

CARE INFORMATION EXCHANGE (CIE)

NORTH WEST LONDON CCGs

INTRODUCTION

The North West London Care Information Exchange (CIE) provides patients – and the health and social care professionals involved in their care – with secure online access to their medical records.

Initially funded by Imperial Health Charity, the programme is led by the eight CCGs which form the North West London Collaboration of Clinical Commissioning Groups. The portal solution is being rolled out initially to patients receiving treatment for particular conditions, including Rheumatology, Renal and Oncology. It uses Patients Know Best technology.

AT A GLANCE

SCALE

L

S = < 5 organisations
M = 5-10 organisations
L = 10+ organisations

MATURITY

4

- 0 – No planned programme for sharing data
- 1 – Sharing one data type or planning data sharing
- 2 – Sharing two data types (inc. GP) at read only
- 3 – Sharing three or more data types at read only
- 4 – Sharing three or more data types, with write capability

*for the purpose of comparison the data types are GP, Acute, Community, Mental Health, Adult Social Care, Child Social Care

HOW THE CARE INFORMATION EXCHANGE IS BEING USED

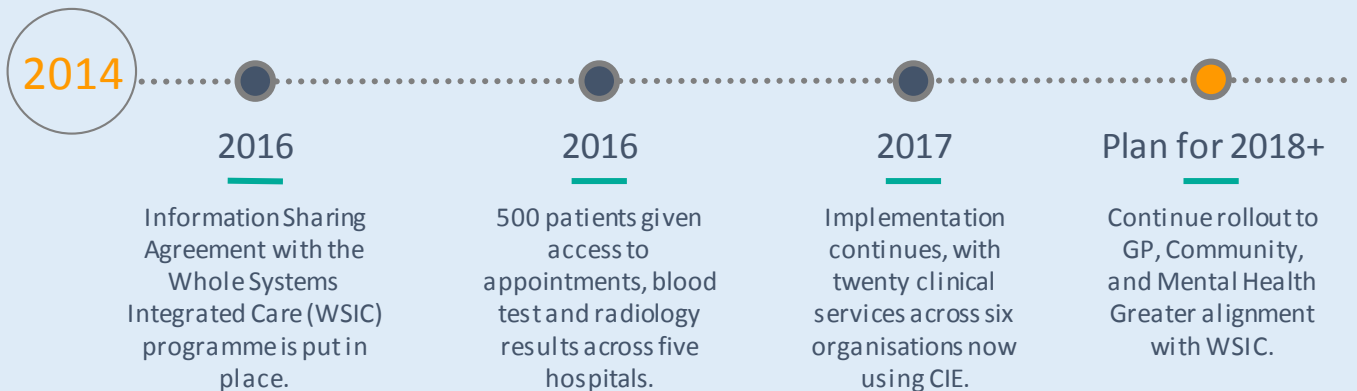
Individual Patient Care	Care Planning & Coordination	Health & Care System Management	Population Health Management	Research
LIVE	LIVE	IN FLIGHT	NOT IN SCOPE	NOT IN SCOPE



We believe better coordinated care starts with empowering patients to become proactively involved in their care.



