



**Gloucestershire  
Clinical Commissioning Group**

## **Joining Up Your Information project (JUYI – Gloucestershire’s Shared Care Record)**

**Proposed Model for Patient Consent to Share Data in Gloucestershire  
10<sup>th</sup> March 2015**

### **Executive Summary**

- This paper is to request LMC approval for the approach to gaining patients’ consent for sharing their health and social care data with other professionals treating them in Gloucestershire.
- There are a number of drivers for sharing patient data for direct care, including: improved patient care, time saved by clinicians and national guidance
- Specifically, the group is asked to agree (with any caveats it would like to introduce) and endorse:
  - i. The approach:
    - The model is one of informed implied consent to share, explicit permission to view, based on the controls and publicity campaign outlined below
    - Patients are written to on the principle of sharing, explaining how broad this could be and given the option to opt out. A publicity campaign will run alongside a letter sent from the practice, to raise awareness.
    - Controls will be in place such that:
      - Access is role-based and monitored
      - GP practices authorise sharing via a Specific information Sharing Agreement, that each practice will sign
      - Any extensions to sharing must:
        - a. be agreed by a suitably-constituted group, that will control the actual data shared and with whom
        - b. be authorised by each GP practice via amendment of the Specific information Sharing Agreement.
  - ii. The Phase 1 sharing data set, outlined below, in principle. This will be finalised before GPs are asked to give their authorisation for data to be shared from their systems (by signing a Specific Information Sharing Agreement)
- Next steps:
  - The Communications Consent & Access group (with representation from patients, carers and care professionals from primary and secondary care and social services) to agree wording of the patient letter and approve other publicity materials
  - Practices to review the patient letter (add/provide their letter head and sign) and sign the Specific Information Sharing Agreement.
  - Publicity campaign to begin



## 1. Background

- i. A project was launched in February last year, to scope out the electronic sharing of patient information in Gloucestershire to support patient care. This is now called the Joining Up Your Information project (JUJI – Gloucestershire’s Shared Care Record). [See Appendix A for a schematic of the scope of the project](#)
- ii. The Project Board has approved the procurement of software tools to begin sharing data, including a limited dataset from Primary Care
- iii. A prerequisite to sharing, is the running of a patient information campaign to gain implied consent to share

### iv. Why share?

#### *Strategic context*

- a. The National information Board released a document, “Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens - A Framework for Action”, on 13<sup>th</sup> November 2014. This contains two key targets:
  - No Paper Records
    - By 2018, clinicians in primary, urgent and emergency care and other key transitions of care contexts will be operating without needing to use paper records.
    - All patient and care records will be digital, real-time and interoperable by 2020.
  - Patient access
    - From March 2018 all individuals will be enabled to view their care records and to record their own comments and preferences on their record
- b. “The Forward View into action: planning for 2015/16, coordinating and establishing a firm foundation for longer term transformation of the NHS”  
This:  
“underlines the NHS’s commitment to giving doctors, nurses and carers access to all the data, information and knowledge they need to deliver the best possible care”

Both of the above will require extensive electronic sharing of data.

#### *GP & OOH use cases/benefits*

These comments are taken from GPs who have access to a local shared care records in other counties. There are similar benefits and testimonies for other types of care professionals:

- a. “Patient given antidepressant by liaison psychiatry after an emergency assessment at the hospital. Discharge summary didn’t say which but I saw the dispensing log from the hospital **so knew which medicine the patient had been given** ”
- b. “My patients tell me they are booked for outpatient clinics but we have no information on where and when, or which consultant. **I can now look at their planned appointments** and usually identify all these bits of information, enabling me to contact the relevant teams to provide them with clinical information and liaison”



