

Person-Centred Records

A high-level review of use cases

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For further research published as part of the Person-centred Records project, please visit <u>http://radar.gsa.ac.uk/6975/</u>

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Summary of key points from the review

Most of the studies reporting on the use of Electronic Health Records (EHRs) by Multidisciplinary Teams (MTDs) or on designing EHRs, emphasise the importance of:

- Placing the patient as the central point of their health record, and coordinating data, communications and actions around that patient.
- Giving all stakeholders (different medical and health professionals, carers, the patient) access to the relevant patient data. This will help pull down disciplinary siloes.
- Supporting seamless communication between the professional groups involved in caring for the patient.
- Keeping the patient and their contribution to their own care at the fore of care planning. Giving patients access to their own data and enabling them to add to their own data helps empower the patient to contribute to their own care planning and is crucial in supporting self-management and the delivery of patient-centred care.
- Identifying the workflows, information sources and information needs of each party involved in the patient's care is a good starting point for the development of a Patient-Centred EHR.
- There is evidence that **top-down**, off-the-shelf implementation of large-scale EHR does not work well.
- There is evidence that **bottom-up**, **agile and incremental co-design** approach, with flat decision-making structures is a more constructive approach to designing, adopting and implementing EHR.
- **Aim high** the future is in the comprehensive patient-centred, patient-owned records, cloud-based and mobile health records.
- Investing in data automation and Clinical Decision Support systems would be prudent.

Introduction

DHI has committed core funding for a Phase 2 project with NHS Grampian to codesign a single, multidisciplinary electronic record for in-patients attending any of NHS Grampian hospitals. The project is called Person-centred Records. The record will be used by all AHPs, nursing staff and medical staff across NHS Grampian's hospitals for all in-patients. This review has focussed on two topics:

- 1 Person-centred/patient-centred record keeping systems and practices;
- 2 Multidisciplinary team record keeping systems and practices.

The focus of this search was requested to be on patient-centred Electronic Health Records, but without the patient ownership of the records. However, a lot of the latest EHR-development points to the benefits of involving the patient in their care, and at the very least granting access to them to their own records, even if they would not hold the right to own their own data.

For the purposes of this report, an extensive literature and web search was performed, and a vast number of documents was reviewed; 64 documents were selected for closer scrutiny; 13 of these made the final cut and are presented as case studies in this report.

The purpose of the search was to find examples of multidisciplinary/interdisciplinary health and care teams and their record keeping systems and practices, as well as of person-centred care and record keeping systems and practices. The focus was requested to be on NHS Scotland.

The search found no relevant academic literature relating to the topic within NHS Scotland¹. Most research articles identified focussed on the use of EHRs by a single professional group, such as nurses or clinicians. These articles were not included in the review.

The most relevant examples selected for this report focus on multidisciplinary teams and their use of EHRs in the US. Many examples are of multidisciplinary teams supporting patients around a single disease. Two studies reported on national attempts at implementing EHR-systems, and one reports of an on-going development of a hospital-wide patient-centred EHRs for one NHS Trust in England.

The report will first give a definition of key terms, then provide examples of EHRs use by multidisciplinary teams for patient-centred care. Many of these give recommendations for which steps to follow in developing such a system. The

¹ This does not necessarily mean it does not exist, but was not found during this brief research exercise.

examples have been selected based on the presumed value for the R&D project for NHS Grampian.

Definitions of terms

EMRs, EHRs, EPRs

The first electronic records were locally stored and owned, digitised versions of patients' paper-based medical charts - *Electronic Medical Records (EMRs)*. They contain the patient's medical and treatment history, including any diagnoses. The advantage EMRs offer over paper records is that they help improve patient care by offering better tracking of data over time, and, for example, contain reminders for patient screenings and preventative check-ups (Garrett 2011; HealthIT.gov 2014; Deloitte 2015; USF Health Online 2019).

Electronic Health Records (EHR) were conceived of in early 1990s. The purpose was to improve quality of care by "*increasing the accessibility and comprehensiveness of health information, providing portability of health records, enhancing connectivity between physicians involved in the care of a patient, encouraging patient engagement and facilitating multidisciplinary care management*". (Kiplagat et al., 2018)

In contrast to EMRs, *Electronic Health Records (EHR)* focus on the total health of a patient and are designed to enable the secure electronic sharing of these data between the different healthcare settings, and in some instances, the patient. EHRs reach out beyond the health organisation, giving authorised users across different health and care providers an instant access to a patient's health record. The EHRs systematically collate and store digitised data on patients from the different healthcare and medical organisations and providers. Health information and data captured by an EHR system must evolve over time as new knowledge becomes available. (Soriano et al., 2017, 307) The information, which includes the EMRs, moves with the patient between different healthcare settings, providing a more holistic view of the state of a patient across time. The EHRs can also provide information on population health by aggregating relevant data (permissions providing). Sometimes EHR is also referred to as an Electronic Patient Record (EPR). (Garrett 2011; HealthIT.gov 2014; Deloitte 2015; USF Health Online 2019). EHRs can also function as enterprise or business management software (USF Health Online 2019). In the United Kingdom and Scotland, the patient data in the EMRs and EHRs are not owned by the patient but by the organisation hosting the records. Currently, patients are unable to access their own records directly, but they have a right to request a copy of their record from the organisation that holds them. (NHS Inform, 2019)

The key differences between EMRs and EHRs, according to USF Health Online (2019):

- An EMR is mainly used by providers for diagnosis and treatment.
- EMRs are not designed to be shared outside the individual practice.
- EHRs are designed to share a patient's information with authorised providers and staff from more than one organisation.
- EHRs allow patients' medical information to move with them to specialists, labs, imaging facilities, emergency rooms and pharmacies, as well as across state lines (in the US).

Electronic Patient Records (EPRs) have two slightly different meanings: they can mean EHRs, where the data is centred around the patient, or in the more modern EHR generation, EPRs refer to a system, where the data is both centred around the patient, but also owned and controlled by the patient. In the latter case, the patient can control who has access to their data, see who has viewed their data and when, and they can also add to and remove information from the record. (e.g. Jormanainen, 2018; Ramsay and Seth, 2017; Elias 2016)

Finally, the most advanced countries in digital health and care have integrated and comprehensive, user-centred national health and social care records, which combine EMRs, EHRs, EPRs and Social Care Records, which the patient/user owns, can access and modify. An example of this is the National EHR system of Finland called "Kanta-services" (e.g. Jormanainen, 2018).

Patient-Centred Care and Multidisciplinary teams

Patient-centred care is mandated by WHO's Global strategy on People-Centred and Integrated Health Services, who call for improved people-centred care that empowers, educates, and engages individuals and incorporates technology in an efficient and effective manner. (Alkureishi et al., 2018).

There are many different definitions of person-centred / patient-centred care. Scottish Government's Healthcare Quality Strategy in 2010 defines it as:

"Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values, and which demonstrate compassion, continuity, clear communication and shared decision making."

In other words, person-centred care is about compassion and empathy with the patient, and about seeing them as the experts of their own condition; it is a way of delivering health and care that places the patient and their families at the heart of decision making, and sees them as equal partners in planning, developing and monitoring care to ensure that it meets their needs. (Health Innovation Network, n.d.)