TIMELINE



100+ registered clinicians

4470 registered patients

Approx. **2.4m** population

LOCAL CONTEXT

- The Care Information Exchange (CIE) is a patient-centric portal solution based on Patients Know Best technology.
- The programme began as an Imperial College Healthcare NHS Trust initiative, with funding from Imperial Health Charity. It now involves health and social care organisations from across North West London, with ownership having shifted to the North West London Collaboration of Clinical Commissioning Groups.
- Patients logging onto the portal are able to see information about their health and care such as test results, clinic letters, appointments, and medication, drawn from a variety of sources. They can contribute information to the record themselves, as well as communicate with their care provider through secure messaging.
- If a patient gives consent, professionals involved in their care can access that patient's record in CIE. Patients manage their information sharing preferences from within the portal. Both patients and clinicians have access to the same set of data, but with a slightly different presentation.
- CIE currently comprises data from three acute hospitals, a community provider, a mental health Trust, and the EMIS GP practices which fall under Hillingdon CCG. The clinical specialties covered are Neuro-oncology, Early Intervention in Psychosis, Rheumatology, Diabetes, Renal, HIV, Colposcopy, Cancer Oncology, and Interstitial Lung Disease and several others.
- Work is underway to extend CIE to two further acute hospitals and a mental health Trust, plus other community services and those GPs using SystmOne (i.e. the majority of GPs in the area), throughout 2018. This ongoing rollout is scheduled to be completed by early 2019.
- To date, clinicians within the clinical specialties have been responsible for inviting patients to join CIE, however a campaign to recruit a broader spectrum of patients is planned.

FOCUS ON: PATIENTS FIRST



We are one of the few areas going down the route of giving patients access to their records first. In many ways, local circumstances have dictated this direction – the fact that it has taken us so long to reach a solution for integrating with SystmOne, for example – but it also makes sense to get patients involved from the start. This is about improving their care, after all, and they have a big part to play in driving changes in the health & care system.

We targeted a number of clinical specialties to get CIE off the ground, and invited patients receiving care within those services to start accessing their records. It has proven to be especially useful for patients who interact frequently with a service, and who want to know the latest status of their care, view test results on a regular basis, or indeed provide input. People with long term conditions are becoming increasingly expert at managing their own care and are looking for tools to help them work more effectively with the professionals involved.



Steve Janering, Project Manager, CIE Programme

THE CARE INFORMATION EXCHANGE SUPPORTS...

INDIVIDUAL PATIENT CARE

The CIE supports individual patient care by allowing health and care professionals and patients to interact in new ways, supported by a range of features, including:

- **Treatment and care plans**
- **Results** – some of which have an associated delay before being released to the patient, to allow the clinician time to contact them about it.
- **Apps** – links to healthcare or fitness trackers, e.g. Fitbits
- **Patient surveys**
- **Collaboration** – including the ability to send messages or join a video conference with a care professional. There are also alerts for clinicians linked to patient symptom tracking.
- **Knowledge-sharing** – there is a patient library where patients and care professionals can add links to useful resources including leaflets, audio files and videos. Patients can also access signposts to local services.



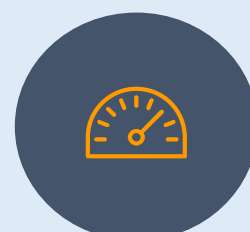
CARE PLANNING AND COORDINATION

- Care plans are created in the patient's shared record in CIE and are used by different clinicians to collectively manage the care of the patient. The care plans summarise the patient's care to date and set out goals and actions. A major part of the exercise has been to refine and clarify the definition of a care plan across organisations.
- Some of the information entered into CIE is then available to other systems through a REST API. For example, special patient notes entered into a care plan is transferred to NHS 111 users in Adastral, providing continuity of care.

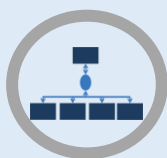


HEALTH AND CARE SYSTEM MANAGEMENT

- A parallel programme, Whole Systems Integrated Care (WSIC), has been running in North West London. This brings together data from numerous sources and provides dashboards and analytics. There is an associated Digital Information Sharing Agreement covering 346 providers and more than 1.3m patients.
- Unlike the data in CIE, the data driving the tools developed by the WSIC programme is not currently real time. It uses SUS feeds and GP data extracts.
- Integration between CIE and the WSIC dashboards is planned for Q2 of 2018.



TECHNICAL SOLUTION



CENTRAL-REPOSITORY ARCHITECTURE

- CIE uses the Patients Know Best (PKB) solution to provide patient and clinician facing portals.
- It is based on a central repository architecture.
- The consent API provides other connected systems with details of what information can be shared.
- CIE is part of the London Digital Programme network which is driving standards for clinical data exchange.

