The first local patient record sharing service in Birmingham, Sandwell & Solihull

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National Clinical Lead – Patient Online programme NHS England
Clinical Information Lead & Senior Information Risk Owner - Birmingham CrossCity Clinical Commissioning Group Governing Body
Chief Clinical Information Officer – Your Care Connected programme

Will Gilmour
Programme Director - Your Care Connected Programme
It’s been a long road

Birmingham LMC objects to shared record

Birmingham rethinks failed record plan

Birmingham reboots central care record

If you stand up and be counted, from time to time you may get yourself knocked down. But remember this: A man flattened by an opponent can get up again. A man flattened by conformity stays down for good.

(Thomas J. Watson)
Your history can save your future
What is Your Care Connected?

Your Care Connected will allow doctors, nurses and other registered healthcare professionals to view vital information from a patient’s GP record, with their permission, to provide better, safer care.

YCC aims to improve the way patients receive and experience care.

The NHS treats about one million people every 36 hours. Having access to accurate, timely information is vital for safer & more clinically effective patient care.
Your Care Connected programme

A simple, yet quite ambitious aim:

To provide a more joined-up NHS service in Birmingham, Sandwell and Solihull

- To support direct patient care
- To give those treating patients the information they need when they need it

The record will be:

- Viewed via “lookup” method – no data warehouse or extraction involved
- Accessed only with the permission of the patient at the point of care, unless they’ve opted out
- Completely auditable
The benefits of Your Care Connected

The benefits of the system are:

• Faster and easier access to up-to-date medical information, which could save lives

• More secure than paper-based access

• Supports the improvement of the safety and quality of patient care

• Enables safer delivery of emergency care

• Less time spent on the phone and fax providing or requesting patient records
Why have we supported the work so far?

Most people know their own history but...at times of illness, they can forget information e.g. medication.

- Vulnerable groups require more support:
  - Complex frail elderly
  - Children who need safeguarding
  - English is not first language

Better access to information means timely decisions can be made – **better for patient care.**
A complex second city

Provider organisations: Clinicians

318 practices in 4 CCGs +...............

- University Hospital Birmingham FT
- Heart of England FT
- Sandwell & West Birmingham NHS Trust
- Birmingham and Solihull Mental Health FT

- Birmingham Children’s Hospital
- Birmingham Women’s Hospital
- Royal Orthopaedic Hospital
- Birmingham Community Healthcare NHS Trust

- WMAS (West Midlands Ambulance Service)
- Out of Hours GP service providers (Badger/Primecare)
## Public information programme

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Preparation development</strong> - engagement with patients and stakeholders in creating information and campaign so we know its clear</td>
</tr>
<tr>
<td>2</td>
<td><strong>GP Practices</strong> awareness raising, engagement events and toolkit to help support practices</td>
</tr>
<tr>
<td>3</td>
<td><strong>For patients</strong> - awareness raising advertising and PR campaign so patients know they should receive information by post – buses, radio, events</td>
</tr>
<tr>
<td>4</td>
<td><strong>Opt out</strong> - Letter and leaflet to patients informing them of what is happening and how to opt out</td>
</tr>
<tr>
<td>5</td>
<td><strong>Ongoing</strong> support through helpline for practices and patients through process</td>
</tr>
</tbody>
</table>
GP Record node – Only available if data is present on the MIG – access controlled by Active Directory group
Consent Continued ...

- Once T&C’s are confirmed:

- NB – in development awaiting wording from the CCG
### What does Your Care Connected show?

<table>
<thead>
<tr>
<th>Information shared via Your Care Connected</th>
<th>Information NOT shared via Your Care Connected</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Allergies</td>
<td>• IVF Treatment</td>
</tr>
<tr>
<td>• Medication</td>
<td>• HIV and AIDS</td>
</tr>
<tr>
<td>• Hospital admissions and referrals</td>
<td>• Sexually Transmitted Diseases</td>
</tr>
<tr>
<td>• Vaccinations and immunisations</td>
<td>• Gender realignment</td>
</tr>
<tr>
<td>• Test results</td>
<td>• Termination of Pregnancy</td>
</tr>
<tr>
<td>• Diagnoses</td>
<td>• Marital status</td>
</tr>
<tr>
<td>• Treatment</td>
<td>• Criminal Convictions</td>
</tr>
<tr>
<td>• Medical procedures</td>
<td>• Complaints</td>
</tr>
<tr>
<td>• End of life wishes</td>
<td>• Free text from GP record</td>
</tr>
<tr>
<td>• Demographics (age, gender etc.)</td>
<td></td>
</tr>
<tr>
<td>• Concerns related to abuse of vulnerable children or adults (if applicable)</td>
<td></td>
</tr>
</tbody>
</table>
Exclusion data set

GP Summary Code Lists releases

GP Summary Exclusion code lists
Released on Wednesday 25th March 2015

GP Summary Exclusion Code Lists contain general practice terminology sets that identify potentially sensitive data that will be excluded from emergency care summary records. This release is consistent with the UKTC bi-annual terminology release 19.0.0 and should be used from 01-Apr-2015.

For any further information, please contact information.standards@hscic.gov.uk

Status: Technology Preview

Would you like to download this release? If so, you need to create an account or log in to your account.