Electronic Health Records (EHRs) are not patient-centred in themselves but they can support the care providers in delivering patient-centred care. Soriano et al. (2017, 307) report (as recorded by the Institute of Medicine in 2012) a range of ways in which clinicians expect Health IT to support delivery of high-quality care. These include:

- Storing comprehensive health data;
- Easy entry and retrieval of data;
- Have simple and intuitive displays;
- Allow easy transfer of data between health and care professionals;
- Providing clinical-decision support;
- Facilitating communication; and
- Reducing medical errors. (Soriano et al., 2017, 307)

Research has found patient-centred care to have a positive impact on a number of measures, such as patient compliance, satisfaction, and health-outcomes (ref 14 in original). (Alkureishi et al., 2018).

Multidisciplinary team meetings have been recommended in several published NICE guidelines about specific diseases and clinical conditions. (National Guideline Centre 2018).

NHS Scotland (n.d) website called Shifting the Balance presents evidence that multidisciplinary teams:

- Are a cost-effective way of delivering improved health outcomes;
- Show increased participation and compliance with treatment;
- Help to reduce length of stay and bed days in hospital;
- Contribute to increased numbers of patients discharged home;
- Contribute to reduced admission to institutional care and acute hospitals, and
- Improve patient/service user and carer satisfaction.

In the following section, 13 divergent case studies on the design, implementation and the future of EHRs and EPRs are being introduced.

Case studies

1. Multidisciplinary use of EHRs to prevent delirium (Soriano et al., 2017)

The study by Soriano et al. (2017) looked at how a multidisciplinary team of **pharmacists**, **physicians**, **nurses**, **data analysts and informatics teams** at Kaiser Permanente (in US) worked together to overcome the challenges of data silos and leverage real-time knowledge from the EHR to prevent delirium in the hospital. This collaboration resulted in the design and use of a delirium risk score and care protocols by the care team. The article details the process of development of the multidisciplinary approach to assessing delirium and how the EHR was improved to support that process.

The article presents the case of Gladys, whose delirium symptoms were missed by the hospital-based multidisciplinary care team, and as a result, she has a serious fall. This is despite the use of an EHR by the multidisciplinary team (MDT).

The issue addressed by the study: To date, the focus has been on implementation of EHRs and each clinical domain has built tools that support their respective workflows, regulatory requirements and data needs. However, *when data is not linked to real-time knowledge and the context of how data fit together for patient-centric care, the potential value of EHR systems is often not experienced by front-line clinicians.*

In Gladys' case and many other patients admitted in the hospital, all members of the care team are using robust EHR systems across the continuum of care—including inpatient, ambulatory, home, and virtual settings, yet we still find opportunities in the industry to improve care coordination to deliver effective, safe, and timely care. How might we optimise team-based care in all settings to be more patient centric through wise clinical decision support and improved data sharing? (p. 302)

As a solution, a comprehensive model for identifying delirium was developed by an interdisciplinary team. Steps taken (summary):

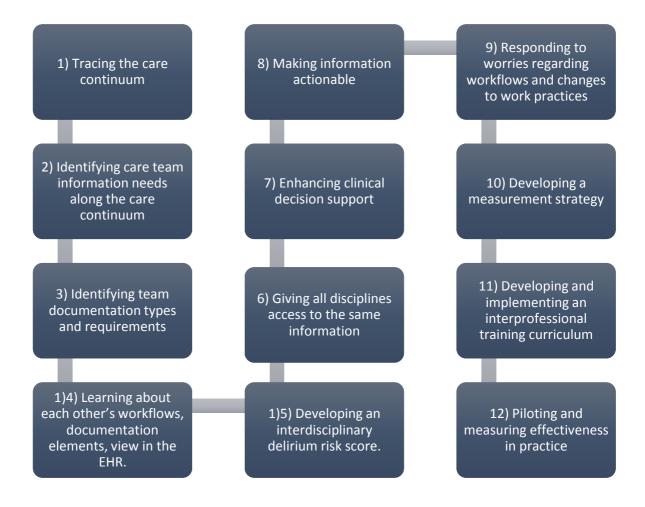


Figure 1: Tracing the steps taken in developing an interdisciplinary delirium score.

1) Tracing the continuum of care for patients at the hospital.

2) Identifying care team information needs along the care continuum.

- a. Clinicians: used diverse types of data from multiple sources. They accessed information in various ways, depending on the source they were using, and whether the query was routine or non-routine. The physicians like to optimise their information seeking processes by accessing resources they believe would maximise their information gain, and that would aid their medical reasoning and decision-making. Clinicians preferred a patient-based information seeking strategies, while nurses and others would use source-based strategies.
- b. Nurses: a range of information sources and activities were appraised and used during practice. What information was accessed was influenced by the specific situation, the surroundings and personal preference. There was a difference in the process for finding information for routine and non-routine decisions. In routine cases, the information that was relied upon was often based on experience; in non-routine cases, more professional information was sought.

c. Pharmacists: require evidence-based information on medication. They would have required more information about the patient and their situation, such as laboratory results and other clinical data as well as pharmacogenic information.

Challenges identified in accessing information:

- A lack of time;
- Inaccessible information;
- The volume of available information;
- Not knowing which resource to search;
- Unfamiliarity with computers;
- Lack of skills for searching information;
- Effort of entering data;
- Not enough computer terminals to meet the needs of all members of the interdisciplinary team.

Structural challenges identified:

- Problems filtering information;
- Lack of context-sensitive, decision support and issue with the usefulness of the data
- Lack of usable functionality;
- Lack of interoperability;
- Lack of technical support. (Soriano et al., 2017, p. 305)

3) Identifying team documentation types and requirements.

- a. Clinicians: enter codes, code diagnoses and document clinical notes.
- b. Nurses: document delirium scores, assessments and care plan interventions.
- c. Pharmacists: enter medical interventions.

Issues that emerged in relation to the use of current EHR:

- EHR was found not to support data transparency in a way that promoted interdisciplinary clinician communications or care coordination.
- Biggest challenge in identifying patient at highest risk for developing delirium: Lack of real-time, contextual information at the point of care.
- Biggest barrier to collaboration: no shared place that presented one view of the patient's story, nor how all team members contributed to the shared care goal.

Soriano et al. (2017, 306) explain: "In the case of accessing delirium information, caregivers were limited to their own views of the EHR. Physicians accessed patient

histories and other notes and were relegated to waiting for a phone call from nurses or pharmacists when a patient began exhibiting signs of delirium. Meanwhile, as nurses were entering information in the EHR, they had no way of knowing at any given time which patient(s) were at the highest risk for developing delirium. Nurses do not routinely have access to other clinicians' data when developing the patient's plan of care. Pharmacists shared a similar frustration in that they only saw screens with medication orders but had no way of knowing that nurses rated a patient at a high risk of developing delirium. These challenges are not uncommon and reflect a current state that can be found across the health system industry regardless of size or EHR vendor used (O'Brien et al. 2015)." (p. 306)

4) Learning about each other's workflows, documentation elements and view in the EHR.

This process helped reveal differences in information sources used between each discipline, and the divergent access to patient information in the EHR.

5) Developing an interdisciplinary delirium risk score.

Based on the initial research and development process, the Informatics team created an interdisciplinary delirium risk score highlighting elements that were already present in the EHR (e.g. age, medical history, surgical status, delirium risk scores, neurological assessment, medications; risk factors, Confusions Assessment Method (CAM) score, nursing assessment and medication). Creating the interdisciplinary delirium risk score translated discreet yet disparate data into actionable information.