SOLUTION FEATURES

FEATURE	IN USE
Coded data	✓
Free text data	✓
Bi-directional	✓
Real time	✓
Role-based access	✓
Clinical Portal	✓
Analytics	⊘
Write access	✓
Notifications	✓
Alerts	✓
Patient Portal	✓

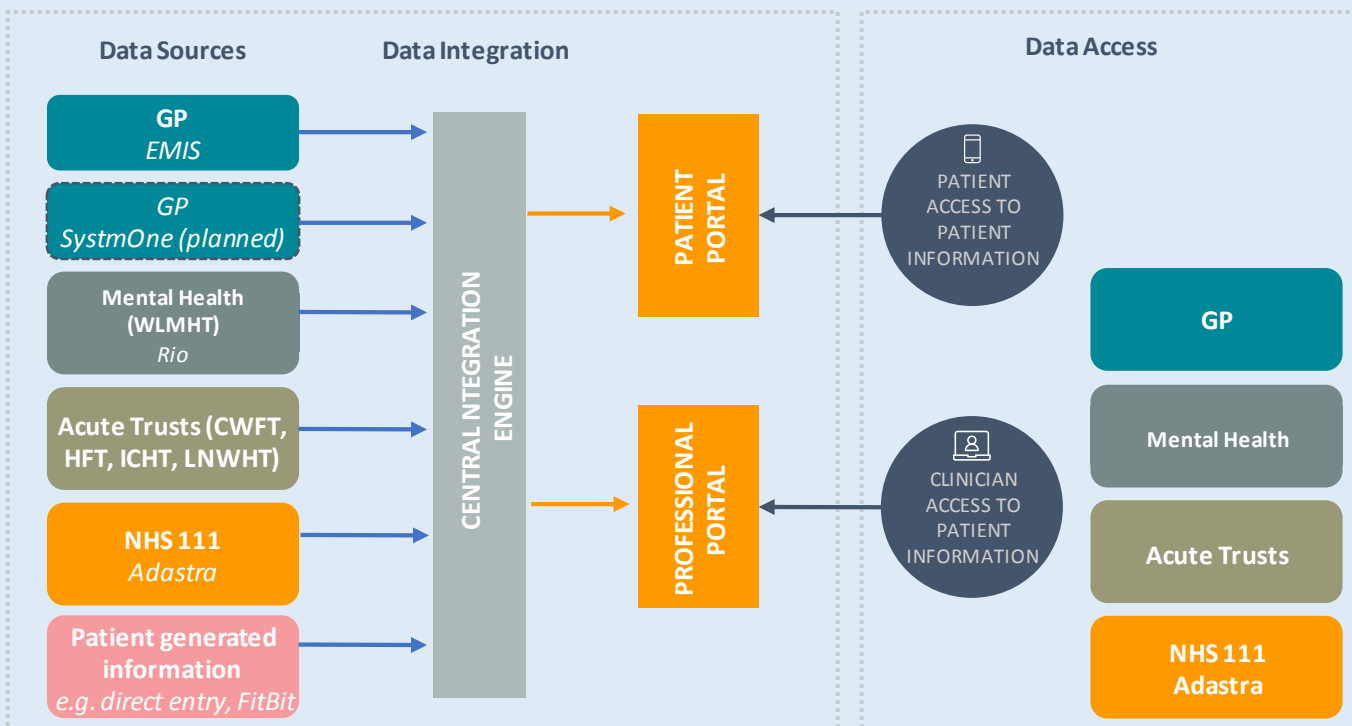
KEY SYSTEMS IN SCOPE

SITE	TYPE	VIEW	SHARE	IT SYSTEM
West London Mental Health Trust	MH	Yes	Yes	Rio
The Hillingdon Hospitals NHS FT	Acute	Yes	Yes	iCS
Imperial College Healthcare NHS FT	Acute	Yes	Yes	Cerner
West Middlesex Hospital NHS Trust	Acute	Yes	Yes	Cerner
Hillingdon CCG	GP	Yes	Yes	EMIS
London NW Healthcare NHS Trust	Acute	Planned	Planned	iCS
Chelsea and Westminster NHS FT	Acute	Planned	Planned	LastWord
Central and NW London NHS FT	MH	Planned	Planned	SystemOne
Brent CCG	Comm	Planned	Planned	EMIS
Harrow CCG	Comm	Planned	Planned	EMIS
Ealing CCG	GP	Planned	Planned	SystemOne
Hounslow CCG	GP	Planned	Planned	SystemOne
Hammersmith & Fulham CCG	GP	Planned	Planned	SystemOne
West London CCG	GP	Planned	Planned	SystemOne
Central London CCG	GP	Planned	Planned	SystemOne
NHS 111 (Care UK)	Urgent	Planned	Planned	Adastra
C London Community Healthcare	Comm	Planned	Planned	SystemOne
Hounslow & Richmond Community	Comm	Planned	Planned	SystemOne
Royal Brompton & Harefield NHS FT	Acute	Planned	Planned	-
The Royal Marsden NHS FT	Acute	Planned	Planned	-
Uni College London Hospitals NHS FT	Acute	Planned	Planned	-

OPEN STANDARDS

STATUS	SNOMED	Read	dm+d	HTML	ITK	HL7	HL7 FHIR
IN USE	✓	✓	✓	✓	✓	✓	
NOT IN USE							
PLANNED							✓

HIGH LEVEL TECHNICAL ARCHITECTURE



IMPLEMENTATION

The implementation approach has been to start small, learn lessons, refine, and then expand. To this end, CIE went live initially with eight services, covering both acute and mental health. These services showed a willingness to come on board and represented a range of service types, each with a slightly different model of care and style of interaction with patients. 2018 will see the extension of CIE out to the other key organisations across North West London, as well as further rollout within those organisations already live.

