

# Challenges for learning health systems in the NHS. Case study: electronic health records in cardiology

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ABSTRACT

Electronic health records (EHRs) are at the centre of advances in health informatics, but also many other innovations in healthcare. However, there are still obstacles to implementation and realisation of the full potential of EHRs as there are with learning health systems (LHS). Cardiovascular disease, in the UK and globally, carries greater morbidity and mortality than any other disease. Therefore, planning and delivery of health services represent major costs to individuals and populations. Both the scale of disease burden and the growing role of technology in cardiology practice make analysis of experiences with EHRs in cardiology a useful lens through which to view achievements and gaps to date. In this article regarding LHS, EHRs in cardiology are used as a case study of LHS in the NHS.

**KEYWORDS:** Cardiology, digital, electronic health record and informatics

## Introduction

Electronic health records (EHRs) are variably defined and variably implemented both within and across countries. The term EHR encompasses a wide range of information systems, from 'files compiled in single departments to longitudinal collections of patient data'.<sup>1</sup> EHRs include data from the routine care of patients, administrative data, registries and possibly clinical research databases.<sup>2</sup> The National Programme for IT (NPFIT) was the first national attempt to implement EHRs across all hospital trusts and failed because of a combination of political, cultural and design issues.<sup>3–5</sup> There is a renewed enthusiasm for digital health, including EHRs, in the 2016 NHS policy.<sup>6</sup> However, there is currently a contrast between the promise and the reality with multiple providers, multiple methods and poor interoperability across different domains, with no system-wide solution on the horizon.<sup>6</sup> In primary care, there has been higher penetration of EHRs, starting in the 1990s, with better interoperability and use of data to drive quality improvement.<sup>7</sup>

The tide may be turning for hospital IT as the need for connection between primary and secondary care grows. The

effects of the large-scale cyber-attack by ransomware on the NHS in 2017 show that modern medicine cannot be practised without informatics.<sup>8</sup>

Several large-scale programmes are underway in the wake of the Wachter review,<sup>6</sup> including the development of an active chief clinical informatics officer network to exchange learning and experiences, the Digital Academy to train aspiring informatics leaders in the NHS,<sup>9</sup> the creation of the Faculty of Clinical Informatics<sup>10</sup> and the Federation of Informatics Professionals,<sup>3</sup> and the Global Digital Exemplar scheme.<sup>11</sup> Health Data Research UK will be established to capitalise on the progress of the Farr Institutes of Health Informatics Research and take forward healthcare data science in the UK.<sup>12</sup> 'Learning health system' was coined as a term to capture the need for information to flow freely between science (researchers), evidence (guideline- and policymakers) and care (health professionals) to reduce waste and increase patient safety.<sup>13</sup> In order for the EHR to fulfil its potential and transform both clinical practice and research in a learning health system (LHS), five challenges need to be overcome:

- 1 the gap between research and service
- 2 the gap between quality improvement/audit and research
- 3 lack of capacity and expertise in informatics among clinicians/non-clinicians
- 4 the trust of patients and public
- 5 the trust of clinicians in big data analytics and EHR.<sup>13</sup>

Cardiovascular disease (CVD) has enormous impact nationally and globally in terms of disease burden.<sup>14</sup> Historically and perhaps also because of this scale of disease, the specialty of cardiology has been at the forefront of both development and early adoption of innovation and technology in research and practice,<sup>15</sup> whether intracoronary interventions to prevent myocardial infarction or clinical trials of new drug therapies, spanning screening, prevention, diagnosis and treatment decisions. The same trends have applied to implementation and use of informatics in cardiology. In this article, I use examples from EHRs in cardiology to illustrate successes and failures with respect to the five challenges for LHS.

## Research and service

Cardiovascular research is on the increase globally and much of the leading clinical research originates from the UK or involves UK collaborators.<sup>16</sup> Moreover, much of the research has exploited the population-wide reach of the NHS and EHRs.

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In primary care, there are multiple resources, including both research (eg Clinical Practice Research Datalink<sup>17</sup> and The Health Improvement Network<sup>18</sup>) and clinical databases (eg Quality Outcomes Framework (QOF)<sup>19</sup>). In hospitals, there are also administrative or routine care datasets (eg hospital episode statistics<sup>20</sup>) as well as research or registry-based data (eg National Institute of Cardiovascular Outcomes Research (NICOR) audits<sup>21</sup>). These and other EHR data have been extensively and intensively used in research, planning of health services and developing the evidence base of cardiovascular medicine. As genomic research advances and the use of genomic information in clinical practice increases, this -omic data will be incorporated into routine EHRs.<sup>22–24</sup> Box 1 summarises the key areas where EHR research can drive forward CVD research and care in the UK.<sup>17,20,25–40</sup>

### Box 1. Potential uses of electronic health records in cardiology research and clinical practice throughout the patient journey

#### Aetiology

- > Disease-specific, eg risk factors for development of AF<sup>25</sup>
- > Across diseases, eg alcohol consumption and CVDs<sup>26</sup>

#### Diagnosis

- > Studying variations in definition, eg aortic dissection during pregnancy<sup>20</sup>
- > Development of diagnostic tools, eg familial hypercholesterolaemia<sup>27</sup>

