

SHEFFIELD CCG

**SELECT COMMITTEE INQUIRY INTO PATIENT
DATA SHARING**

STAGE 1

INTERIM REPORT

Version: 1.0

Group Approved by: Commissioning Executive Team

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Sheffield CCG

Select Committee Inquiry into Patient Data Sharing

Stage 1 Interim Report – Sign-off by Select Committee

This document is our report on the outcomes of the above Inquiry and we, as the members of the Select Committee, confirm that it is a balanced account of the evidence submitted to the Committee.

We, the undersigned, therefore approve the report for wider circulation.



Idris Griffiths



Dr Charles Heatley



Dr Chris Bronsdon



Dr Jo Buchanon



David Chapman



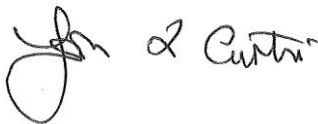
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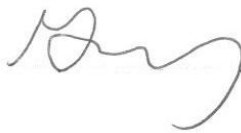
John Connolly



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SHEFFIELD CCG SELECT COMMITTEE INQUIRY INTO PATIENT DATA SHARING

STAGE 1 INTERIM REPORT

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GLOSSARY OF TERMS

Caldicott Reviews

These are reviews, commissioned by the government, into how data is collected, managed and shared in the NHS. There have been two reviews – in 1997 and 2013 – both chaired by Dame Fiona Caldicott. The first review made recommendations on data protection. The second review, to which this interim report refers, was undertaken in response to the recommendation from the Future Forum (a clinically led group set up by the government, to provide independent advice on integrated care, information, education and training and promotion of healthy living) to undertake a review *‘to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of patient information to improve care’*. This review found that *‘safe and appropriate sharing in the interests of an individual’s direct care should be the rule and not the exception’*.

CCG

Clinical Commissioning Groups are clinically led groups of GPs and other professionals responsible for designing and commissioning local health services in England. They work in partnership with patients, healthcare professionals, local communities and local authorities. The aim is to give GPs and other care professionals the power to influence commissioning decisions for their patients. CCGs are run by Governing Bodies.

EMIS

Supplier of computer systems – EMIS Web and EMIS PCS - used by 18 of Sheffield’s 88 practices

EOL

End of Life. Refers to those groups of patients who have a terminal illness which is advanced, progressive and incurable.

GMC

The General Medical Council exists to protect, promote and maintain the health and safety of the public. It maintains a register of GPs, sets standards for medical schools and is responsible for the licensing and revalidation for all doctors.

ICE (or Sunquest ICE)

A computer system used by hospitals and GP practices to exchange test requests and results.

Information Governance

The term used to describe how organisations and individuals manage the way information is handled in the health and social care system

Integrated Care

The coordination of care between primary, secondary, tertiary and social care

Interoperability

The process of computer systems working together to allow the effective flow of electronic information

OOHs

Out of Hours Services. Healthcare services provided by primary care outside the normal practice opening times.

SystemOne

The main computer system used by Sheffield’s GP practices (70 out of 88 practices) and all community and therapy services. In Sheffield, SystemOne is used as an electronic patient record and the data includes contributions from several clinical teams. Supplied by TPP.

Summary

Safe and appropriate data sharing among care professionals to support direct patient care is universally accepted as being in the best interests of the patient. Both the Caldicott Review and the GMC state so. Furthermore, patients expect that those involved in their treatment to have access to all relevant information and that their rights to privacy are protected at all times.

We, the Select Committee, found, however, that sharing was not universally practiced for a variety of reasons and understanding these reasons was the purpose of Stage 1 of the Inquiry. We were directed by the CCG Governing Body to initially focus on GPs where the current level of sharing is impeding progress on the integration of care (which is a strategic priority for the CCG). Stage 2 will identify courses of action which will help GPs, patients and others improve the level of sharing.

Overall, we concluded that the benefits of sharing outweigh the risks. Put another way, the appropriate and safe sharing of patient data improves integrated patient care and there are clinical risks of not doing so.

