successful cost-effective national integrated EPR.

INTRODUCTION

Although computing in the form of devices such as the abacus that speed up arithmetic calculation have a long history extending back over two millennia, it is only in the last three decades that powerful digital technologies have become widely available and are now ubiquitous in modern life. With the introduction of the internet, cloud virtualisation and improved processing speed and power, the technology is now available to support an "electronic NHS" with fully integrated care records. Health provision is multifaceted and unlike many other industries such as food retailing and banking, it has proved difficult to fully exploit the potential of contemporary computing technologies in the NHS. However this is changing and there is a new impetus to integrate digital technologies acknowledging that a "one thing does not fit all" approach is key to the delivery of a more efficient, safer and user-friendly NHS. This short review explores the past, present and future development of electronic patient records in the UK and explores how some of these advances are impacting on the Electronic Paper Records (EPR) system in the Leeds Cystic fibrosis Unit[1].

THE PRIMARY CARE REVOLUTION

The health informatics revolution was spear-headed in the 1980s by pioneers in primary care who worked in an opportune environment and who were early to recognise the potential benefits of EPR within the health service. The advantages that GPs had over secondary care included the fact that they were independent contractors, worked in a relatively closed environment and had direct access to the long established Lloyd George envelopes[2]. These key documents had been in existence since the first world war and not only held the basic health record but also followed the patient if or when they moved practice[2]. By the 1990's the majority of GP practices had installed digital clinical records which have since evolved into high quality EPRs. Despite early incentives and investments in primary care, the opportunity of developing true interoperability between best in class systems both within primary, community and secondary care was missed.

THE NATIONAL PROGRAM

The introduction in 1990s of the NHS number, shared NHS administrative registers and an information network established a national user identifier and an early infrastructure for data sharing[3]. This was followed by the ambitious National Programme for IT (NPFIT), which cost over £10 billion and failed to deliver a national integrated electronic patient record [4–6]. The failure of this high cost scheme highlights the pitfalls of over ambitious top-down projects that are broad in scope, lack rigorous methodology, are deficient in practicality and fail to ensure user engagement. Lessons should have been learnt since an estimated 60-80% of healthcare IT projects had already resulted in failure[3,7]. Despite the negativity associated with IT failure, important successes were achieved. These include the creation of

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http://dx.doi.org/10.1016/j.prrv.2016.06.005
1526-0542/

the Spine, a secure N3 Network, the introduction of "choose and book" and a picture archiving and communication systems (PACS). While it is highly unlikely that the government's ambition of making the NHS paperless by 2018 will be achieved, some of the legacies from NPFIT will have long-term influences on future developments.

SECONDARY CARE

Secondary care has long been plagued by a severe lack of resources, under investment in IT infrastructures and the inherent complexity of having to connect a large number of legacy systems which are often incompatible. Early investment has tended towards administration systems (PAS) which have been central to secondary care infrastructure. Unfortunately the NPFIT inadvertently delayed many in-house developments and stopped secondary care from procuring commercial software. Despite this some hospitals have successfully introduced EPR with variable functionality and real change is taking place within the NHS with the launch of exciting new projects focusing on true integration and secure data flows across primary, community and secondary care. These changes have been brought about by the realisation that linking "best in class" is more likely to secure a successful cost-effective national integrated electronic patient record. However there is still a long way to go.

THE BENEFITS

The successful introduction of user-friendly and efficient EPR has the potential to deliver significant benefits. Examples include fast, reliable access to patient data for health care professionals, performance and resource data, automation of routine processes, improved accuracy of data, standardisation of codes, patient access, automated registry data completion, bidirectional integration with patient data, data mapping, research and improved safety. These long-term benefits will only be achieved if there is user "buy in" and appropriate integration with key hospital systems such as the patient administration systems and order communications. Full integration is some way off but the benefit of the functionality of specialist systems should always be assessed as conformity to common standard processes within any institution can significantly impact on efficiency and quality of data. Seamless integration with mobile technology will also be important as it will form an increasing part of the professional's interaction with EPR.

DATA LANGUAGE

Many EPR are electronic versions of the paper records with facilities for digital dictation and links to secondary systems such as e-prescribing, clinic lists and electronic order communications. This type of system can be efficient but is unlikely to herald a new era of data integration. While natural language processing and data mining techniques can be used to extract codes, they can struggle to extract data context and the accuracy of the original text terms may be ill defined and not always as accurate as they could be. This is in contrast with many primary care systems which use a more integrated approach where data is often inputted through coded templates and where the health care professional can choose and/or change the various diagnoses. Only a fraction of this functionality is presently being used in primary care but the tools for high quality data input are available. In a recent study from Leeds, we assessed the quality of diagnoses in more than 100 consecutive discharge summaries from the respiratory wards. We found that the primary and other diagnoses extracted from the discharge summary and notes were often inaccurate or absent. By not coding and linking all data within a record, a standard language is not created capable of delivering standardised communication between teams and networks as well as support to administration, high quality audit and research. The use of coded information allows data to be recorded in a consistent and transferrable way. This process will be helped by the move towards a common coding language, namely the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) which will become the standard clinical terminology for the NHS in England.

PATIENT ACCESS IN PRIMARY CARE

The majority of GP practices now offer online appointment booking and the ordering of repeat prescriptions. From April 2015, patients have been able to access their primary care summary information online[8,9]. Benefits to patients has been reported including increased control over their own health, greater understanding and improved adherence to both care plans and medications[9–11]. In contrast access to health information can cause anxiety over security and privacy and can make patients feel less optimistic [10]. Additional potential benefits include improved patient and MDT relationships, more empowered and satisfied patients, time saving, transparency, shared decisions, positive behavioural change and opportunities for education[9,10,12–14]. In some studies, online access has results in increase workload and usage of clinical services [9,15,16].

Over 40 million patients now have their data for demographics, current medications, adverse reactions and allergies held in the national summary care record which is a copy of information from the GP record. Individuals can opt out from sharing their primary care record with the national summary care record.

THE PERSONAL HEALTH RECORD

The explosion in mobile devices, improved internet connectivity and the wide array of user-friendly applications has heralded a new era of personal health records. Third party devices, health tracking apps and the mobile phones can automatically collect health-related data, including physiological measurements which can be integrated and displayed in third party platforms or free applications such as Google Fit and Apple Health. This "big data" has significant commercial value and can be linked to lifestyle metrics, service planning, patient-based research (eg Apple Research Kit) and importantly the EPR[17]. While many companies are investing heavily in new products and functionality, optimization for secondary care will only occur if platforms are able to integrate with future EPRs. Similarly collaboration across mobile platforms would be hugely advantageous.

THE LEEDS CYSTIC FIBROSIS EPR

We have previously described the successful implementation of the EPR in the Leeds adult and paediatric CF Units [1,18]. The move away from handwritten and typed paper records has been very successful and delivered cost savings, improved efficiency, high quality audit, research and positive user and patient feedback. The key components which led to the success of this project included fully configurable interface, user buy-in, continued clinical development and leadership. The system uses an intelligent graphical interface that tailors the way information is presented to both clinicians and patients. Over 600 codes have now been embedded in templates allowing all physiological, clinical, medication and pathology data to be collected in real time [1]. Patients can view and obtain graphical feedback at each clinic visit including trends in parameters such as lung function, weight and inflammatory markers. This visual data has provided invaluable feedback with