6) Giving all disciplines access to uniform information.

In tandem with making the multidisciplinary delirium risk score (MDRS) available, all three disciplines were given access to the same information in the same format in the EHR to help them immediately to identify the patients at highest risk for delirium.

7) Enhancing clinical decision support.

The informatics team developed clinical decision support tools based on the delirium risk score.

a. For clinicians - the MDRS served as a tool to identifying patients who were at highest risk of delirium. The score allowed them to make changes to medication orders as needed, or if no alternative existed, work with the geriatric nurse specialists and nursing staff to implement non-pharmacologic interventions to prevent delirium.

- b. For nurses the MDRS sent automated alerts to trigger a delirium care plan so that the most appropriate clinical interventions could be applied based on the assessments and risk scores entered in the EHR.
- c. For pharmacists the MDRS was used as a foundation to build a prioritisation dashboard. This afforded the pharmacists an insight into which patients had deliriogenic medications as part of their hospital orders along with seeing the nursing risk assessments for those patients.

8) Making information actionable

In order to make the information actionable, the team developed and implemented new workflows for all three disciplines.

- a. The attending clinician will:
 - i. Review the patient's medication(s) with pharmacy;
 - ii. Change the deliriogenic medication in the EHR as appropriate;
 - iii. If no alternative medication is possible, the physician will work with the geriatric clinical nurse specialist (**if available**) and primary nurse to provide non-pharmacologic delirium interventions.
- b. The primary nurse will:
 - i. Validate the Confusion Assessment Method (CAM) score for the patient;
 - ii. Apply the appropriate care plan interventions for the patient;
 - iii. Perform pharmacologic and non-pharmacologic interventions in collaboration with pharmacist and attending physician;
 - iv. Continue to document the CAM as per policy and update the plan of care in the EHRs based on the patient's condition.
- c. The pharmacist will:
 - Review the medications and notify the attending physician and geriatric clinical nurse specialist (**if available**) via phone call or EHR in-basket message;
 - ii. Present possible medication alternatives to the attending physician;
 - iii. Document their intervention in the EHR.

9) Responding to queries and worries of staff

The Informatics team would be available to respond to any queries and to alleviate worries that staff raise regarding the new workflows and changes to work practices.

a. Clinicians were concerned about the expectations that medications would be modified and raised concerns that this was not always possible;

- b. Nurses raised concerns about their bandwidth to coordinate between clinicians and pharmacists for all high-risk delirium patients since they were already so busy caring for other patients in their assignment;
- c. Pharmacists raised concerns about a potential lack of resources to handle the volume of patients identified as having a high risk of developing delirium.

10) Developing a measurement strategy

By way of responding to the operational questions of the delirium risk score raised by staff, the team consisting of clinical leaders, data analysts and clinical informaticists developed a measurement strategy. This also contained process metrics for each discipline.

Baseline information was gathered to set the stage for current state of delirium care before the adoption of the delirium risk score:

- Number of patients in the hospital who had coded diagnosis of delirium;
- Rate of deliriogenics prescribed;
- The quality of documentation of the nursing assessments; and
- Confusion assessment measurement (CAM) risk scores.

Success measures were developed to help evaluate the usability and value of the new delirium risk score.

11) Developing and implementing an interprofessional training curriculum.

An interprofessional training curriculum was developed to educate the interdisciplinary care teams on how to use the delirium risk score tools. This also helped to set up process measures to study the usefulness of the information and the usability of the tools within the workflows of each discipline.

"With the ability to see delirium risk scores in real time, it is important to evaluate effects on clinical efficiency and communications between team members in order to truly find the value in using these tools. Once the tools become hardwired into the workflows of clinicians, potential outcome measures could also include length of stay, incidence of delirium, complications related to delirium, and read- mission rates (Gleason et al. 2015). " (Soriano et al., 2017, 309)

12) Piloting and measuring effectiveness

At the time of writing of the article, the pilot was only being planned.

"EHRs are intended to support the safe delivery of evidence-based and personalised care. The challenges of seeking clinical information in silos and the first generation of EHRs were reviewed. With the emergence of predictive analytics and early warning scores using EHR's data, the promise of best care at lower cost is within our reach. With increasing attention being given to care coordination industry-wide, the Kaiser Permanente delirium pilot provides an exemplar of best practices including interprofessional data sharing, data visualisation, data integration into a risk tool, smart and timely clinical decision support and a culture of team- based care. " (Soriano et al, 2017, 310).

2. EHR facilitating multidisciplinary management of thyroid cancer (Kiplagat et al., 2018)

Thyroid cancer patients are treated and cared for by a collaborative, multidisciplinary teams consisting of **endocrinologists**, **nuclear medicine physicians**, **pathologists**, **surgeons**, **radiologists and primary care physicians**. The current, web-based (cloud-based) EHRs have started hosting disease-specific databases that can be easily integrated into the physician's workflow to improve the quality of care for patients with the specific needs. The study by Kiplaga et al. (2018) looks at one of these, the Thyroid Care Collaborative (TCC), formerly known as the Thyroid Cancer Care Collaborative. Web-based disease-specific electronic records are dynamic and can be readily modified in the light of new information. This patient-centred record is controlled by the patient, who have to invite care team members to share in their data.

This study reviews how the TCC improves the multidisciplinary management of thyroid cancer by:

- 1. Enhancing communication between physicians;
- 2. Providing a platform for active surveillance in patients with low-risk thyroid cancers;
- 3. Establishing electronic feedback loops that inform the providers as to the results of further testing as well as the clinical course of that patient;
- 4. Implementing imaging modules that help to standardize the performance and the reporting of imaging results; delivery of specific clinical practice guidelines (CPGs) to the clinicians and the patient that are specific to where they are in their thyroid journey, to ensure adherence and standardisation of care;
- 5. Providing relevant and disease-specific data that facilitates clinical research studies; and
- 6. Storing patient health records in one central location accessible to all members of a patient's care team.

Communication

- Traditionally, thyroid cancer teams have communicated in archaic, paperbased methods, which have led to fragmented patient information and poor communication between distributed teams.
- TCC is a patient-based, disease-specific EHR that connects all parties involved in a patient's care through giving everyone direct access to the most up-to-date records, once the patient invites them to participate in the TCC. This is an innovative approach, which:
 - Places the patient at the centre;

- Allows the medical professionals in the care team to communicate regardless of hospital affiliation, which eliminates "clinical silos" and disjointed communication of relevant health information between the team members.
- The TCC also promotes active follow-up of patients. It contains a physician banner, a thyroid timeline to help retrieval of patient information that is readily available when a patient's record is opened.
- Patient enrolment into TCC is based on a consent-model: the patients can consent for their data to be used in thyroid cancer research. The platform also contains a lot of educational material, FAQ etc.
- TCC is HIPAA-compliant and meets the strictest standards for data encryption at the server and browser level.

Adherence to Clinical Guidelines

- In the US, standardisation of thyroid care is poor; lots of variability between treatment sites and physicians.
- TCC supports adherence to Clinical Practice Guidelines.