Given the overwhelming evidence in favour of sharing, why is sharing not practiced more widely? We identified two specific barriers. Firstly, the perceived impracticalities of obtaining patient consent to sharing their data. Secondly, the record sharing models used in SystemOne require the GP to set the patient's sharing preferences in their 'unit' and, if this is not done, other care professionals cannot otherwise access this data. The record sharing model was questioned by the majority of the Committee but it has been confirmed by the IT suppliers that it will not change. It is incumbent upon GPs to share so we would seek to work with GP representatives, IT suppliers and national Caldicott representatives to improve the guidance and support for GPs. We found a number of other common issues which could be broadly categorised into lack of awareness and understanding of consent and sharing processes (GP practices and patients), concerns about consequences of sharing, security controls not fully utilised and a resistance to change. We found therefore that changes to GPs' working practices were needed and should be undertaken with caution, consideration and with a high level of support and guidance. Stage 2 needs to focus on improvements to consent, record keeping & sharing and security processes thereby making it easier and safer to share. Together with improved communication and guidance, the changes will give confidence to all concerned that the sharing of patient data is safe, hugely beneficial and will reduce clinical risk.

In accordance with Select Committee rules, the report's findings only uses evidence that was submitted to the Committee and no external sources have been considered.

1. INTRODUCTION

Improving integrated care is a strategic priority for Sheffield CCG. Good quality, seamless, integrated care across health and with social care is compromised if patient data is not effectively shared with care professionals involved in a patient's care.

Across Sheffield, the different organisational approaches have led to highly variable levels of sharing with a potentially adverse impact on patient care. In particular, the CCG Governing Body is concerned that the level of sharing of GP-input data does not meet the needs of patients receiving care outside their registered practice. The Governing Body decided to set up a parliamentary style Select Committee Inquiry to understand why this is so and to draw up an action plan to address the issues.

The Inquiry was run in two stages. Stage 1 collected evidence from witnesses and ran from February to May 2014. Stage 2 will assess options which address the findings and produce a set of recommendations for the Governing Body.

This Stage 1 interim report summarises the findings and recommends objectives for Stage 2. The report only uses evidence that was submitted to the Select Committee and no external sources have been considered. This is a standard Select Committee approach and is intended to maintain the integrity and transparency of the Inquiry.

2. TERMS OF REFERENCE

The full Terms of Reference (ToR) for Stage 1 of the Inquiry is given in Appendix A.

The Committee is charged with examining the hypothesis that:

the efficient, effective, secure, ethical and proportionate sharing of clinically relevant primary care information among those responsible for a patient's care will benefit the patient and the care professionals

The ToR summarises the Select Committee objectives, scope and process and explains why this particular approach is being taken to identify issues and solutions. The approach will facilitate acceptance of the findings and adoption of the recommendations. The ToR also describes the governance arrangements and how success is to be measured.

The ToR was approved at the first meeting of the Committee on the 5th March.

3. BACKGROUND

3.1 Organisations

There are 88 practices and around 400 GPs in Sheffield who are involved in 90% of all patient care activity. There is one Adult and one Children's Teaching Hospital, a Health & Social Care trust and one Local Authority. Large numbers of patients are transferred around these organisations - for example, every year there are approximately 200,000 referrals made by GPs, 200,000 visits to A&E, 50,000 patients are seen by the OOHs Collaborative and there are 80,000 face-to-face Ambulance contacts. It is therefore imperative that the patient's information is shared in order to allow each care professional to

provide the most appropriate care based on the best information available. Patient information is transferred using a combination of media: electronic, paper, phone, fax, etc.

3.2 Computer Systems

TPP's SystmOne is used by 70 GP practices (80%) and the rest use EMIS Web or EMIS PCS. All of the city's community nurses, physiotherapists, podiatrists and intermediate care teams use SystmOne.

The Sunquest system (ICE) is used to transfer pathology and radiology information between the Teaching Hospital and GPs. Although information is generally not shared electronically with Social Care, a number of systems can hold the NHS Number.

