A qualitative evaluation of the CIE Programme implementation in North West London
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1. Foreword

The NHS Five Year Forward View addressed the ever increasing need for the improvement of NHS digital technologies, with the aim of establishing fully interoperable electronic medical records (EMRs). The Care Information Exchange (CIE) allows for the transfer of these records between different health care organisations. With the financial strain on the NHS, it is a crucial time to realise the opportunity that robust and safe data sharing will enable in terms of quality, safety and cost-effectiveness.

This report jointly funded by the Imperial College Healthcare Charity and the Peter Sowerby Foundation aims to evaluate the Care Information Exchange (CIE) in North West London. It aims to provide lessons for future Healthcare Information Exchange implementation plans by understanding factors that influences the implementation of the CIE Programme at various levels. The report evaluates the barriers and enablers to successful adoption of the CIE, the optimum clinical settings for the adoption of the CIE and best approach for successful stakeholder partnership.

Thanks to the Peter Sowerby Foundation for their continued support in providing us with the opportunity to lead a major programme of research in the area of e-health and to develop this report. As a pioneer of electronic health records, the development of the Care Information Programme takes forward this work through the ongoing research into technologies that improve the delivery of healthcare.

I hope this publication will give readers a better understanding of the challenges faced in establishing the CIE and encourage providers to review their own systems with an eye toward improvement.

Professor the Lord Ara Darzi
Director, Institute of Global Health Innovation
2. Introduction

The NHS Five Year Forward View plan, which sets the strategic direction for the health service, focuses heavily on improving NHS digital technologies with the aim of fully interoperable health medical records (EHR). EHRs are used to improve health outcomes and patient satisfaction, and national interests are further moving towards enabling clinical providers to transfer information between health care organisations in health information exchanges (HIE).

An HIE is a technology platform that enables patients to view details of their health and social care and coordinate various elements of their own care. They are being incorporated into national healthcare IT programmes that seek to meet overall goals of 1) allowing patients to access and control their own health records 2) defining the core content of these records and standardising the way that this information is entered and analysed 3) developing data security and national data sharing policy, and finally 4) producing standardised, interoperable EHR systems for data sharing and information management. An HIE further seeks to improve population health by sharing patient information across integrated systems of electronic medical records (Figure 1).

However, novel IT programmes that involve data sharing often face delays and challenges in implementation due to many issues including difficulties gaining clinician buy-in, or concerns from patient groups about privacy. The UK’s National Programme for IT (NPfIT) was the largest national IT programme launched in 2002 as a way to integrate EHR in order to improve service delivery and patient care. However, the programme was met with resistance from healthcare professionals due to concerns about a top-down imposition of a national IT programme onto local systems. As a result, the programme was discontinued in 2011, and healthcare providers continued to seek local solutions to integrate electronic medical records through the use of HIEs. This report will describe one such implementation programme known at the Care Information Exchange (CIE) in North West London.

*Figure 1: Digital records as a tool to lead to increased patient engagement, integrated care, and improved population health*
Context of the report

This is the first of two linked reports that evaluate a HIE known as the Care Information Exchange (CIE) in North West London. When evaluating a complex intervention such as a HIE, it is important to analyse the impact in various ways, using a mixed methods approach to gain a full picture. The initial proposal was to evaluate the CIE in NWL across four domains:

- How the CIE is utilised by patients?
- How clinicians perceive the CIE?
- Whether the CIE improves patient activation?
- Whether the CIE changes service utilisation?

Whilst the Imperial College research team were able to collect a small amount of baseline data, the services they had selected to evaluate did not reach roll-out within the necessary timeframe. The selected services were diabetes and later, elderly care. The decision to focus on these areas was supported by the evaluation steering committee.

In order to deliver a useful product within the timescales for which funding was available, it was agreed with the steering committee in November 2016 that the research team would instead focus their efforts on evaluation methodologies which would not require service roll–out:

- An assessment of the cost-effectiveness of electronic health records
- A reflective qualitative evaluation of the implementation of an HIE

This is a report summarising the project set out in the final bullet point – a qualitative evaluation of the implementation of the CIE in NWL.

The intention is to capture some of the lessons from this implementation which could be useful for both the Imperial implementation team and other implementation teams across London and the rest of the country.

Aims and objectives of implementation evaluation.

The aim of this implementation evaluation was to provide lessons for future HIE implementation plans by understanding factors that influenced the implementation of the CIE Programme at various levels (policy, technical, organisational, information governance, consumer). This evaluation addressed three key questions of the CIE in North West London:

- What are the barriers and enablers to the successful adoption of the CIE?
- In what kind of clinical settings are the CIE more readily adopted?
- What is the best way to persuade stakeholder groups to take part in the CIE?