In-built Feedback Loop

- To keep abreast with constantly evolving national guidelines and body of scientific knowledge, healthcare providers and information technology professionals must work in partnership to generate methods of continual self-assessment through electronic feedback loops.
- TCC has an in-built electronic feedback loop system that helps with selfmonitored modification and fine-tuning of diagnostic and therapeutic interventions.
- The feedback loop also helps eliminate clinical siloes, as the members of the MDT can keep up to date with the development of the shared patient's status through an notification system, which sends automated emails to the approved members of the care team each time the patient undergoes a new treatment, encounter or diagnostic work up. For example, normally those performing ultrasounds never receive feedback on the final pathology. The built-in system for automatic feedback to care team members helps to promote continuous quality improvement in a multidisciplinary setting.

TCC encourages "Disease mapping" to support MDT communication

• The physicians can use an imaging module, which allows the doctor to create a visual thyroid map of specific lymph nodes and nodules with their imaging and cytologic characteristics attached.

 "By disseminating this accurate, portable and real time information to the patient's care team, disease-understanding and treatment accuracy is improved. By creating a disease map that follows a patient on their clinical journey, the 'handoffs of care' that take place between clinicians can be done more accurately and safely. Specifically, the disease-mapping modules aim to improve the accuracy of ultrasound and cytologic reporting, lymph node mapping, nodule tracking, surgical planning, pathologic reporting and posttreatment surveillance." (Kiplaga et al. 2018, p.3)

The TCC provides a platform for meticulous disease surveillance

- Active surveillance is a thyroid cancer-management strategy that entails observation using ultrasonography to monitor disease progression for low-risk thyroid cancer.
- For patients who have chosen active surveillance, the TCC provides the technology for physicians to monitor their patients' progress and to capture data that would be essential for long-term follow-up.
- By capturing important data points, the TCC is an effective vehicle to follow patients long-term and can act as a safety net to prevent lost follow-ups.
- Communication between physicians is also enhanced since all the physicians in the care team have access to the patients' medical reports. Longitudinal care requires cooperation from the patient.
- TCC encourages patient involvement in their own care.

Clinical Trials

- TCC enables a seamless and efficient enrolment of patients into clinical trials due to the comprehensive clinical registry TCC creates.
- Care team members can actively use TCC to direct their patients towards specific trials based on their unique health status:
 - Passive method: Using a query function in the database to identify suitable patients based on specific inclusion and exclusion criteria. After a list of suitable candidates is generated, TCC can reach out to those patient's care team to inform them of the availability.
 - Active method: programming the inclusionary and exclusionary criteria of the approved clinical trials into the TCC, generating an automated email to the care team members of candidacy for clinical trials. The enrolment of the patient would be discussed with them by the HC providers.

Disease and research specific registries

- Health registries play a powerful role in utilizing clinical data with the aim of advancing research and outcomes, improving quality of care and understanding disease processes.
- "Mehra et al. reviewed population-based cancer registries, health systemsbased registries and patient-based registries to elucidate their efficacy in cancer research [5]. According to their analysis, population-based cancer registries and health systems-based registries are effective in demonstrating the following: trends in cancer incidence nationally; survival status and cause of death data; and elucidating the geographical data with respect to new cancer cases. However, several limitations persist [5]. First, active follow-up for specific variables is unavailable in these registries. Second, follow-up for surveillance and/or treatment in different health systems is difficult. Third, data entry does not occur at point-of-care allowing for discrepancies. Finally, case reporting and data analysis are not timely [5]." (Kiplaga et al., 2018, 4.)
- Thyroid cancer registry has overcome the shortcomings of current registries by:
 - By collecting dynamic data fields;
 - Integrating data entry into a physician's workflow;
 - Enabling patient-driven lifetime follow-up for treatments;
 - o Diagnostic tests, etc. irrespective of health system;
 - Representing an entire spectrum of disease; and
 - Providing a comparative lens by which physicians can measure their data against national trends.
- Limitation of TCC include the lack of integration into providers' EHRs (lack of interoperability). This is a major obstacle facing the EHR systems in the USA. The TCC aims to bridge the gaps between hospital affiliation and EHRs, thus making critical health information available to all members of an individual's care team.

Conclusion

The TCC is a powerful web-based tool for facilitating management of thyroid nodules and thyroid cancer by enhancing communication between physicians, ensuring adherence to clinical guidelines, generating electronic feedback loops for quality care, improving physicians' reporting of imaging details through disease maps, providing a platform for following active surveillance candidates, serving as a disease specific platform for clinical trials and acting as an effective disease-specific registry for thyroid cancer. In this discussion, we demonstrate that **by transforming the way physicians communicate with each other and with patients, we can make significant strides in healthcare quality and delivery.**

3. Multidisciplinary process of care planning (Laleci Erturkmen et al., 2019)

A study by Laleci Erturkmen et al. (2019) looks at a multidisciplinary process of care planning, which is a common approach in integrated care to bring together multiple professional partners, the patient and their carers. Their study addresses "care bottlenecks" caused by three main issues.

Care bottle-necks addressed by the study:

- Clinical Practice Guidelines (CPG), which normally focus only on a single disease rather than co-morbidity and multimorbidity, and the difficulty in simultaneously trying to review multiple CPG.
- Managing multi-morbidity. The current treatment methods often result in clinical silos, as the multiple health and social care providers cannot communicate and share information efficiently.
- Patient involvement. Often, patients and their carers do not have a voice in planning their own care. (Laleci Erturkmen et al., 2019)

The paper presents a method and corresponding implementation of a semi-automatic care plan management tool, called "Coordinated Care and Cure Delivery Platform (C3DP)". This allows collaborative creation and execution of personalised care plans for multi-morbid patients by a multidisciplinary care team (MDT) including GPs, specialists, study nurses, pharmacists, physiotherapists, geriatricians, nutritionists, social care and homecare workers. The platform is integrated with clinical decision support services, which can seamlessly access and assess the electronic health records (EHRs) of the patient and compare these with evidence-based clinical guidelines to suggest personalised recommendations to be added to the individualised care plans.

"In the C3-Cloud architecture, C3DP sits at the top of the hierarchy and is directly integrated with all the other C3-Cloud components and indirectly with the local EHR/EMR systems of the pilot sites. All the patient data required for care planning are fetched from the C3-Cloud FHIR Repository, which is continuously fed with existing EHR data of the pilot sites via our interoperability architecture composed of the Technical and Semantic Interoperability Suites (TIS and SIS). With the help of Clinical Decision Support Modules (CDSM) automating multiple clinical guidelines, C3DP processes electronic health records of the individual patients and provides guidance to the multidisciplinary care team members for **i**) **risk prediction and stratification**, **ii) personalised selection of treatment goals and interventions in the light of evidence based guidelines, iii) reconciliation of conflicting treatment options and iv) management of polypharmacy.** Active patient involvement and treatment adherence is achieved through a Patient Empowerment Platform (PEP), ensuring patient needs are respected in decision making and taking into account preferences and psychosocial aspects. Finally, the Security and Privacy Suite (SPS) provides common security features for user authentication, authorisation and audit logging to all of the other components."