SystmOne Viewer has been installed in the Teaching Hospital's A&E department and in OOH Centres which allows the care professional to view patient data if consent has been given. There are other well-established and functioning systems now available to allow transfer of clinically relevant data between different systems.

3.3 Patient Consent

There is a patient consent process which governs access (viewing and contributing) by users to the patient's information. This requires GPs to inform the patient of why, how and with whom their data needs to be shared in order to provide optimal treatment. The patient leaflet explaining the consent process is given in Appendix F. The process and supporting material has been based on national guidance notably that from the GMC and the Caldicott Review. Training and guidance has been made available to all practices but there is some uncertainty over the level of take-up by GPs.

The application of the consent process and level of data sharing is much higher in community care and in secondary care than with GPs. However, it is access to the GP-input data that is most valuable throughout the care pathway. If the GP fails to set the patient's preference, or the patient has dissented, other care professionals cannot access the data in the patient's electronic record (unless confidentiality can be breached for ethically and legally acceptable safety reasons, such as child protection).

4. DATA SHARING ACROSS SHEFFIELD

4.1 The Current Situation

Patient data is held in centralised and highly secure systems. Patient data is owned by patients who are entitled to access their own medical records.

GPs' application of the patient consent process is variable across the city. Over 60% of patients have not been asked for their consent (based on information gained from GP users of SystmOne - 80% of Sheffield practices) and the level of consent gained varies significantly from 2% to 88% of patients within each practice. See Section 4.1 for reasons that consent is not requested by practices.

The patient also decides whether their personal data that is input by the GP is shared (sharing out) and also decides which other units (which are caring for them) can access the GP-input or other shared data. Other primary care staff (eg health visitors, intermediate care teams) add their data to the patient's record.

Caldicott Guardians provide support for consent and record sharing processes in line with information governance policies and practices.

As stated above, data sharing is variable and is having an adverse impact on care given in other parts of the patient's pathway. The first Caldicott Review emphasised the need for good data protection but was

interpreted by many as a reason not to share if they had doubts about the levels of security and confidentiality. However, the second review in 2013 redressed the balance and made it clear that there are risks to the delivery of safe and appropriate care if data is not shared. It found that data sharing should be the rule not the exception.

There are a number of other reasons cited for GPs not sharing. Broadly, these include (but are not limited to):

- benefits and risks of data sharing not clearly understood
- cultural/attitudinal resistance
- concerns that patients will withhold sensitive but important information to health professionals if they believe their privacy may be breached
- wider fears around security and confidentiality
- general fear around change and disruption to ways of working
- lack of resources and time within consultations to inform the patient, gain and record their consent and set their sharing preferences;
- lack of understanding of how to share (what can and cannot be legally shared). It is consequently safer and easier not to share - a 'culture of anxiety' as expressed in the Caldicott Reviews. GPs are not always getting the necessary information governance support.
- concerns around impact on data integrity if GP data is pooled with data from other sources

This is impeding motivation and commitment to make the changes required to share.

Patients want to be treated holistically with all their medical conditions taken into account. Patients assume and expect all care professionals to share their data safely and appropriately for the purpose of diagnosis and treatment. A negligible proportion of patients would explicitly dissent from sharing for these purposes (as shown by the Summary Care Records experience). Most are surprised and concerned that this is not taking place as a matter of routine. Patients' views vary on the amount of information they need to make an informed decision but most just need confirmation that the privacy of their data will be fully protected and it will be used for their care only.

4.2 The Risks

There are risks to both sharing and not sharing information for direct patient care. The risks to sharing include: concerns over confidentiality and inadequate IT security which could lead to breaches; low level of IT literacy and poor record keeping/data management which could lead to sharing poor quality information and unsafe care; rules for sharing being too complicated or time-consuming to implement making it simpler not to share

However, the Committee found that, on balance, not sharing information presented a greater risk to patient care and that there was an overwhelming case for sharing across organisational boundaries to ensure the effective co-ordination of care. Individual care organisations often diagnose a variety of issues with their patients that need to be addressed by other care professionals. Often these practitioners are unaware that others are involved in the individual's care. They may be collecting the same information, undertaking similar assessments and tests and producing care plans from their perspective rather taking a more holistic view of the needs of the patient. This results in unnecessary duplication of effort, poor co-ordination and a lack of a joined-up approach to a patient's diagnosis and treatment which could have an adverse impact on the quality of care.