GP Summary Inclusion code lists
Released on Wednesday 25th March 2015

The GP Summary Inclusion Code Lists provide a list of clinical codes relevant to additional information for inclusion in the Summary Care Record (SCR), should a patient consent to additional information being added to their SCR. This release is consistent with the UKTC bi-annual terminology release 19.0.0 and should be used from 01-Apr-2015.

For any further information, please contact information.standards@hscic.gov.uk

Status: Technology Preview

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# Your Care Connected and other data sharing initiatives

<table>
<thead>
<tr>
<th></th>
<th>Your Care Connected</th>
<th>Summary Care Record</th>
<th>Care.data</th>
<th>GPES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>Clinical care</td>
<td>Clinical care</td>
<td>Research</td>
<td>Research</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Local</td>
<td>National</td>
<td>National</td>
<td>England</td>
</tr>
<tr>
<td><strong>Information shared</strong></td>
<td>Read coded information • Medications &amp; allergies • Problems &amp; results • No free text • sensitive codes excluded</td>
<td>Medications &amp; allergies</td>
<td>Read coded information • Medications &amp; allergies • Problems &amp; results • No free text • Information effectively anonymised unless otherwise stated</td>
<td>Read coded information • Medications &amp; allergies • Problems &amp; results • Information effectively anonymised unless otherwise stated</td>
</tr>
<tr>
<td><strong>Storage</strong></td>
<td>Real-time lookup (data is not extracted and stored elsewhere)</td>
<td>Central database (data is extracted and stored elsewhere)</td>
<td>Central database (data is extracted and stored elsewhere)</td>
<td>Central database (data is extracted and stored elsewhere)</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>Legitimate relationship Smartcard and/or secure login</td>
<td>Legitimate relationship Smartcard</td>
<td>Effectively anonymised for research purposes unless otherwise stated</td>
<td>Effectively anonymised for research purposes Smartcard required</td>
</tr>
</tbody>
</table>
Over 9 in 10 patients would be happy for doctors and nurses in hospitals and paramedics to view their GP medical record.
But don’t just take our word for it…what we have heard and learnt during our local Proof of Concept

“The fact that I could view my patient’s blood results meant I didn’t need to repeat the blood test”

“Very useful - means we don’t have to wait ages on the phone to GP practices”

“Patients assume we have full access to their medical history and therefore they may not reveal medical conditions which might impact their treatment”

“YCC was extremely easy to use, being accessed intuitively through the existing Clinical Portal”

“On accessing the patient’s record, I became aware of a range of medical conditions and past illnesses I didn’t previously know about. Without this information there could have been a serious impact on the care of my patient”
For the benefit of all

“Your Care Connected can’t come quickly enough. It will take a lot of the stress away from hospital visits; and having one system that tells my story, holding all the relevant, reliable and essential information will provide me with better care”

Adrian Ball, Patient
The Journey to date

- Proof Of Concept 120,000 patients mailed out 1.7% opt out
- 4 Acute providers covering specialist, maternity and paediatrics, large DGH with multiple sites and mental health
- Proven use & benefits in A&E and community mental health hubs
- Established clinical panel across primary & secondary care to support usage
- Work with BT to resolve technical challenge to filter sensitive data
Letters sent to 1.8 million patients explaining sharing with implied consent, opportunity to opt out and participating organisations defined.
Your Care Connected – phase one

1. **Soft-Token Two Factor Authentication**
   - Context Management
   - Patient Summary
   - Charts
   - Detailed Care Record
   - Secure Messaging
   - Clinical Document Editor

2. **Clinical Provider Portal**
   - Audit Logs
   - Portal Services

3. **Integration Engine**
   - BT Developed Adaptors to Clinical and Social Care Systems

4. **HGL MIG**
   - Vision360 GP
   - SystmOne GP
   - EMISWeb GP
Your Care Connected – phase two potential

Integration Engine
BT Developed Adaptors to Clinical and Social Care Systems

Soft-Token Two Factor Authentication

Electronic Master Patient Index
- Context Management
- Patient Summary
- Charts
- Detailed Care Record
- Secure Messaging
- Clinical Document Editor

Clinical Provider Portal

Audit Logs

Patient Portal

Portal Services

BT Data Centre
Health Platform

Clinical Data Repository
- Appointments
- Secure Messaging
- Charts
- Health Links

Analytics and Reporting Products

Integration Engine
BT Developed Adaptors to Clinical and Social Care Systems

HGL MIG

Acute

Mental Health

TeleHealth/TeleCare Monitoring Platform

Social Care

Vision360 GP

SystmOne GP

EMISWeb GP

Community Health

EPR

EDM

Departmental Systems

N3 and internet
Shared information is a relationship of trust

Patients and information are the two most under-used resources in the NHS

Dr. Richard Fitton

Cartoon with thanks to the British Medical Journal
Decision Making

Governance group to consist of CCG SIRO’s, IG leads, LMC, Clinical Leads, Safeguarding Leads, Patients

“OK, all those in favour of delegating decision-making, shrug your shoulders.”
Next steps for 2015/16 – practices

- System functionality
- Benefits & evidence
- Local Digital Roadmaps
- Guidance & support
- Track and support progress
“ALONE WE CAN DO SO LITTLE; TOGETHER WE CAN DO SO MUCH.”

- Helen Keller

Thank you!