This work was conducted as a reflective process evaluation of the implementation of the CIE. Whilst an outcome evaluation describes the outcomes of an intervention, for example the number of patients who signed up for a CIE and whether patients derived any clinical benefit from its use, a process evaluation describes key factors about how and why those outcomes were achieved. This type of knowledge enhances the practical utilisation of an intervention by considering contextual issues that could affect intended outcomes, for example by describing factors that impact the implementation of an intervention into real world settings. Funders, policy makers, researchers and project managers could greatly benefit from an increased focus on integrated evaluations that address both process and outcomes. The research conducted and the report was prepared as part of an independent evaluation by researchers from the Sowerby eHealth Forum at Imperial College London.
The CIE in North West London served as a case study to explore issues of wider implementation of HIEs. The CIE programme aimed to put patients at the centre of their care through an electronic portal that contained health records, correspondence from various providers and forums to discuss care. The principles of this programme fit within the political framework to enhance NHS digital maturity and promote a more patient-centric care system.

The CIE Programme, led by the Imperial College Healthcare NHS Trust and funded by the Imperial College Healthcare Charity, was launched in 2014 as an early adopter programme with the intention of future rollout. It aimed to recruit GPs from eight CCGs, social care organisations, and acute, mental health, and community trusts across North-West London.

Day-to-day management of the programme was carried out by the Imperial College Healthcare NHS Trust, who subcontracted development of the CIE platform to an external supplier Patients Know Best (PKB). A steering group met every month to discuss progress. The NW London CIE Programme was projected to last 36 months. The CIE Programme Team initially enrolled patients into the CIE at each participating clinical service, and then trained local teams to complete the registration process.

### NW London CIE Programme

<table>
<thead>
<tr>
<th>Description of CIE NW London Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The NW London CIE Programme faced challenges in implementation and saw delays in the uptake of the programme into clinical services. This section describes the outcomes of the implementation process. The CIE Programme Team provided the Sowerby eHealth Forum team with data pertaining to the uptake of the CIE across services. This data included dates when the CIE began, functionalities of the CIE in different treatment settings, and the number of patients registered and consented into the CIE Programme. The CIE Programme Team did not have access to the total number of patients for each service to account for the sampling strategy employed at each clinic to recruit patients.</td>
</tr>
<tr>
<td>The CIE team was initially approached by clinicians representing six clinical areas who sought to implement the CIE within their services. Two of the original services - neuro-oncology and early intervention psychosis - went on to participate (Table 1). Six additional clinical services that were not on the original proposal were recruited into the NW London CIE Programme and represented diverse clinical specialties. No primary care services had implemented the CIE System at the time of this report.</td>
</tr>
<tr>
<td>At the beginning of February 2017 eight services across two organisations were using the CIE platform. Imperial College Healthcare NHS Trust implemented the CIE System in seven services while the Early Intervention in Psychosis team was the first service at the Central North West London NHS Foundation Trust. The Hillingdon Hospital NHS Trust was in the process of preparing for the system to be launched in its services.</td>
</tr>
<tr>
<td>Early intervention psychosis teams were also recruited from the original grant bid, but took substantially longer to implement than neuro-oncology. As will be described later in this report, this may be due to the sensitivity of mental health conditions and the increased need for privacy amongst patient groups. Therefore, psychosis teams did utilise the CIE later on in the programme implementation, but did so with limited functionality.</td>
</tr>
</tbody>
</table>
Duration of site setup

Overall, the NW London CIE Programme faced delays in implementing the CIE across sites and recruited only two services from its original bid by the time it had aimed to complete its evaluation of the CIE. Table 1 indicates how quickly it took sites to implement the CIE System from the time that the platform went live and recruitment to the Programme began. Sites that were pre-identified early on in the CIE Evaluation Programme (e.g. those who volunteered to participate at grant proposal stage) were not faster to implement the CIE than sites that were recruited once the NW London CIE Programme had already begun. For instance, neuro-oncology began signing patients up immediately upon launch of the NW London CIE Programme, whereas psychosis services took up to nine months to adopt the CIE. This may be due to the perceived sensitive nature of mental health conditions and the need to address potential privacy concerns before rolling out the CIE.

Other services such as colposcopy were approached for participation much later in the programme, but adoption of the CIE occurred more quickly. Individual differences in the time that it took for clinical services to adopt the CIE may be accounted for by clinical specialty types, readiness to adopt a new system, and the functionality of the CIE required for those services. Potential reasons for these delays will be explored qualitatively later in this report.