5. THE SELECT COMMITTEE INQUIRY (SCI)

5.1 The Approach

In government, a select committee (SC) is a small group of members of parliament who have been given a remit by parliament to investigate and report back, usually in public, on a specified matter of interest. Information is gathered by members through the questioning of witnesses; through this approach, witnesses submit evidence in support of their views.

The SCI approach is used to examine some of the most important issues in government. The process therefore has to be proven, rigorous, fair and open. A SCI takes place mostly in public and all issues submitted to the SC are examined by members asking questions of witnesses. In this case, a witness can be any stakeholder eg care professional, patient or expert in a particular field. The Committee can also examine written evidence and can commission research if necessary. In the case of this SCI, the Committee may also ask for the findings to be independently scrutinised if they feel it would add weight to the recommendations. In other words, the Inquiry must be as comprehensive, rigorous and thorough as members and stakeholders wish it to be.

This approach will give the findings credibility and encourage the implementation of the recommendations.

5.2 The Committee and Witnesses

The Sheffield CCG Select Committee (Stage 1) comprised eleven members who represented health and social care stakeholders who receive, deliver or support direct patient care (see Appendix B for the list of members).

The Committee called 14 witnesses (see Appendix C) to three meetings during March 2014. These witnesses included care professionals from all parts of the health and social care system, patients, data experts and academia. The members and witnesses represented a range of views.

Through the communications and engagement process, written evidence was also sought although only two formal submissions were received.

The first witness called was an academic ethicist, Dr Yonatan Shemmer, who got to the heart of the privacy and consent debate. When considering future changes it would be valuable to return to the fundamental principles and objectives he raised to assess the risks and benefits of any changes to sharing models from the perspective of the patient as well as the care professional. His evidence is reproduced in Appendix E.

The last witness called was from outside Sheffield - Dr William Lumb from NHS Cumbria. He leads the Cumbria information sharing programme which is a national exemplar health community. He provided the Committee with his experiences and lessons learnt (see Appendix D).

5.3 Communications and Engagement

The Inquiry was publicised during March and April via the media (press), the CCG website, health professional magazines, Twitter and Facebook. The call for written evidence was made and links to evidence submission templates and guidance were provided. Progress was reported via the media and website and detailed minutes were posted on to the website to demonstrate openness and transparency.

6. SUMMARY OF FINDINGS

The findings reflect the balance of evidence from the oral and written submissions and from no other source. The minutes of the three meetings (available on the CCG website) provide the raw material for the findings which are summarised in this section. The detailed findings are described in Appendix D.

6.1 Overall Conclusion

The remit given to the Committee was to examine the hypothesis stated in the Terms of Reference which they found, on the balance of evidence, to be true ie

that the efficient, effective, secure, ethical and proportionate sharing of clinically relevant primary care information among those responsible for a patient's care will benefit the patient and the care professionals

The Committee found considerable evidence that the appropriate and safe sharing of patient data improves integrated patient care and there are clinical risks of not doing so.

6.2 Summary of Findings

- a. The record sharing model was questioned by the majority of the Committee as it was felt to be impractical and deterring GPs from sharing. However it is incumbent upon GPs to share so we would seek to work with GP representatives, IT suppliers and national Caldicott representatives to improve the guidance and support for GPs. The IT suppliers have confirmed that it is not an option to change the model in their systems.
- b. The patient consent process undertaken in its entirety for all patients similarly creates a significant workload for GPs and a simpler, less time-consuming approach should be investigated.
- c. The patient record should be available at the point of care on the patient's pathway.
- d. Caldicott states that sharing should be practiced wherever it is in the best interests of patients. The GMC state that there is a duty to share.
- e. Patient information and understanding is patchy and needs to be improved.
- f. Patients expect that sharing is happening and trust the care professionals to share appropriately
- g. Lack of sharing potentially affects all patients but children and those with learning disabilities or other cognitive impairments were highlighted as at particular risk
- h. Many barriers to sharing are linked to information governance, for example:
 - GPs not undertaking patient consent
 - IG leads not understanding their role and the risks of not sharing
 - insufficient clarity on whether or not data can be shared
 - lack of awareness of good record keeping needed to promote effective sharing
- i. Other barriers include lack of understanding of benefits & risks and concerns about confidentiality and security safeguards.