C3DP is based on cloud architecture and FHIR standard. C3DP processes electronic health records of the individual patients, offering guidance to the multidisciplinary care team members through:

- Offering a Clinical Decision Support System to manage Multiple Clinical Practice Guidelines through proposing personalised treatment goals and interventions for the care plan of the patient based on the most recent context of the patient and evidence-based guidelines; Also offers risk prediction and stratification.
- Reconciliating conflicting treatment options: The platform helps with managing multi-morbidity and polypharmacy, which currently emerge from clinical practice taking place in specialty siloes. C3DP offers a secure information exchange and a process to reconcile potentially conflicting treatment plans helps with avoiding unnecessary and potentially harmful interventions for those involved in health, social and informal care services.
- **Supporting informed decision making** by enabling sharing information between regional/institutional EHRs, Social Care records and Homecare services. The software also allows the MDT members to share a single, coherent view of that data.
- Bringing in the patient and their informal carers into the management of care circle through a "patient empowerment platform", which offers complete information about the benefits and risks of treatments; real opportunities for shared decision making, expressing preferences and engaging in self-management. It also collects data on patient reported outcomes measures, patient's activities and problems they may encounter.
- Two-way communication between MTD and the patient.
- C3-Cloud software encompasses interoperability adapters that allow heterogeneous data sources to share their EHR data securely.
- The interoperability architecture also **enables the clinical decision support services to seamlessly access and assess the electronic health records** (EHRs) to offer personalised recommendations for goals and interventions to be added to the individualised care plans of the patient. (Laleci Erturkmen et al., 2019, 6-7)

4. Implementation of an EHR system within an interprofessional model of care (Elias, B et al., 2015)

The study by Elias et al., (2015) examines the challenges of implementing and evaluating an EHR for a selected case of an interprofessional collaborative practice model (ICPM) in an interprofessional, interagency, free-clinic setting in an urban south–central region of the United States.

Moving to patient-centred care model assumes multidisciplinary healthcare teams as part of this change, with HIT as a means to support the resulting complex team and patient interactions (Institute of Medicine, 2011).

The aim: In the interprofessional team model, the patient moves through a trajectory of care, seeing different team members at each visit, depending on his or her current needs. For example, a patient with hypertension may return to the clinic a week after initiation of an anti-hypertensive medication. At the return visit, the patient is seen by a provider (physician or nurse practitioner) for chronic disease management, a dietitian for a nutrition consultation, and the dispensary personnel for instructions regarding medication adjustments. **Data gathered from each provider must flow seamlessly to the next provider, and at the completion of the visit a summary must be compiled in a manner that can be efficiently referenced in a subsequent patient encounter**. The model examined in this study uses a formative evaluation process that is rooted in usability to configure the EHR to fully support the needs of the variety of providers working as an interprofessional team. For this model to succeed, it must include informaticists as equal and essential members of the healthcare team. (Elias et al., 2015)

Challenges in the development process include:

- The fact that typical decision-making model in healthcare organisation is strictly hierarchical, executive-led and often focussed on the physician as the leader of patient care. This extends to decisions made about Healthcare Informatics Technology (HIT) and EHR: what systems are procured and how these a configured.
- Moving into patient-centred care model, which entails the participation of multidisciplinary care teams, this decision-making model has to change.
- Patient-centred care model should be the driver for Health IT redesign and implementation, so that the tools used can support the care providers and patients more effectively. (Leventhal et al., 2012)
- Decision-making regarding configuration involves interprofessional stakeholders, including advanced practice nurses, educators, physicians, a dietitian, mental health providers, clerical staff, and dispensary personnel. The

main focus is the timely information flow as a patient moves through scheduled appointments with multiple team members.

- In the multidisciplinary team model, where the power structures are less clear, the sense of leadership becomes more fluid and distributed, which makes identifying and prioritising the needs of the primary stakeholder more complex.
- Ensuring a smooth information flow in a multidisciplinary clinic. **Information continuity** –a particularly important collaborative feature of multidisciplinary clinic; information technology is a particularly efficient means for achieving it.
- Lessons learned to date include the importance of developing new models of decision-making around the use of HIT in a patient-centred, interprofessional care model.

1) Researcher defined the multidisciplinary team members workflows and information flows. 6) Decision-making about the rollout of the EHR was also grassroots in nature. It used the providers' information needs and information flow as a guide, starting with the scheduling module for patient appointments in support of the morning huddle.

1)2) Formative usability evaluation was carried out in order to develop initial configurations for EHR form drop-down menus and coding options.

1)5) Configuration decisions were then brought to a team of representatives from each agency for review before implementation.

1)3) Follow up to see how the configuration worked out in practice (shadowing patients and practitioners).

4) Engaging all practitioners in evaluation and decision-making about the configuration.

7) Simultaneously, registry volunteers identified current patient paper charts and began a process of entering patient data into the EHR from current time back through previous visits. The INS regularly worked with front-desk staff, volunteers and early adopter providers on usability issues in a spiral development model.

8) Using EHR during triage. Engaging triage nurses, who initially see patients ahead of the provider visit – documenting vital signs and patient history data in he EHR. The providers' workflow indicate that this step is essential before engaging all providers in use of the EHR.

 9) Using EHR during patient visits – configuring e.g.
dispensary module to allow for electronic prescribing and dispensing in house.

Figure 2: Steps in implementing EHR supporting MDTs, based on Elias et al., 2015

5. How to design an EHR to help patients, pharmacists, and physicians participate in interprofessional shared decision making. (Mercer et al., 2019)

EHRs have emerged as a powerful tool for improving communications between healthcare professionals (HCPs) and patients. There is strong evidence that EHRs can successfully improve care coordination by improving communication and collaboration among HCPs.

The article calls for EHRs to evolve from being a resource for healthcare professionals to one that supports all members, including the patients, of the decision-making team.

Challenge addressed in this study: how to incorporate EHRs in patient-centred care at all touch points, including visits with the physician, pharmacist, emergency care?

One aspect of patient-centred communication approach for medication decisions is shared decision making (SDM). SDM is defined as "an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care." Although SDM supports patient-centred care, there is limited understanding of how to adapt EHRs to support SDM.

The article suggests that adding Pharmacists, who are often not co-located with physicians and nurses into shared decision making, EHR becomes a great platform for improved communication between the parties.

The study identified four main themes to take into account when designing an EHR to support MTD decision making:

- (1) complexity of <u>patient decision making</u>: who, where, what, when, why;
- (2) relationships with physicians and pharmacists: who do I trust for what?;
- (3) accessing health information for decision making: how much and from where?; and
- (4) patients' methods of managing information for health decision making.

The article presents a table of findings on the design of EHR relating to medicationrelated decision making:

| Theme | Description | Relevance to EHR |
|--|---|--|
| Complexity of patient decision making: who, where, what, when, why | The context significantly influences health decisions. Emergent situations are approached differently from chronic health conditions, and | EHR can help people make decisions by providing access to their health information and give an understanding of why |

| | the different contexts include past experiences, physical location, and availability of health information. Patients describe how interactions with HCPs | physicians give recommendations. |
|---|--|--|
| Relationships with physicians and pharmacists: who do I trust for what? | influence their health decisions. Participants described the nature of the relationship with different HCPs (physicians vs. pharmacist) and how this influences health decision making. Family, friends, and HCPs all influence decisions being made but in different ways. | Participants trust different people for different types of health information. Designing EHR to account for different relationships influencing health decisions can allow for greater awareness of the different roles people play in decisions. |
| information for | Even though there may be similarity in experience, patient diversity leads patients to feel hesitant about making decisions outside of their experience. Patients require information to make health decisions, most of which is not easily available to them. The amount of information desired varies on a case-by-case basis, often dependent on if patient is in a crisis situation. Most critically, patients are often getting information outside of traditional contexts (i.e., an HCP), which means that there is potential for misaligned information between patients and HCPs. | The amount of information a patient wants changes based on chronic and acute health situations. EHR would benefit from being able to provide different amounts of information based on patient preference. |
| Patient's ways of managing information for health decision making | Patients shared strategies on managing and sharing health information. Current EHR did not appear to support required communication. | Participants expressed a desire for EHR to transmit health information between their various HCPs, lessening their perceived need to be the one to transmit health information. |

Conclusion: Patients make decisions with their healthcare providers as well as with family and friends. The pharmacist and physicians play different roles in helping patients in making decisions. We found that making EHRs accessible not only to health care providers but also to patients can provide a cohesive and clear context for making medication-related decisions. EHRs may facilitate clear communication, foster interprofessional understanding, and improve patient access to their health information.