**Gloucestershire  
Clinical Commissioning Group**

- c. "A patient's carer contacted OOH with a concern as the patient had a rapid and irregular pulse. The patient was normally confused and unable to state whether this had happened before. It was associated with some shortness of breath.  
Such a scenario could lead to admission to hospital. However from the Oxfordshire Care Summary (OCS) I was able to determine that she had had Atrial Fibrillation (a common cause of irregular pulse) for some time and that there had been previous episodes of shortness of breath and a medication which was put down for occasional use. Administration of this medication with telephone follow up 2 hours later alleviated the symptoms and confirmed **the decision to treat at home rather than readmit the patient.**"
- d. "It would be great if it could somehow be integrated with social services care. Only last week I saw a man with a serious progressive neurological disorder who thinks he has been assessed by occupational therapy but wasn't really sure. If I could check their records, **it would have saved letters and phone calls** to find out what is going on."

2. The proposed patient data sharing consent model

A Communications, Consent and Access workstream (with representation from patients, carers and care professionals from primary and secondary care and social services) has been convened to look at the issues around patient consent required to share information. The conclusion of the second meeting in September 2014 was to pursue a "middle ground" of:

- sufficient publicity to achieve Informed implied consent from the Gloucestershire public to share their information
- health professionals to ask explicit permission to view, where practical (not required when direct referral or patient incapable)
- role-based access with audit of usage

The rationale behind sharing model

- The BMA, among others, stipulates the need to give people the option to opt out of sharing. Thus, there are 2 levels:
  - Consent: allowing the patient to opt out of sharing entirely, so that their data is not available to other care professionals
  - Permission: care professionals to ask patient at each contact if they can view their information
- This is the model in use in over 25 other such projects in England
- Identifying high-risk patients and gaining explicit consent in advance has the following disadvantages:
  - Requires GP time to identify patients and is an ongoing process
  - Patients who are not high risk can still present at other provider organisations (e.g. a patient's first psychotic episode)
  - It has proved to be impractical
  - Care professionals will only use a system/solution if data for a patient is on there more often than not

3. Patient Communication



**Gloucestershire  
Clinical Commissioning Group**

- The aim is to contact patients once about this and, thus, ensure that the publicity covers the sharing of a broad range of patient data. This is designed to alert those who have concerns to take action and seek more information (a hotline, email response service and a website will be in operation). As an example, the wording in the Oxfordshire leaflet was:

“A standard set of information will be available to be viewed by authorised healthcare professionals in Oxfordshire. This will be pulled automatically from the various electronic care records that local NHS organisations hold about you. This set of information will be agreed and reviewed regularly. You will be able to see a list of the information to be shared on the website xxx”.

- It is proposed that
  - Letters be sent from GPs to their patients; all administration, including handling queries and responses will be done centrally (practices will need to code opt-outs but support will be available for this)
  - A publicity campaign will run alongside the letters, to raise awareness, including: posters, leaflets, public events, attendance at special groups (e.g. carers’ forum, diabetes group, ethnic minority groups), articles in parish magazines and rolling PowerPoint presentation (for displaying in practice surgeries)

#### 4. Data to be shared and with whom in Phase 1

- From Primary Care, with the exception of Care Plans and correspondence, this is Read coded data only (with the option to include the associated text for specified Read codes), with sensitive codes (such as sexual health) excluded
- This will be view-only (cannot be amended)
- Please see Appendix [BA](#) for details

#### 5. Controls

- Exclusions on data that can be shared (i.e. some items that will never be shared)
- Who the information can be shared with (the audience),
- The security around user access
- Monitoring of access (audit)
- A “Data Sharing Control Group” with suitable membership (including a GP, ideally from the LMC) and lay representatives will control the extent of data to be shared and approve proposed extensions to the dataset, for phases following the initial one. [The details are to be worked through, but are expected to be along the following lines:](#)
  - [Membership to comprise Clinical/Care Professional Reference Group \(so all providers represented including GPs, with the addition of an Information Governance expert \(to give guidance on the latest legislation to ensure the proposals are legal and patient representatives](#)
  - [Proposals for extensions to sharing come to this group, most likely from the business change/transformation team, as a result of their work with users and their work to realise benefits](#)
  - [Requests could be for additional data to be viewed by existing user groups or for a new group of users to have access to data already being shared](#)