<table>
<thead>
<tr>
<th>Clinical specialty of service</th>
<th>Considered at start of project?</th>
<th>Time from CIE programme start (Mar 2016) until implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology</td>
<td>Yes</td>
<td>Not recruited</td>
</tr>
<tr>
<td>Diabetes primary care</td>
<td>Yes</td>
<td>Not recruited</td>
</tr>
<tr>
<td>Diabetes secondary care</td>
<td>Yes</td>
<td>Not recruited</td>
</tr>
<tr>
<td>Integrated care</td>
<td>Yes</td>
<td>Not recruited</td>
</tr>
<tr>
<td>Neuro-oncology</td>
<td>Yes</td>
<td>0 months</td>
</tr>
<tr>
<td>Early Intervention in Psychosis</td>
<td>Yes</td>
<td>8 months</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>No</td>
<td>4 months</td>
</tr>
<tr>
<td>Renal</td>
<td>No</td>
<td>5 months</td>
</tr>
<tr>
<td>HIV</td>
<td>No</td>
<td>5 months</td>
</tr>
<tr>
<td>Colposcopy</td>
<td>No</td>
<td>7 months</td>
</tr>
<tr>
<td>Cancer Oncology</td>
<td>No</td>
<td>9 months</td>
</tr>
<tr>
<td>Interstitial Lung Disease</td>
<td>No</td>
<td>9 months</td>
</tr>
</tbody>
</table>

Table 1: Duration of site setup from the time the CIE Programme went live

CIE functionality

The CIE had core functionalities that were offered to all participating clinical services, who could also choose whether to enable sub-features of these core functionalities, such as a messaging service between patients and clinicians (Table 2). All services gave patients access to a general library, discussions-, laboratory-, imaging-, and calendar-tabs. Furthermore, the CIE system could automatically create patient records that initially included adding inpatient activity, outpatient appointments, pathology, and radiology reports and would later include documents such as clinic letters and discharge summary letters. While almost all services provided patients with access to additional service specific content in a library section, only some used the other functionalities.

<table>
<thead>
<tr>
<th>Core Functionality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussions</td>
<td>Gives information about A&amp;E attendance or stays on wards and may offer the possibility for contact with healthcare professionals.</td>
</tr>
<tr>
<td>Health</td>
<td>Users choose from additional options such as laboratory and imaging providing information about test results and patient entered health data.</td>
</tr>
<tr>
<td>Treatments</td>
<td>May offer details on care plans and medication and a library function with advice materials.</td>
</tr>
<tr>
<td>Diary</td>
<td>Displays clinic appointments and can be used to note patients’ thoughts and observations about their health.</td>
</tr>
<tr>
<td>Files</td>
<td>Gives patients the opportunity to save and store scanned documents.</td>
</tr>
<tr>
<td>Apps</td>
<td>Allows for data from personal healthcare or fitness trackers to be uploaded into the record.</td>
</tr>
<tr>
<td>Sharing</td>
<td>Controls access to the record such as the type of information individuals can see.</td>
</tr>
</tbody>
</table>

Table 2: Core functionalities of CIE across services
Patient registration to CIE

Services could enable additional functionalities according to their requirements of a CIE (Table 3). Neuro-oncology was the quickest to commence with implementation, but it also had less functionality and fewer patients enrolled in the service. By contrast, Interstitial lung disease had similar patient throughput but subscribed to a much wider range of functionality. Therefore, whilst the CIE functionality of an individual service may impact the duration of implementation, this factor alone cannot account for delays in the implementation.
While patients had the option to share their CIE records with carers from their families and friends or external medical professionals the frequency with which patients did so was relatively low (Table 5). This could indicate that this functionality is not particularly useful to patients, however this finding may be explained in an alternative way. Patients accessing these particular services may be less reliant on a coherent network of carers and medical professionals to deliver their care. It could also be argued that the ability to actively share your record with others is one of the more unusual features of the PKB software, and this kind of behaviour change will take more time and effort to encourage.

Table 4: Description of patients consented and registered to the CIE Programme. Data from 06.02.2017

<table>
<thead>
<tr>
<th>Service</th>
<th>Patients approached</th>
<th>Patients registered</th>
<th>Percentage of consented patients who registered</th>
<th>N patients consented per month (avg)*</th>
<th>N patients registered per month (avg)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuro-oncology</td>
<td>9</td>
<td>5</td>
<td>55.6</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>204</td>
<td>145</td>
<td>71.1</td>
<td>29</td>
<td>31</td>
</tr>
<tr>
<td>Renal</td>
<td>478</td>
<td>321</td>
<td>67.2</td>
<td>80</td>
<td>54</td>
</tr>
<tr>
<td>HIV services</td>
<td>20</td>
<td>13</td>
<td>65.0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Colposcopy</td>
<td>500</td>
<td>187</td>
<td>37.4</td>
<td>185</td>
<td>47</td>
</tr>
<tr>
<td>Cancer/Oncology</td>
<td>128</td>
<td>65</td>
<td>52.4</td>
<td>62</td>
<td>33</td>
</tr>
<tr>
<td>Lung Disease</td>
<td>1</td>
<td>4</td>
<td>50.0</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Psychosis</td>
<td>15</td>
<td>12</td>
<td>80.0</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>1358</td>
<td>758</td>
<td>55.4 (avg.)</td>
<td>123</td>
<td>68**</td>
</tr>
</tbody>
</table>