6. Lessons learned: Implementation and adoption of Nationwide EHR / NHS England (Sheikh et al., 2011)

Sheikh et al., (2011) study evaluated the implementation and adoption of the NHS electronic care records service in "early adopter" hospitals in England. The article gave a detailed review of different aspects of the implementation, but here only their main findings and recommendations are presented.

- Three national EHR systems were implemented (detailed descriptions of each system and how they were set up in the article):
 - o Cerner Millenium
 - o RiO
 - Lorenzo Regional Care
- Top-down implementation;
- Happened much slower than anticipated;
- Delays due to:
 - "complex and constantly shifting national set-up characterised by complex politically shaped contractual relationships that largely excluded NHS HC providers";
 - Lack of appreciation of social and organisational consequences of technology implementation - a lot of resistance from staff;
 - Unrealistic expectations regarding the capabilities of the software system and the time required to build, configure and customise the software;
 - Lack of appreciation the effort required to make sure the systems were supporting (rather than hindering) the provision of care;
 - Not taking sufficiently into account the training and support-needs of end users.
 - Different HC organisations implemented different functionalities of the software locally resulting in unanticipated consequences in terms of cost, time and effort in making the new technology "work out".
- Locally some benefits in terms of improved data sharing and organisational learning.

What is already known on this topic:

- Many countries are now actively pursuing the implementation of electronic health records on a national scale;
- In 2002, England embarked on implementing electronic health record systems with clinically rich functionality spanning both primary and secondary care settings;
- Major challenges associated with the government led "top down" implementation strategy have been identified.

What this study adds:

- All 377 hospitals in England should have completed the implementation of electronic health record systems by December 2010; only one in five, however, had begun implementation;
- There is a need to move away from technology centred models of "implementation" and focus more attention on the process of "adoption," which needs to be seen as an ongoing "working out" between staff and technology;
- Important learning within and between organisations occurred in "early adopter" sites, which needs to be drawn on to support the ongoing implementation efforts.

Implications for the international community

Sheikh et al., (2011, 11) write: "As we have shown, the procurement of national systems in England had a range of unanticipated consequences. Large scale procurement was undertaken to save costs, but this meant that implementation timelines were rushed, being driven according to political timeframes in line with procurement arrangements. Hospitals have coped differently with these pressures, often heavily influenced by the particular type of software implemented. Despite the important learning within and between organisations that had taken place across the sites we studied, these national pressures have, in some cases, resulted in software being deployed prematurely with adverse consequences for local organisations, users, and patients' care. We therefore recommend that procurement decisions should not be based on unrealistic assumptions of achieving cost savings or even short term returns on investment, but rather on introducing clinical and associated decision support functionality early so that these systems are used and deliver demonstrable clinical benefits. Adequate national investments also need to be made to support interoperability, which is fundamental to enabling reuse of data. Recent announcements in the English strategy, however, indicate that only 2% of the total IT modernisation budget has been allocated to support interoperability."

Summary of key policy recommendations (Box 5, Sheikh et al., 2011, 11):

Overall strategy:

- Build on a **coherent vision** of shared electronic health records to improve the provision of joined up patient centred care;
- **Devise a strategy** that is characterised by flexibility and the ability to respond to evolving needs, while ensuring that there is a clear local rationale aligned with national purposes;
- Move away from technology driven models of implementation and refocus attention on adoption as ongoing "working out" between staff and technology; think of technology as an enabler of improved care processes rather than an end in itself.

Architecture:

• Ensure that **software is assessed to be fit for purpose** by users in the implementing organisations

Process:

- Make software work well in the NHS organisations that have already started implementation;
- Ensure that **procurement decisions** are not based on unrealistic assumptions of achieving cost savings or even short term returns on investment, but rather on introducing clinical functionality early so that these systems are used;
- Balance central incentives to implement with large scale interoperability and local input in decision making;
- Ensure sustained **efforts and appropriate funding** characterised by a coherent strategy with realistic timelines to allow local organisations time to "work out" the consequences of the change;
- Consider the merits of participating in the development of open source systems as opposed to the purchase of commercially developed systems;
- Retain hard won knowledge at both local and national levels and make appropriate use of these skills and expertise both in and across sites;
- Facilitate the sharing of experience and learning both nationally and internationally.

7. My Care Programme. Clinical Transformation enabled by a comprehensive electronic patient record (EPR). Royal Devon and Exeter NHS Foundation Trust. (6th June 2018; 2018; 2019.)

Royal Devon and Exeter NHS Foundation Trust given "green light" for new patientcentred comprehensive electronic health record (RD & E NHS Trust, 6 June 2018).

Royal Devon and Exeter NHS Foundation are implementing a new patient-centred comprehensive EHR (EPR). The work is expected to complete in June 2020. There were a few online news items and documents relating to the project.

The trust had relied on a 32-year old paper-based clinical information system. Insufficient paper-based records system causes:

- Significant variations, duplications and manual workarounds in our current processes;
- Variation in care, and the consequences for individual patients,
- Extends length of stay, and
- Creates inefficiencies within the way that we operate and the resources that we consume.
- Basic details and medical history are taken from patients several times as they move through their pathway.
- The paper-based system provides insufficient and untimely prompts to clinical staff, meaning that early warning signs related to a patient's health may be missed and treatment becomes reactive and urgent.
- Treatment can be provided in departmental 'silos', which complicates handoffs between departments along patient pathways and may increase variation of how care is delivered and outcomes." (RD&E NHS Foundation Trust, 2018) (RD & E NHS Foundation Trust, 6 June 2018)

The Trust had three options: A) do nothing, B) do minimum, C) transform acute and community pathways and implement EPRs.

The Trust decided to move from the paper-based records straight into an EPR.

- The EHR programme used to create a comprehensive electronic patient record (EPR) is based on Epic (<u>https://www.epic.com/</u>), a US-based Healthcare technology company. (Broadly and globally used system)
- The decision is the corner stone of the broader programme of change to create patient centred care and making the RD&E more clinically and financially sustainable for the future, enabled by new tech.