**Gloucestershire  
Clinical Commissioning Group**

- The group would then appraise the proposal with reference to the benefits identified as a result of this extended sharing, the stated benefits of the project and the Vision & Principles for the project
- The group would then decline, with the justification or accept, with any safeguards or restrictions, as required
- Their recommendations for extending of sharing would then go to the Project Board for sign-off
- Following approval, the necessary Specific Information Sharing Agreements would be amended and signed by the data controllers of the data under discussion (this will not always be GPs)

6. Draft timeline

Note: NHS funding has been awarded by the Integrated Digital Care Fund 2, which must be spent in 2015/16

Month	Task
<b>January 2015</b>	<ul style="list-style-type: none"> <li>• Consult on Patient Consent Model</li> </ul>
<b>February</b>	<ul style="list-style-type: none"> <li>• Consult on Patient Consent Model</li> </ul>
<b>March</b>	<ul style="list-style-type: none"> <li>• Agree Patient Consent Model</li> <li>• Confirm current requirements with nominated care professionals</li> <li>• Design Publicity Campaign to inform public</li> </ul>
<b>April</b>	<ul style="list-style-type: none"> <li>• Run campaign</li> <li>• Procure tools from framework</li> </ul>
<b>May</b>	<ul style="list-style-type: none"> <li>• Run campaign</li> <li>• Procure Primary Care data sharing tool</li> <li>• Specific Information Sharing Agreements signed and returned by Practices</li> <li>• Procure software tools</li> <li>• Develop data feeds</li> </ul>
<b>June</b>	<ul style="list-style-type: none"> <li>• Run campaign</li> <li>• Configure &amp; test Primary Care data sharing tool</li> <li>• Specific Information Sharing Agreements signed and returned by Practices</li> <li>• Engage with supplier</li> <li>• Develop data feeds</li> </ul>
<b>July</b>	<ul style="list-style-type: none"> <li>• Record Patient Opt-outs</li> <li>• Configure &amp; test Primary Care data sharing tool</li> <li>• Supplier development/configuration</li> <li>• Develop data feeds</li> </ul>
<b>August</b>	<ul style="list-style-type: none"> <li>• Primary Care data sharing tool go-live</li> <li>• Supplier development/ configuration</li> </ul>
<b>September</b>	<ul style="list-style-type: none"> <li>• Pre live testing</li> </ul>
<b>October</b>	<ul style="list-style-type: none"> <li>• Go live phase 1</li> </ul>
<b>November</b>	<ul style="list-style-type: none"> <li>• Post go-live support</li> </ul>
<b>December</b>	<ul style="list-style-type: none"> <li>• Post go-live support</li> </ul>
<b>January '16</b>	<ul style="list-style-type: none"> <li>• Post go-live development/ configuration</li> </ul>
<b>February</b>	