#### Screening

- > CVD, eg AF<sup>28</sup>
- > CVD in non-cardiovascular disease, eg late CVD in cancer survivors<sup>29</sup>

#### Public health

- > Incidence and prevalence, eg AF<sup>30</sup>
- > Trends in management, eg prescription of novel anticoagulants in AF<sup>31</sup>
- > Resource utilisation, eg cost of AF<sup>32</sup> or HF<sup>33</sup> management
- > International comparisons, eg NSTEMI management<sup>33</sup>
- > Risk of CVD with non-cardiovascular diseases and drugs, eg CVD events with clarithromycin<sup>34</sup>

#### Prognosis

- > Outcomes, eg HF<sup>35</sup>
- > Derivation and validation of risk prediction tools, eg QRISK2<sup>17</sup> and 10-year risk of HF<sup>36</sup>

#### Intervention

- > Comparative effectiveness, eg statins in different chronic diseases<sup>37</sup>
- > Cost effectiveness, eg evolocumab<sup>38</sup>
- > Trials, eg automated software to improve anticoagulation uptake in AF<sup>39</sup>
- > Clinical decision support, eg dual antiplatelet therapy<sup>40</sup>

AF = atrial fibrillation; CVD = cardiovascular disease; HF = heart failure; NSTEMI = non-ST-segment elevation myocardial infarction

The potential value of EHRs for cardiovascular research is not in question. However, currently research and routine clinical care are largely parallel activities. Rather than using data from real-time EHRs, use of retrospective administrative data and linked datasets is the norm. For example, the CALIBER database has been constructed to link retrospective data from primary care (Clinical Practice Research Datalink), Office of National Statistics, national registries (eg Myocardial Infarction National Audit Project) and hospital episode statistics.<sup>41</sup> There are relatively few examples of research occurring as care is being delivered, using an integrated EHR. There are multiple contributory factors, including data security, ethics, infrastructure and culture. Clinical trials, whether in terms of recruitment, outcome ascertainment or follow-up, would be made far more efficient with greater integration of EHRs.<sup>42</sup> Until the alignment of research and care happens, it is difficult to envisage a true LHS and there will continue to be waste both on the side of care provision and research. Specific areas of research, such as precision medicine or personalised medicine, require detailed EHR data, whether for patient selection, disease phenotyping or patient follow-up, and lack of integrated EHR will stifle progress.<sup>22,43</sup> It is important to note that the existence of silos in research and clinical practice is not unique to EHRs or health informatics; these are problems that have been encountered by other social movements within medicine, including evidence-based healthcare, quality improvement (QI) and precision medicine.<sup>44,45</sup>

### Quality improvement and audit versus research

NICOR is one of the most established national audit programmes in the UK and currently manages national clinical audits in six areas:

- 1 adult cardiac surgery
- 2 adult percutaneous interventions
- 3 cardiac rhythm management
- 4 congenital heart disease
- 5 heart failure
- 6 Myocardial Infarction National Audit Project (MINAP).

These audits have become a powerful resource, enabling trends in disease and management to be monitored, and have played a role in policymaking for specific CVDs at system level. For example, NICOR data have been used to give individual operator-specific outcomes for percutaneous coronary intervention and have shown the increasing use of transcatheter aortic valve implantation with reducing complication rates.<sup>46</sup> Other diverse uses include showing ethnic variation in incidence rates of congenital heart disease around the UK<sup>47</sup> and the potential for post-marketing surveillance of prosthetic aortic valves.<sup>48</sup> Electronic data in the form of the QOF have been used to show that high-quality primary care is associated with improvements in outcome measures for coronary heart disease.<sup>49</sup> Local primary care data have been used to show that 'managed geographical practice networks' produce improved CVD performance indicators in east London.<sup>50</sup>

However, NICOR data are separate from routine EHR data and therefore involve separate data collection and analysis. The data are available retrospectively for research and are not usually used in real-time, locally or nationally. In terms of QI, there have been discrete projects; however, system-wide initiatives such as

NHS Health Checks are relatively uncommon.<sup>51</sup> Research using EHRs is generally not embedded in audit and QI activity. The effect, as with the divide between clinical service and research, is that the research that is done is not always aligned with clinical service and health system priorities. Similarly, analyses of audit data, rather than being targeted and proactive, are often *ad hoc* and reactive. Perhaps a more serious issue for the field of informatics is that, as a result of lag in coordination of research and QI/audit approaches, the evidence base for effectiveness or benefit of EHR-based approaches, such as decision support, is in its infancy.<sup>52</sup>

An alternative and entirely plausible model would be for continuous and semi-automated audit to be occurring using routine data. QI, trials of interventions and service provision could occur simultaneously using the same data in EHRs.<sup>53,54</sup> Box 2 summarises the potential impact of narrowing the gaps between research and service provision, audit and QI.