Table 5: Number of patients sharing their record with a carer or an external medical professional of total registered
3. Methods

Twenty-three individuals who were directly involved in the NW London CIE Programme were purposively invited to take part in a semi-structured interview with a Sowerby researcher. Individuals invited to interview represented a heterogeneous spread of stakeholder interests in the CIE, including funders, clinicians in services where the CIE was targeted for adoption, CCG representatives, the CIE system supplier, and authors of the original funding bid. In line with the aims of this project, interviewees had varying levels of engagement with the CIE to provide a wide range of perspectives (e.g., policy, technical, organisational, information governance, consumer). While some interviewees were involved in the day-to-day CIE implementation and could speak to programme specifics, others spoke to general issues of implementation such as government policy. The list of potential interviewees was regularly reviewed by a project management team, and reviewed by the CIE evaluation steering committee, to ensure that each stakeholder perspective was adequately represented in the sampling approach.

Sixteen of 23 individuals consented to be interviewed between November 2016 (the time of sign off from the steering committee for this project) and February 2017. Interviews lasted between 30-45 minutes. Interviews were structured around key themes the implementation evaluation sought to address, including:

- General views towards NW London CIE
- Key stakeholders in CIE programmes
- Processes of stakeholder engagement
- Barriers and facilitators to implementation
- Communication approaches
- Advice for future programmes

Interviews were transcribed verbatim by a professional transcribing company. Interviews were then coded by hand using framework analysis to establish key themes that arose across stakeholder interests. The topic guide was used as an initial coding structure. Views presented were from the perspective of interviewees and subject to their individual interpretation of their own experiences with the CIE. All interviews were anonymised and collated by overarching theme.
4. Qualitative findings: Key questions for CIE Implementation Evaluation

This section of the report qualitatively describes some of the processes of implementation, for example why the CIE was not implemented in its original proposed clinical settings or why it faced delays in its uptake. Questions posed to interviewees focused on three main areas: 1) barriers and enablers to the successful adoption of a CIE programme, 2) differences in CIE uptake by clinical provider uptake, and 3) using knowledge gained about barriers and enablers to CIE adoption in order to effectively recruit clinical services in different settings.

National data sharing policy

Clinicians did not always feel that national policies towards data sharing and data management policy were clear, and this lack of clarity fed into healthcare organisations’ information governance policies. This served as a barrier to getting services to participate, particularly amongst GPs who did not have clear direction about data ownership, particularly about who owns patients’ data, whether it is the patients or the system, and what happens to patient data if a site or individual decides to withdraw from the CIE. When faced with this uncertainty, local GPs turned to their Local Medical Committees (LMC), who advised them to proceed with caution regarding data sharing. LMCs took some time to decide whether GPs should release information, as there was a perceived risk that they would be liable for sharing information. Each organisation owned its own data and each GP practice owned its own data. Therefore, data owners had obligations to protect the data and did not always allow patient data to be moved and shared. The CIE had to go through each GP system to get permission to access their data. These safeguards put into place in the context of unclear national guidance on data sharing policy inhibited the implementation of the CIE.

Technical barriers

When the CIE product was commissioned by the CIE Programme, it had been tested and demonstrated successful implementation on a small scale in a few clinical services but it had not seen implementation on a scale as large as that of the NW London initiative. There were technical challenges in scaling up of the CIE system to meet the needs of clinical providers across NW London.

The project experienced difficulties scaling up the product at the pace required to meet key milestones according to its timetables. The product was not mature enough for data to be entered into it, how it displayed results, or how it handled specific pieces of patient information. Technical problems made it difficult to disseminate the software across services, but many interviewees felt that the technical difficulties faced during the project were inherent in any programme that is testing new, innovative practice.

Interoperability

The technical challenges faced in the scaling up of the CIE took on various forms. Firstly, the CIE system had to overcome issues of interoperability in drawing data from various interfaces. Each health and social care provider that had a different ICT system, and the CIE system had to have the technical capability to draw data from these providers. Without national interoperability standards and without a requirement for GP record providers to accede promptly to requests, the CIE Programme team expended a significant amount of time and energy in addressing these challenges.
Developing a system of value to clinicians

- As the scope of the CIE Programme expanded, the CIE system also had to adapt to tailor specific functionalities to diverse clinical settings. The CIE held the greatest value to clinicians depending on the utility of its functionalities. For example, in colposcopy services, patients had expressed that it would be convenient for them to access information about their appointments online. Because the CIE could offer colposcopy patients this functionality, the service felt that the CIE was valuable. However, the nature of these desired functionalities varied from service to service. Each clinical setting had their own needs from a CIE, and the technical development of a CIE platform was delayed to tailor the platform to each of these individual requirements.