- The proposed My CareProgramme has been planned based on three key elements:
 - 1) Pathway redesign;
 - 2) EPRs implementation, and
 - 3) Enhancement of the IT 'Warranted Environment' infrastructure. (RD&E NHS Foundation, 2018)
- Epic provides an integrated platform just one record for each patient to give care providers a full view of each patient's story. This replaces the fragmented, largely paper-based system.
 - "For the first time ever at the RD&E, key aspects of a patient's care their medical history, current medications and latest test results – will be available in a single encrypted interactive digital care record which can be updated in real time." (RD&E NHS Foundation, 2018)
- MyChart portal, available via an app on smart-phones or online, will contain the patient's:
 - o Medical history
 - o Test results
 - Secure messaging with providers
 - Appointment scheduling
 - Health reminders for overdue health maintenance screenings, wellness visits, etc.
- The implementation of MY CARE started in September 2018 with the work expected to last 23 months prior to going live in the summer of 2020.
 - "Extensive work in preparing our people, patients and our public for this new way of health care provision will be undertaken including patient engagement, redesign of clinical services and pathways, IT system testing and staff training."
- The process has been given £42M funding (RD&E NHS Foundation Trust, 2019)

MY CARE will provide a range of benefits to patients, including:

- Easy and secure access to their own records empowering them to take more control of their own health and wellbeing;
- Removing the need to repeat their information over and over again, and getting their test results quicker;
- Receiving alerts if an appointment becomes available due to a cancellation;
- Patients and the staff caring for them will have an easy and immediate, realtime access to a comprehensive picture of the patient's healthcare history and treatment plan. Also the GPs and staff providing care within patients' homes

will be able to access the information, as well as having the latest tech devices to manage care in a more mobile way;

• The new way of working and the use of cutting-edge technology mean the current frustrations faced by staff from having to log in multiple times to several computer systems, and the use paper documentation and forms will be eliminated. This will give clinicians more time to care for patients. (RD&E NHS Foundation Trust 2018)

8. Features that can make an EHR more patient centred (Gur-Arie, 2011)

• **Transparency:** e.g. sharing a full, well-documented medical record with patients via a Patient Portal. Currently EHR can be too long and complex for that. Providing a longitudinal view of patient's condition, treatments and progress would be helpful for people managing their LTCs. This is rarely available to patients.

"It would be infinitely more conducive to transparency if Patient Portals would include full subscriptions to such sites as <u>UpToDate</u> and test results documentation, including reference ranges and abnormals for each test resulted in the chart, in plain and simple language. Another patient-centred feature available in many EHRs is the longitudinal record (or flowsheet)"

- **Individualisation**: helping to tailor care experiences to individual needs. E.g. EHRs should know the age and educational level of the user and adjust the available information accordingly.
- **Recognition, Respect and Dignity:** allowing patients to insert small reminders to their details, e.g. afraid of needles.
- Choice in all matters without exception: aiding patients with obtaining the necessary information to make choices allowed by the system they find themselves within. Ensuring the algorithms in the EHR adhere to integrity of clinical information and don't allow management manipulation of vulnerable patients for financial gain. Regulatory intervention is recommended.

Things to avoid in EHR design:

• Over-structuring and designing with rigid rules to encourage data standardisation, can lead to Patient-related Information Problems (PIPs). (Murphy et al., 2017)

9. Me to We: Introducing Collaborative Health Record (Ramsay and Seth 2017)

"Patients are the most under-utilised resource in health care". (de Bronkart, 2011)

A lot of the dissatisfaction of the medical professionals with the EMRs stems from feeling overwhelmed by "redundant data entry tasks", while patients' frustration with EMRs is down to not being able to access their own data. In their article "From Me to We", Ramsay and Seth (2017) introduce the concept of "Collaborative Health Records" (CHR), as a way to improve communication and engagement between patients and their health care teams, while recognising that health care needs are not restricted to regular office hours. They advocate moving away from managing documents in EHR design to managing relationships.

(NB! The concept of CHR is close to the "next generation EHRs" idea, where the patient is a core user of the EHRs).

The increasing adoption of patient-centred, multidisciplinary care team approach to health care requires the facilitation of communication and collaboration between the following relationships:

- The patient and the physician;
- The patient and the care team;
- The physician and the care team.

In contrast to the EHRs, the Collaborative Health Record (CHR) can ensure digital engagement by relying on the following principles:

- Involving patients as active participants in their own health record;
- Integrating patient-reported outcome measures (PROMS) in the workflow.
- Facilitating collaboration between patients and the care team that goes beyond in- person visits, including synchronous (e.g., videoconferencing) and asynchronous (e.g., secure messaging) communication.

The traditional EHRs were designed around the assumption that clinicians and other health care providers were the only sources of medical information. However, many studies have raised questions about the quality of data entered into the medical records by physicians, showing discrepancies between patient histories and physician notes. Having patient-generated information stored in discrete data packages coded according to international standards (SNOMED CT, ICD-10, etc.) would allow physicians to focus on health promotion and treatment rather than data management

To enable such collaboration, new CHR information systems take different approach to user and access control structures than the traditional EHRs. The record keeping systems acknowledge that:

- Non-physicians, such as nurses, Allied Health professionals and meaningful partners play a role in providing care along with healthcare professionals;
- Different users require fundamentally different access levels;
- Unique personalisations of the software are available to them:
 - E.g. physiotherapist would not be granted access to lab results or prescription data but could access clinical notes e.g. about muscleskeletal issues.

This kind of personalised access acknowledges that the role of a given health care provider may vary from practice to practice and may evolve over time, and that it is impractical to restrict a provider's access based simply on the record system.

CHR system enables team members to communicate with one another and loop in the patient as appropriate in care-related discussions, and conversations are made even more productive with the integration of online message threads for a specific item (e.g., a lab test result, a prescription). Ideally, CHR would fully involve patient in their own care; enable them to fill in their own health data.

Integration of patent-reported outcome measures

Having the mechanism to collate patient reported outcomes at the level of a medical condition is the single highest priority in improving the performance of the healthcare system, according to Harvard economics professor Michael Porter. However, to date, collection of PROMS has been largely absent from EHR designs.

The CHR model aims to make a mechanism available to patients to report longitudinally on the outcomes that are relevant to them in terms of quality of life and other measures based on interventions that are suggested to them by their care team. The aggregated data can then serve as the foundation for personalising care and validating health care spending on a systems level. Seth and Ramsay (2017) envisage, for example, that a patient, who books to discuss concerns of depression would automatically be asked to fill in a Depression Test questionnaire on their smart phone before the visit.

By way of conclusion, Seth and Ramsay (2017) call for the physician community to embrace the new developments in electronic record keeping technologies, and advocate moving away from managing documents to managing relationships.

10. Creating Patient-Centred Health Records (Elias, 2016)

This is a blog post describing a different model for EHRs, a Patient-Centred Health Record, to overcome issues with interoperability with institution-owned EHRs. The text spells out the next generation of Person-Centred Health Records idea.

- The cornerstone of the EHR is a record unique to that patient to store his or her health information.
 - It is recommended the EHR is based on 'open source' code (e.g. New Open Source Health Charting System or NOSH, by Michael Chen. Read more about this at <u>https://noshemr.wordpress.com/</u>.)
 - The EHR is owned and controlled by the patient.
 - All health information relating to that individual patient is stored in it.
 - It functions as the 'Source of Truth.'
 - The patient has full access to their data.
- The patient-centred record (such as NOSH) has a component that allows the patient to control who can see, change or use the information.
 - This is sometimes called UMA (for user management and authentication).
 - It has other names such as HIE of One (health information exchange of one).
 - This is what allows the patient to manage who has access.
- Clinicians access the system through their own software using one of two mechanisms:
 - They use a parallel open-source software system that has a list of the patients using individual patient records they have been authenticated to use.
 - They use (work in) their institution's proprietary system which is linked to and synchronised with the official patient-owned record.
 - In both cases, the patient's record is the Source of Truth and fully accessible to the patient.
- There are interfaces that make connections work.
 - FHIR (pronounced fire) is the one talked about here.
 - Other 'application program interfaces' (APIs) can be developed or used, especially if the system is open source.