### Lack of capacity and expertise in informatics among clinicians/non-clinicians

At present, there is relatively little ‘e-health’ or EHR training in undergraduate medical curricula.<sup>55</sup> The higher specialty curricula of all clinical disciplines are replete with content relevant to that specialty and selected subspecialties. Informatics is still not considered a key component of the

core skills that a clinician requires and cardiology, like other specialties, barely pays lip service to IT or informatics at present. However, just as it is now considered essential that all clinicians have knowledge of audit cycles, QI methodology and principles of critical appraisal of research, informatics has become a necessary core competency that needs to be recognised, as in other countries.<sup>56,57</sup>

EHR and different linked data platforms mean that complex big data analytics are not only possible, but necessary to make optimal use of resources and also to improve patient outcomes. Techniques such as machine learning<sup>58</sup> and natural language processing<sup>59</sup> may have the potential to transform cardiovascular medicine in both service provision and research, but they are mostly in the latter. Without training, awareness and capacity building among non-clinical and clinical professionals, big data analytics using EHRs will be difficult to scale up across the health system.

An additional hurdle is that within the hospital the informatics departments are often not well-funded and do not always have resources for audit and research, despite the high incremental gain from these activities. The current initiatives to create leaders in both clinical and non-clinical spheres are to be applauded, but need to be supplemented by training of the wider healthcare profession and informatics workforce. Otherwise, the research and service potential of EHRs will fail to be realised because of motivational and capacity constraints.

### Box 2. Impact of gap between research and clinical service/audit/quality improvement

#### Convergence of research and clinical service

- > Disease and outcome phenotypes
- > Research and clinical agendas
- > Research and clinical cultures

#### Improved quality of data

- > Better motivation to complete full dataset in electronic health records and long-term follow-up data
- > Better interoperability between research and clinical systems
- > Reduction in transcription errors because of lack of duplication

#### Less resource waste

- > Improved use of routine data
- > Less duplication of data
- > Less duplication of resource (human, financial)
- > Better use of synergies between evidence-based healthcare, quality improvement, informatics and service delivery

#### Better science

- > Better translation of bench-to-bedside research
- > Science more aligned with clinical need
- > Better alignment of research interventions and clinical service needs

#### Improved patient care

- > Better implementation of evidence-based guidelines
- > Increased real-time monitoring in acute and chronic care
- > Reduction in clinical errors and improved patient safety

### Trust of patients and public

Administrative databases, clinical registries and EHRs have been joined by multiple, additional data sources, such as biometric and other data directly from patients (eg via wearable technologies), patient-reported data (eg health surveys), social media, medical imaging data and biomarker data (including ‘omics’ data).<sup>52</sup> The rise in m-health and other technologies has the potential to transform diagnosis, screening and monitoring of CVD.<sup>60</sup> However, integration of these data with routine clinical data is far from straightforward.<sup>61</sup> Moreover, the validity and quality of data from wearables and novel sources may not be adequate for use in clinical care.<sup>62</sup>

The public has conflicting concerns regarding data security, ownership and inadequate use of data. Direct-to-consumer advertising and sales have created a thriving health technology sector, but may be fuelling unrealistic expectations, which are not necessarily supported by evidence and are driven by commercial factors.<sup>63,64</sup> Patient engagement and trust are crucial for collection and use of data, particularly secondary use for research and data linkage, as shown by recent mixed-methods studies from the UK.<sup>65–67</sup> Giving patients access to their own health data is part of the solution.<sup>68</sup>

### Trust of clinicians in EHRs

The quality improvements that have occurred using NICOR data and QOF data exemplify how clinicians can drive system change using EHR data, whether in primary angioplasty<sup>69</sup> or control of hypertension in chronic renal impairment.<sup>70</sup> Professional organisations must ensure that clinical practice embraces the LHS approach, as a recent American Heart Association scientific statement exemplifies.<sup>71</sup> The EHR ‘faces the same implementation challenges as other healthcare

quality interventions, and will require the same skill sets and resources...to be integrated successfully into the clinical workflow and achieve clinical utility'.<sup>52</sup> Any move towards an LHS will need to engage the clinical workforce because without 'buy-in' from clinicians, there will be incomplete implementation, wastage of resources and poor data quality.

## Conclusions

EHRs are integral to the modern practice of cardiovascular medicine and LHS. Although there are convincing examples of their value in improving research and clinical practice in both the UK and other countries, the implementation and optimisation of use of EHRs faces significant barriers. Through EHRs and LHS, there are huge opportunities to bridge gaps across diseases, as well as research and clinical spheres, in order to improve patient outcomes. Research and service requirements need to be assessed and incorporated at the planning, procurement, implementation and evaluation stages of EHRs. QI and audit must be coordinated and integrated into EHRs to make the process continuous and semi-automated. Informatics capacity and expertise need to be addressed at local and system level. Patient and public engagement at planning, implementation and evaluation stages will increase acceptability and usability of EHRs. Clinician trust and engagement are a prerequisite to the successful use of EHR from an early stage of planning. Capitalising on the opportunities of EHR will require investment in infrastructure and people as well as changes in culture. ■

## Author contributions

AB was solely responsible for this manuscript.

## Conflicts of interest

The authors have no conflicts of interest to declare.

## Twitter

Amitava Banerjee tweets using the moniker @amibanerjee1

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