- The CIE Supplier integrated any feature required by services into its systems as part of an iterative and collaborative process to prove the feasibility of the concept on a large scale. For example, the CIE developed a feature of privacy labels (labelling data by general, sexual, mental health, or social care data) for clinical services to give patients the power of control over their privacy settings for each label. The system also had to ensure that patients did not feel that control over their privacy settings was a burden where they would have to authorise everything. There was also a need for the provider to have ongoing discussions with clinicians to understand how the development of these privacy labels impacted their workload. With this iterative process of product development to build a system that was acceptable to patients and clinicians, came delays in implementation.

- Clinicians expressed that they wanted particular functionalities from a CIE, but also that it should be a system that would be convenient for them and minimise the impact on their day-to-day basis. The CIE Programme took a phased approach to the implementation by ensuring minimal impact on doctors and instead focusing on giving patients access to the CIE system. However, the CIE would have greatest value if clinicians also interacted with the system. Challenges in interoperability meant that each clinical system had its own sign-in system, and clinicians would have to have a new username, password, and clinical system to learn. Clinicians were sometimes reluctant to use the CIE because there was no single sign-on system in place. They also potentially disengaged if they experienced bugs in the system that were not addressed quickly enough.

Clinician engagement

Two barriers to clinician engagement were their concerns about an increase in their workload generated by a CIE, and a lack of clear direction about whether patients wanted their data to be shared between organisations. Overcoming these clinician barriers and gaining engagement from individuals within services was critical to implementation, but as implementation was delayed, these champions potentially lost their enthusiasm for the CIE. In some services, stakeholder engagement was more complex and where negotiation processes were protracted, the CIE implementation team had difficulty keeping all parties involved, happy and engaged. Delays in the implementation of the CIE generated by slow technical development of the product and by delays caused by information governance increased the likelihood that clinicians would lose interest and enthusiasm in adopting the CIE.
Increase in workload

- A frequently cited barrier in the implementation of the CIE was concern amongst clinicians that the system would increase their workload once the system was in use. Increased workload could be generated in several different ways:
  - Due to the risk of increased enquiries from patients if they had access to their results.
  - The need for clinicians to change the way they work for patients to see benefits from the CIE.
  - The workload of creating useful resources for patients that would be uploaded onto the CIE.
  - Concerns about safety of patients when releasing their medical information to them.
  - The increased workload of a system that does not integrate with pre-existing systems.

In sites where the CIE had been utilised before this implementation, clinicians claimed that the software actually reduced the amount of time that they spent sorting through patient enquiries, and that there was no increase in the number of problems and enquiries faced. However, this continued to be a concern amongst clinicians when approached to participate in the NW London CIE. Furthermore, clinicians chose what functionalities they would like to be enabled in the CIE, such as messaging services. Therefore, they had the option to choose what functionalities would impact their workload.

Lack of awareness of patient view towards data sharing

- Clinicians did not always have a clear understanding of patients’ views towards data sharing, and therefore their default stance was to protect data rather than to share it. In colposcopy services, patients had completed a patient survey indicating that they would like easier access to their test results and appointments. Therefore, colposcopy services responded to patient views about this, and implemented the CIE with these specific functionalities.

Clinical champions within services

- Clinical services needed to have a clearly identified clinical project leader to champion the CIE within services. This clinical champion could either directly negotiate CIE access to their services or to provide “insider intelligence” on how to negotiate with clinical services. Finding clinical champions may in some cases have been hampered by the fact that the CIE was being led by the dominant provider in that area. Pre-established relationships between the Programme Team and acute care providers may have facilitated the implementation of the CIE.

Acute care provider engagement with the CIE

- Acute care providers thought there was value in giving patients access to their record, particularly in clinical treatment areas where patients had increased contact with services. The CIE Programme Team may have had easier access to acute provider services because of pre-existing relationships with services that were part of its own acute care treatment provider.

- Additionally, acute care providers were more willing to take part in the CIE because they identified value to a patient seeing their data, enabling doctors to have a more informed conversation with their patients. The CIE also presented opportunity for acute providers to interact with other acute providers and patients, which was particularly beneficial in the treatment of long-term conditions.

- Services such as rheumatology, renal, and colposcopy services were all deemed by those interviewed to be clinical settings that were particularly amenable to the CIE. In these clinical areas where clinicians saw the greatest benefits to data sharing, the CIE was championed.
Clinical areas that were considered to be more sensitive in nature, such as HIV or psychological services were thought to be less favourable environments to start up the CIE. Whilst these services were initially considered for implementation, they saw delays that meant the programme was not yet implemented at the time of this report. However, these delays may have also been caused by a lack of resources and availability from clinical staff.