A number of challenges have been identified from the early adopter services, not least the practical impact of patients accessing their own records. For example, there is an overhead associated with the support mechanisms that need to be in place to help and advise patients. At present, patients with access to CIE who have queries about either the registration process or their record itself are directed to contact the local Patient Advice and Liaison Service (PALS). This has worked well to date but as the scope of CIE expands, it is likely to require a larger team.

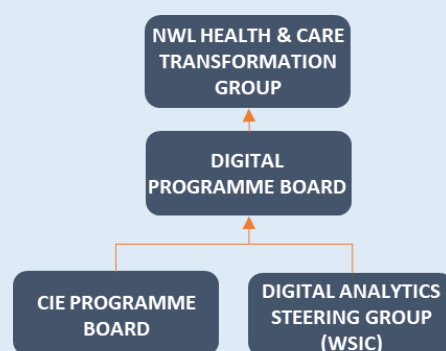
GOVERNANCE

Both the CIE and WSIC programmes feed into the Digital Programme Board. A regional Information Sharing Agreement across the partner organisations is in place.

Consent model

Patients signing up to CIE set their sharing preferences within their view of the record. This gives them direct control over who can view their data. Healthcare staff are set up in teams related to the service they provide, e.g. the renal team, and patients can allow a team to see their record. Once permission is granted to that team, it persists for the duration of the care episode.

When accessing a patient record, the clinician is asked to justify their reason for access e.g. explicit consent. They can also use a one-time “break glass” function by selecting the emergency access option. All access is fully audited and can be seen by the patient. Patients can also control how much of the record a team can see, as all data is labelled with one of four categories: general, mental, sexual or social. The data is assigned to a category according to clinical code or the originating organisation, and the patient can re-categorise items if they wish.