There are several important considerations in a system like this:

• Open source improves security, adaptability, flexibility.

- It is based on the assumption that patients should have full control over their health information according to their own needs, not just be given limited access by clinicians or their systems.
- If patients have full control over access to their health information, it goes without saying that they can access their own health information without either delay or barriers.
- The system can be adopted incrementally rather than requiring the entire healthcare system to do it in one go.
- Patients and clinicians can help us move from where we are now to a patientcentred health record system by:
 - Understanding the concept.
 - Being at least somewhat familiar with the terminology.
 - And MAKING NOISE about wanting a system like this in their local setting.

11. Reimaging the Future of EHRs: Doctors subscribing to the newsfeed on their patients? (Choi et al., 2018)

The article by Choi et al. (2018) suggests that the EHRs should be restructured from digital remakes of the paper records into platforms that allow doctors to subscribe to their patients' clinical information to receive real-time updates when an action is required, similar to social media feeds and notifications.

The research team developed a Web application to retrieve real-time information from the health system's multiple digital sources and allow it to be reassembled into customisable dashboards, mobile displays, and push notifications. The result was a platform able to tailor streams of data for particular clinical scenarios and measure the impact.

In an early pilot, clinicians who opted in were subscribed to push-notices about their patients' medication expirations.

The major changes from the trial:

- Digitisation made medical charts more legible and accessible remotely;
- The subscription service meant that the clinician did not need to visit the chart to be on top of things.
 - For example, inpatient teams subscribed to text reminders for "last call" deadlines for ordering services and medication to do this on time.
- The subscription services can shorten the lag time between when information became available and when it was used.
 - For example, the evaluation of mechanically ventilated patients can be done automatically according to specified readiness criteria based on digital information, rather than having to wait until a physician is able to attend to the patient. Now clinicians receive automated prompts from the system to act when the criteria are met. Freeing these evaluations from dependence on the whims and routines of the day reduced delays so that patients spent, on average, a half day less on a ventilator.
- The subscription services allow for **filtering of information to emphasise** what's important and relevant.
 - For example, monitoring patients discharged on intravenous (IV) antibiotics previously relied on a process similar to picking out patients needing long-term follow-up. When the infectious disease team began subscribing to all patients slated for discharge on IV antibiotics, handoffs happened within hours rather than days after discharge, and in some cases plans for IV treatment were redirected to oral treatment. For these teams, the ability to define first which patients they wanted to

follow and then what they wanted to know about them replaced the older, more laborious and error-prone practice.

- The subscription services permit **management of panels of patients** (stratification). Pushed alerts work for patients in any setting.
 - For example, Choi et al. (2018) report that one of their programs monitored the 30 highest users of care in one hospital, using a dashboard to follow their needs. Key details, such as the best ways to communicate with the patient and engage with the family, and the next steps for setting up social services were kept on the dashboard. The cross-disciplinary team involved was automatically alerted to these patients' arrival in the emergency department and were pointed to the previously prepared action plan, which guided them in real time.
- After a year of using the system, 30-day readmissions had decreased by 67%, and total hospital days by 56%, respectively.
- Subscription services help erode the distinction in follow-up care between inpatients and outpatients, focusing on what patients need rather than on where they are.
- Creating a subscription service requires
 - Programming skills;
 - Clinical sensibilities;
 - Foundational platforms;
 - Application programming interfaces providing access to real-time data;
 - Leadership commitment to providing the time and license to test clinicians' imagination of how things might be different.

12. Integrated, national EMRs + EHRs + PHRs + Social Security System (Jormanainen 2018)

This is a future-oriented example of actual implementation and adoption of a nationwide, comprehensive and integrated health and social care records system - Kantaservices in Finland. The system brings together national EMRs, EHRs, PHR and Social Security system. The implementation has taken 20 years in two phases. If this is of interest for the programme, please, see Jormanainen 2018: https://journal.fi/finjehew/article/view/74511. 13. Bonus - The Improvement Journey: Why organisation-wide improvement in health care matters and how to get started. (Jones et al., 2019)

Key points:

- Building an organisation-wide approach to improvement is a journey that can take several years. It requires corporate investment in infrastructure, staff capability and culture over the long-term.
- An essential early step is securing the support and commitment of the board for a long-term programme, including their willingness to finance the skills and infrastructure development needed to implement it.
- The report includes case studies of three English NHS trusts with an outstanding CQC rating that have implemented an organisational approach to improvement.

Organisational approaches to improvement are underpinned by several key elements:

- Leadership and governance visible and focused leadership at board level accompanied by effective governance and management processes that ensure all improvement activities are aligned with the organisation's vision.
- Infrastructure and resources a management system and infrastructure capable of providing teams with the data, equipment, resources and permission needed to plan and deliver sustained improvement.
- Skills and workforce a programme to build the skills and capability of staff across the organisation to lead and facilitate improvement work, such as expertise in QI approaches and tools.
- Culture and environment the presence of a supportive, collaborative and inclusive workplace culture and a learning climate in which teams have time and space for reflective thinking and feel psychologically safe to raise concerns and try out new ideas and approaches.

Link to the visual guide on improvement journey: https://www.health.org.uk/sites/default/files/2019-05/2019-THF Improvement journey visual.pdf

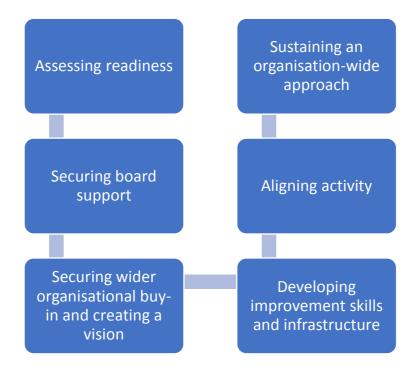


Table 3: Six key steps in Improvement Journey.

- Assessing readiness: How ready is the organisation for improvement, in terms of its learning climate, infrastructure, governance and leadership? Tools are available to help with assessing the organisation's readiness and addressing any gaps.
- Securing board support: Implementors must have confidence in and commitment to the organisation's improvement strategy, and to building the required skills and infrastructure. A strong clinical voice at board level can help make improvement a priority.
- 3) Securing wider organisational buy-in and creating a vision: Staff at all levels need the permission and time to engage in improvement. Consider rolling out the project in stages, starting with enthusiasts then encouraging others to follow.
- 4) Developing improvement skills and infrastructure: Teams will need the capability and resources to support the improvement programme. Make sure you have necessary the data and systems to measure impact, and that the staff teams have the necessary skills to use them.
- 5) Aligning activity: As the improvement programme grows, aligning activity with the organisation's overall strategy is crucial. Making sure that clinical, managerial and corporate teams are pulling in the same direction should help overcome barriers to improvement.
- 6) **Sustaining an organisation-wide approach**: It takes time for an improvement programme to embed. Maintaining momentum takes as much effort and skill as getting started. The board must stay focused and supportive in the face of external pressures, despite the uneven pace of improvement.

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