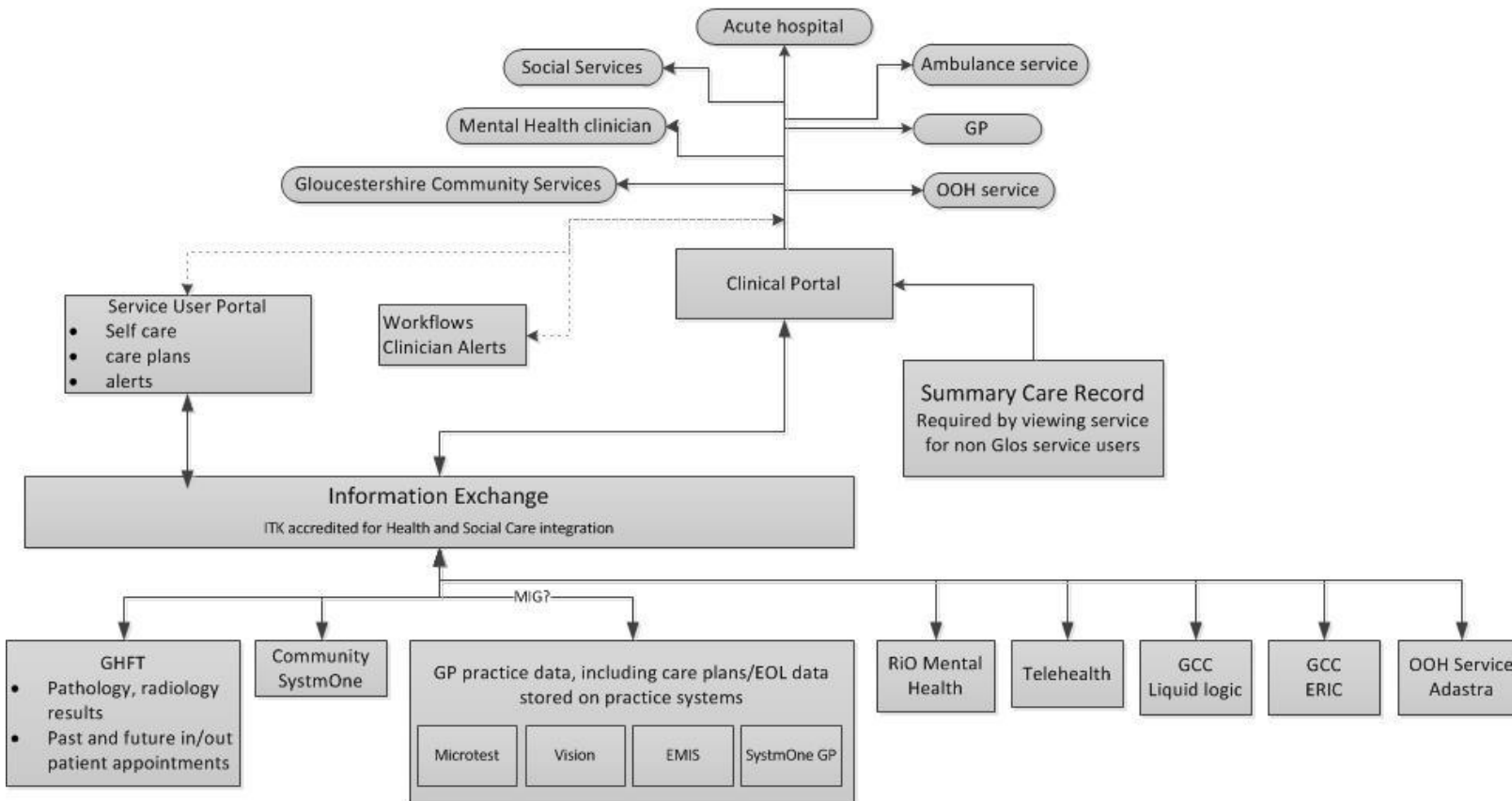
**Gloucestershire  
Clinical Commissioning Group**

<b>March</b>	<ul style="list-style-type: none"> <li>• Update Requirements (including user feedback)</li> </ul>
<b>April</b>	<ul style="list-style-type: none"> <li>• Update Requirements (including user feedback)</li> </ul>
<b>May</b>	<ul style="list-style-type: none"> <li>• Review phase 2 requirements and procurement options.</li> <li>• Decide procurement approach for phase 2.</li> </ul>
<b>June</b>	<ul style="list-style-type: none"> <li>• Procure phase 2 tools.</li> </ul>
<b>July</b>	<ul style="list-style-type: none"> <li>• Supplier development/configuration</li> </ul>
<b>August</b>	<ul style="list-style-type: none"> <li>• Supplier development/configuration</li> </ul>
<b>September</b>	<ul style="list-style-type: none"> <li>• Phase 2 go live</li> </ul>