Primary care provider engagement with CIE

Technical barriers were presented in the recruitment of primary care providers into the CIE due to the lack of interface to GP systems, but there were also other issues that impeded CIE uptake amongst GPs. Whilst primary care providers were independent clinical services, they were also part of GP collaborations or LMCs that reached group consensus about whether to proceed with CIE implementation or not. As mentioned previously in this report, GPs expressed resistance to the CIE largely because they were unclear about data sharing policies and turned to their LMCs for advice. LMCs, in turn, did not feel that they had adequate guidance on information governance around data sharing and thus discouraged GPs from taking part in the CIE pilot. This led to a delay in the development and agreement of information sharing agreements, and referrals back to LMCs further delayed the agreement.

The necessity for GPs to seek advice from LMCs before agreeing to participate in the CIE lengthened the negotiation process of implementation. CCGs were initially approached to lead CIE negotiations on behalf of their GP practices, with each representing about 50 practices. It soon became clear to the CIE Programme team that each GP practice had its own internal data sharing policies and processes. Whilst the team did not have to negotiate directly with each GP practice, the need for bespoke agreements did lengthen negotiations, and in some cases, stall them altogether. Ultimately it is the responsibility of individual GP practices to decide whether to share information.

In addition to the complexities of negotiation amongst GPs services and lack of clarity around data sharing policy, GPs also did not always see the benefits of a patient-led system or see how they would directly benefit from the CIE. It was not clear to GPs what would happen to patient data if they withdrew from the CIE, and therefore the act of signing up may have seemed irreversible.

Case study: Colposcopy services in North West London

Colposcopy services were not included on the original NW London CIE Programme bid, but directly approached the Programme Team for participation. Clinicians in the service first began to consider the need for a patient-accessible care record after patients expressed interest in being able to access their appointment times and tests results online during a survey conducted by the service. The clinic’s consultant then approached the NW London CIE Programme Team, who presented the system to the Colposcopy team. Once they expressed interest in taking part in the CIE Programme, the initiation period was quick, and the service implemented the CIE within the same month.

Colposcopy nurses were initially concerned that the CIE would increase their workload due to patients not understanding their test results and inundating the service with queries. In routine practice, test results are sent to patients in a letter that fully detailed what the results meant in textual detail. However, in the CIE, test results were presented without elaboration, and therefore the service took care to create new patient information leaflets in case patients had concerns about their CIE record. The CIE was used as an adjunctive measure in colposcopy services, and therefore patients still received a letter detailing their test results alongside a leaflet that explained their results. This letter was sent to patients before they were able to access their results through the CIE System. There was a 28-day delay in the time that laboratory results were received and uploaded onto the CIE System for patients to access.

Clinic staff reported that they did not see an increase in queries after the implementation of the CIE System, but thought this may have also been attributed to the increased provision of information to patients. Clinic staff reported that the CIE System did not add to their workload or increase the amount of time they spent per day.
Developing a joined up communications strategy

- The implementation team utilised a communication strategy that used clinicians as gatekeepers to access patient groups, but a wider more joined up communications strategy was recommended to gain interest from potential participants (both clinical settings and patients). For example, a communication strategy that reached out to the patient population in NWL as a whole might have created grassroots pressure on more services to implement CIE. It was suggested by almost all interviewees that there needed to be a more comprehensive communications plan so that more patients and healthcare workers were aware of the CIE. However, it should be acknowledged that this approach risked creating high expectations about roll-out that could not be met.

- Interviewees recommended for future implementations to use a multimedia approach, through websites, posters, flyers, and social media. Where services were fatigued with CIE implementation negotiation, a communication strategy was seen as a tool to re-engage those services through a multimedia approach. And a communication strategy needed to make the process of taking part as easy as possible. There was also a suggested need for increased visibility on the website. It was recommended that CIE implementation programmes start small in scope in order to build up a communication model to recruit other services into the project.

- Furthermore, the communications strategy utilised by the CIE implementation team was perceived as being driven by the implementation team, but there was a recognised need for engaged, local clinicians to champion the CIE within a service. Where those champions existed, as above, sites were more engaged and willing to participate. Getting more organisations on board increased the value of the CIE, and therefore more organisations were needed to build a persuasive case.

Communicating the benefits to individual stakeholder groups

Each stakeholder group involved in the CIE had unique interests in participating in the programme.

Clinicians

- Clinicians wanted to see that a CIE would benefit patient populations, but also that patients wanted access to their records. This was particularly the case with GP providers, who were not yet convinced that a CIE was something that patients wanted. If patients did not know about the existence of the CIE, then they could not express interest in it. An effective communication strategy would make a clear case for the value proposition of clinician involvement, for instance ensuring that the CIE was simple to use and did not take up much clinician time, but also led to significant patient benefit.