FUTURE AMBITIONS

As part of the future development of CIE, there are specific milestones and plans to:

- Increase the cohort of registered patients with a mass campaign, allowing patients to register via self check-in kiosks
- Extend medical device connectivity for patient self-testing
- Integrate with the [Health Help Now](#) app
- Integrate with WSIC dashboards
- Support radiology image viewing
- Integrate with the London Health & Care Information Exchange
- Rollout multi provider collaborative care and support planning
- Deploy acute provider appointment booking functionality and cross organisation task management

COMMUNICATION

Patient uptake

Registering patients to use CIE has been done on a relatively small scale to begin with. The approach has been to target patients receiving care from one of the eight early adopter services. Clinicians within each service were tasked with identifying patients who may benefit from signing up. They talked to those patients about the advantages of CIE and gave them specially designed patient information materials. Over 4000 patients have registered so far.

Self service check-in kiosks

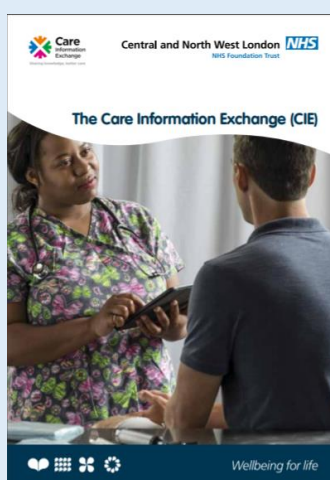
The programme is about to move into the next phase of the implementation, with a wider communications campaign, aimed at getting a much broader range of patients to register. Patients will be able to register for CIE using the self service check-in kiosks in the region's hospitals, starting with Imperial College Healthcare NHS Trust.

Service specific collateral

Service specific information leaflets were designed, to ensure the wording reflects the way in which the record is likely to be used within that service. Messages are also tailored to the particular audience.

The leaflet used by the Early Intervention in Psychosis team was designed by service users in collaboration with thinkpublic, the service design agency.