#### 7. Common Queries

- What will practice have to do?
  - *Display materials in the practice and answer patient queries or sign-post them to where answers can be found (hotline and website)*
  - *Opt out patients (the national average is 5% of patients); the project team can assist with this or fund the time taken by practice staff*
  - *Sign a Specific information Sharing Agreement which details the data to be shared, with whom and for what purpose*
  - *Configure clinical system to allow sharing (10 minutes only in total)*
  - *Provide letter header and the list of patients for the mailing and sign the letter. The project will arrange printing and posting of letters and handle responses*
- What will happen to data recorded in the practice, that is shared?  
*Data will only be provided to users as a temporary view, i.e. not copied & stored anywhere. (Note, it is unlikely to be feasible to share correspondence via this mechanism and so it would have to be stored in a document repository in order to share with other services.)*
- What have other projects done?  
*Used the informed implied consent to share, explicit permission to view approach. Examples are Oxfordshire, Hampshire, Bristol, Cumbria and Sussex.*

## Appendix A: Scope of Project



Formatted: Font: (Default) Arial, 13 pt, Bold



Central Southern  
Commissioning Support Unit



Gloucestershire  
Clinical Commissioning Group

**Appendix BA: Proposed Phase 1 data to be shared**

Provider	Source system	Service(s)	Data sets	Data items
GCS	SystemOne	Community	Demographics Referral Details Event Details Discharge Details	Date, Time, Reason, Source, Outcome, Priority Date, Time, Type, Details, location, Staff name Date, Time, Reason
General Practice	Primary Care data set from: <ul style="list-style-type: none"> <li>EMIS</li> <li>Vision</li> <li>SystemOne</li> </ul> <p>Note: Read coded data only (see below for exclusions). The free text of consultations will not be shared, but there is the potential for sharing the associated text with selected Read codes</p>	Primary Care	Summary view Demographics Problems Diagnoses Medication Risks and warnings Procedures Investigations Examinations Events	Past & current  e.g. blood pressure, ECGs Encounters, admissions, referrals





Central Southern  
Commissioning Support Unit



Gloucestershire  
Clinical Commissioning Group

Provider	Source system	Service(s)	Data sets	Data items
	Adastra (currently as an interim measure pending solution to extract directly from practice system eliminating double entry)	Primary care	Care Plans	Admission-avoidance and EOL data
	Practice systems		Correspondence (after a given date, e.g. 1/1/15)	e.g. discharge summaries, referral letters
2G	RiO Mental Health module	Mental Health	Demographics Services involved in care Diary Next of kin	Key worker contact details Attendances, referrals
GCC	Liquid Logic		Demographics Current care package Current care manager Safeguarding issues Emergency next of kin details Does this person have a carer? Is this person a carer?	



Central Southern  
Commissioning Support Unit



Gloucestershire  
Clinical Commissioning Group

Provider	Source system	Service(s)	Data sets	Data items
	ERIC		Demographics Current care package Current care manager Safeguarding issues Emergency next of kin details Does this person have a carer? Is this person a carer?	
SWASFT	Adastra	OOH	Attendances	
GHFT	DSCRO (via daily feed, covers previous 24 hours)		Daily admissions Inpatient data Outpatient data Referral information Radiology	Date, time, diagnosis, treatment Date, time, diagnosis, treatment Date, time, diagnosis, treatment time, date, reason Date, time, type of scan

- Users who can Access**

Doctors and nurses from Acute, Community, Mental Health & Urgent Care Services (999, 111, MIU, OOH, SPCA, GHAC) plus paramedics

**Exclusions**

Suggested Primary Care data to be shared (Read codes only) and **exclusion list** [http://www.oxfordshireccg.nhs.uk/wp-content/uploads/2013/03/OCS-GP-Read-codes\\_v1.0.pdf](http://www.oxfordshireccg.nhs.uk/wp-content/uploads/2013/03/OCS-GP-Read-codes_v1.0.pdf)