- CIE Programme teams should not assume that the case for taking part in a CIE is self-evident, and should rather consider a persuasive case to address each barrier or concern towards participation held by clinicians. Many clinicians articulated concerns about workload increases as discussed before, but these fears were not realised in real practice. In order to communicate the benefits and overcome the concerns that clinicians had about the CIE, it was suggested to demonstrate previous successes in the programme and, that in early adopter sites, the CIE wasn’t shown to increase workload. Financial incentives for participation could have been offered to clinical services, particularly GPs, to encourage them to test the CIE.
An effective communication strategy to clinicians would emphasise the benefits of patient-driven systems. Clinicians needed evidence that patients desired access to their own records in order to persuade them to participate. Thus, a CIE programme should be pitched as one that seeks to benefit patients, rather than a technological programme. Clinicians wanted to see something that benefits both them and their patients. Because GPs showed more resistance to the CIE than acute care providers, interviewees suggested engaging with GPs earlier on in the process to minimise delays in implementation to overcome the technical barriers they faced in sharing data. The CIE team also needed to make data sharing desirable to the GP practice point of view.

Funders

The CIE Programme was initially funded by a charity to build evidence demonstrating the effectiveness of a CIE in improving patient care. The funding charity had to see that it was aligned with the aims of their organisation, and that it was a system that was desired by patients. Therefore, the CIE Programme had to put patients at the forefront, and needed to gather data to show that it was a useful tool to them.

CCGs

The CIE Programme demonstrated that teams must engage with CCGs in order to gain continued participation from primary care providers. While the CIE Programme was funded by a charitable organisation, continued funding to ensure routine implementation of the CIE would come from other sources, including CCGs. In order to achieve this, CCGs needed evidence that the programme would reduce workload, cost, and improve patient outcomes. They also needed clear guidance on government data sharing policy, the conditions under which data can legally be shared and protected, and ultimately that patients want access to their records.

Patients

Patient interest in accessing their records could be utilised as a tool by CIE Programme teams to gain leverage amongst all stakeholder groups, but interviewees felt that they were often the last to hear about the CIE through their doctor. A wider communications strategy would enable patients to hear about the CIE and ask their doctor about it rather than relying on clinicians to serve as gatekeepers to patients. During the implementation of the CIE across NW London, there was some press coverage about the CIE supplier. However, interviewees felt that when patients approached their clinician about the CIE, their clinician may not have yet known about the programme due to the lack of a universal communications strategy for the CIE Programme that sought to educate all clinicians and patients about the CIE.

Different patient groups saw different benefits from accessing the CIE, and these findings could also be used to feed into an effective CIE communications strategy. Some of those interviewed noted that patients over the age of 50 were the most keen to access their health records. This was due to the greater frequency with which they presented to health care settings thereby increasing the value of being able to readily access their own medical records and to share them across care settings. Younger users were thought to have greater ICT literacy, but did not always demonstrate the same level of engagement with health services and therefore did not always have the same level of interest in gaining access to their records.

Patients expressed interest in the ease of accessing their records through a CIE, but they also wanted to see that they were in control of their records, for instance who can access particular types of information about them. There needed to be technical capability to enable these user-friendly privacy controls. Early data indicated that patients were using functions to share data with other medical professionals (who may not have been signed up to the CIE) and carers. Patients should be involved in a CIE implementation from the start of a project to ensure that the product being developed is useful and acceptable to them, and that there is greater patient awareness of such programmes.
5. Discussion

The CIE was a complex, dynamic project that had to continuously adapt to the needs of the individual stakeholders whose engagement was pivotal to the successful implementation of the programme. These stakeholders included policy-level stakeholders to clinicians and patients, but the drive of the project occurred through an interaction with all of these groups. For instance, policy-level issues around national data sharing agreements influenced the willingness of clinicians to take part in the CIE, as did patient level engagement. Where patients expressed interest in the functionalities of the CIE, clinicians engaged more readily with the programme. Clear direction on policies around data sharing was necessary to ease barriers faced by clinicians, and there was a demonstrated need to engage more with clinical champions who served as critical gatekeepers to service participation in the CIE. Furthermore, there were key differences in the way the programme team engaged with GPs and acute care providers because of the differences in the ways that those providers responded to the CIE programme team.

What were the barriers and enablers to the successful adoption of a CIE?

National data sharing policy

Stakeholders indicated that national data sharing policy was not clear enough to clinicians, and this served as a substantial barrier to the uptake of a CIE amongst clinical providers.