Central and North West London NHS FT

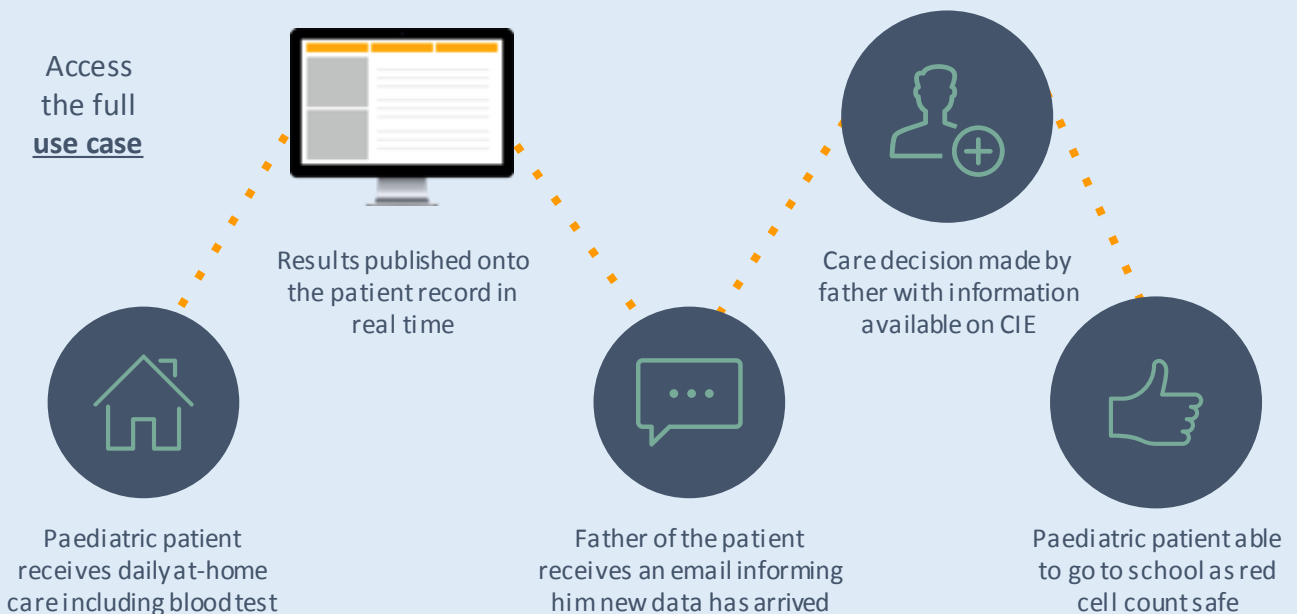


West London Mental Health NHS Trust



PATIENT USE CASE

“My eight year old daughter suffered for five years with neuroblastoma. We had over 800 nights in hospital and our care pathway was very complex, spanning three hospitals and community care at home.”



SUCCESS FACTORS



SUPPLIER

GOOD RELATIONSHIP WITH SUPPLIER

- PKB was chosen to provide the platform for CIE for a number of reasons. One of these was budget but the other was the supplier's agility, due to its relatively small scale, and willingness to innovate.
- The project team are working closely with PKB to ensure the solution supports their aspirations and have developed a good relationship which has led to a more responsive service.



PROCESS

CONTINUOUS IMPROVEMENT APPROACH

- The approach has been to start small and then expand based on key learnings from the early adopter rollout.
- In October 2017, an evaluation of CIE was undertaken to review progress and document key lessons learned. The report was funded by the Imperial College Healthcare Charity and produced by the Peter Sowerby Foundation. It highlighted a number of factors to be taken into consideration in future work.
- The programme team has taken these findings on board and where applicable is building them into its processes and approach.



COLLABORATION

JOINING UP WITH OTHER PROGRAMMES

- North West London is a very complex ecosystem with a large number of different providers and systems. The potential for overlap with other pan-London and local programmes is significant.
- The CIE programme has looked to join up with other initiatives to explore the opportunities afforded by collaborative working or technical / process integration.
- Plans include integration with the WSIC dashboards to enable patients to see their long term condition dashboards, and with the London Health & Care Information Exchange to share information more widely across London.
- Wherever possible, the team is seeking to extend standards across the surrounding footprint and do the work "once for London".

LESSONS LEARNED

INTERFACES

Challenges: There are a limited number of open interfaces available for GP systems. Building bespoke interfaces can cause time delays, dependencies on vendors, and may require additional investment.

Lessons Learned: Factor in the potential time and cost impacts of interface developments on plans. Work with vendors to promote developing with open standards and understand what commercial levers there are to do this.

BUSINESS CHANGE

Challenges: Allowing patients to access their records represents a huge opportunity – but it is also a significant business change. It necessitates a big shift in mind-set and this needs to be taken into account when working with stakeholders (staff and patients alike).

Lessons Learned: In order to realise the full potential of local shared care records, the programme needs to be treated as a change exercise, not the rollout of IT. This means investing in business change resources and including business change activities in the plan. The programme team know that the conversation needs to be about how CIE can be used to evolve services and change the way patients interact with the healthcare system, not simply how it can be used to digitise existing processes.

SUPPORT SYSTEMS

Challenges: Patients needed help registering for CIE and they needed to be supported with any queries they had once they gained access. Likewise, clinicians needed to be given support so that they felt confident answering patients' questions. They needed reassurance that this wouldn't add to their workload and guidance relating to the IG implications of shared records, particularly relating to data ownership, which some found confusing due to record access and management having shifted to the patient.

Lessons Learned: Patients and clinicians need to be supported with the new processes and know who to contact for help. There is a significant overhead involved in getting these support mechanisms established. The CIE team has been working on this prior to scaling up the rollout of CIE. With over 4000 patients having registered based on a few services alone, demand for access to CIE is set to escalate significantly and the organisations involved need to be ready to cope with this.

FURTHER INFORMATION

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INFORMATION CORRECT AS OF 27/04/2018

LINKS

NWL Local Digital Roadmap

Care Information Exchange

Patients Know Best

Whole Systems Integrated Care

Produced in collaboration with [NECS](#) and [Accenture](#)