Technical barriers

Technical barriers around interoperability further impeded the uptake of the CIE. Improved interoperability and functionality of medical records was recommended by the 2016 Wachter Review, and government policy has sought to address these recommendations through policies such as Personalised Health and Care 2020. These policies could pave the way for future implementation programmes, and whether this occurs will reflect the success of these policies in achieving their objectives.

Clinician engagement

Clinicians’ concerns that communicating with patients through messaging services will add to their workload have not been proven.

Project management

Finally, the scale of the implementation barriers was not predicted by the project team, and therefore the timescales of the project were inaccurate.

In what kind of clinical settings are CIEs more readily adopted?

The CIE saw implementation success depending on the type of clinical treatment setting that was adopting it. All stakeholders interviewed identified potential challenges in implementing a CIE in primary care settings and at the time of this report, the CIE had yet to be implemented in primary care. Acute care settings were deemed to be more tenable, as evidenced by the successful uptake of the CIE in those clinics. However, even in acute care settings, the CIE was adopted more readily in services where patient data was not considered to be sensitive in nature. The complexity of workflow of particular clinical settings impeded implementation in many ways, and thus the project may have had more success if it had selected clinical settings where patient pathways are more straightforward in the beginning. There were delays in trying to get complex services up and running.
The CIE was an adjunct to patients’ traditional means of interacting with their health care provider. Other research carried out by the Sowerby team has shown that patients are much more likely to access their record if it offers them full functionality. However, some of the services involved in the CIE roll-out did not make use of the full functionality offered by PKB, or had engagement with patients over a limited period. For example, in colposcopy services, patients do not typically have a long-term relationship with the service. The CIE may have more potential in other clinical settings where the patient interaction with services is on-going, such as renal services.

**What is the best way to persuade stakeholder groups to take part in a CIE?**

The diversity of stakeholder interest in the CIE demonstrated that there was not an effective “one-size-fits-all” approach to implementing the CIE across services. Each clinical service had unique requirements of the CIE, and had different levels of readiness to adopt a new system. The time that it takes to account for those individual requirements must be considered when developing timelines for implementation.

Interviewees suggested that data from early adopter sites be used as a source of early learning to recruit other services into the programme, but indicated that this needed to be part of a wider communications strategy. Interviewees indicated components of a successful strategy that would potentially facilitate CIE uptake.

### 6. Limitations

Interviews reflected the opinions of individuals who were active and engaged in the CIE Programme or CIE Evaluation. Clinicians from other clinical organisations who were not participating in the Programme did not respond to requests for interview, but could have provided more detailed insight into barriers amongst particular stakeholder groups.

### 7. Future recommendations

On the basis of the findings of this CIE implementation evaluation, several recommendations for future similar programmes can be made:

- Move away from centralised models of programme management in similar programmes by using a multilateral communications strategy to engage all stakeholder groups. This can be achieved by embedding patient and clinician co-design from the outset, in both the development of HIE systems and in strategies to communicate them. Communications approaches associated with implementation of programmes. Communicate the benefits of an HIE to stakeholders who act as gatekeepers to patients; “championing” the benefits of the HIE could come from patients as well as stakeholders who are not directly involved in an HIE. A sweeping marketing strategy could bring more external interest into the programme. Ultimately, clinicians want to see data that shows that patients want the HIE and benefit from an HIE, and patient-targeted communications could generate grassroots interest in future projects. However, a caveat to this approach would be that patients and clinicians might be informed about a product that is not yet available to them, creating disappointment and distrust.
• Allow enough time to develop a product that is acceptable to stakeholder groups. In order for an HIE to be adopted by services, the system has to be one that is useful to patients and clinicians by being responsive to their changing needs. An HIE must have the technical capacity to address patient needs around convenience and privacy. Primary care providers are complex organisations rather than single bodies to be negotiated with. Therefore, implementation teams should approach them early to account for these longer and more complex negotiation processes.

• Start small in order to establish “proof of concept” by beginning implementation in service types that would see the greatest benefit to participating in an HIE.

• Clinicians’ reluctance to participate in an HIE when there was a limited evidence base underscores the importance of conducting evaluations to develop a case to present to clinicians in order to generate that evidence. Embedded process evaluations like this one are critical, particularly because a system can, in theory, lead to substantial benefit to clinicians and patients. But if there are too many factors that inhibit its implementation and uptake into routine practice, the full benefits of an HIE will never be fully realised.

• HIE programmes should profile the populations they wish to target and consider developing system functionalities that align with patient need. This will maximise patient willingness to engage with HIE programmes.

• Data sharing policies should be clearly communicated to healthcare professional groups so that they understand the circumstances when patient data can be shared, and with him. Local information governance should ensure that national government policy around data sharing is effectively communicated on a local level.

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9. Acknowledgements

We are very grateful to the significant contribution of the following individuals who provided information used to shape the content of this report.

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