- j. GPs fear patients will withhold sensitive information if they do not feel it is being held securely enough or may be shared inappropriately. This could result in the loss of trust between a GP and their patients.
- k. Changes are required to the current GP culture and attitude. These need to be undertaken with care and consideration and with appropriate support and guidance.
- l. Audit trails and other checks and balances to monitor inappropriate access and reassure patients and care professionals are not being fully utilised.
- m. Understanding of good record keeping, data quality and recording data for the purposes of sharing was variable among primary & community care. This needs to be addressed.
- n. GPs wanted clear, unambiguous data sharing guidance from a single source and with adhoc support available if needed.
- o. Cumbria has a single global information sharing agreement across the health community. Health and social care organisations in Sheffield are reviewing current agreements.
- p. The lack of interoperability among systems in Sheffield health and social care organisations hinders the effective flow of information. Many systems can hold the NHS number but it is not used for sharing.
- q. Implementation of changes will have some financial implications
- r. Visible leadership from senior clinicians and managers is vital

7. **STAGE 2 OBJECTIVES**

- a. Put call out for further written evidence
- b. Draw up a blueprint of a 'good' information sharing process.
- c. Identify the criteria which define a good process
- d. List different options for sharing;
- e. Assess options against the criteria and identify a preferred option
- f. Identify the changes required to move from the current situation to the preferred process. Stage 1 found that changes are needed to the:
 - consent process
 - provision of information to patients and their understanding of this information
 - support, guidance and training for the record sharing model
 - information governance awareness, training and guidance
 - record keeping and data sharing awareness, training and guidance
 - use of checks and balances in the system
 - information sharing agreement(s)
 - systems interoperability
- g. Identify appropriate approach to managing changes and realising benefits; establishing the benefits baseline

- h. Widen communication and engagement and obtain feedback; identify and recommend actions to address apathy, concerns and resistance
- i. Gain buy-in from the recommendations from the health and social community and from public/patients groups especially those who will need to implement the changes

APPENDIX A TERMS OF REFERENCE

BACKGROUND

The CCG wishes to improve integrated care and believes the appropriate sharing of information between care providers is essential to support better care. This will require the adoption of practical measures of data sharing that also appropriately address issues of protecting patient confidentiality.

The CCG wishes to explore the pros and cons of data sharing and recommend a way forward – these recommendations will influence CCG policy on the matter.

The recommendations and CCG policy are intended to provide clarity, reassurance and guidance to GPs and other clinicians.

The CCG wishes to hold an inclusive and public assessment of the issues and wishes the assessment to operate under the principles of openness, transparency, independence, rigour and fairness

The CCG Governing Body has decided to set up a Select Committee style Inquiry (SCI) which will allow anyone involved in direct patient care to give evidence for or against (either in principle or the way that it has been implemented operationally).

TERMS OF REFERENCE

The Select Committee has the following terms of reference:

(1) Aims

The Committee shall:

- receive submissions of evidence to allow it to test the hypothesis that:

the efficient, effective, secure, ethical and proportionate sharing of clinically relevant primary care information among those responsible for a patient's care will benefit the patient and the care professionals

- produce a set of findings which could be used in Stage 2 to recommend the actions required to practically address the issues raised which in turn will instil confidence in both the care professional and the patient that data can be shared safely

(2) Approach

The Committee shall:

- a. Follow the Select Committee Inquiry process to test the hypothesis and identify the findings ensuring openness, transparency, equity, inclusivity and rigour
- b. Take oral and written evidence from a range of care professionals, patients/public, experts and others
- c. Ensure that the Select Committee comprises a representative balance of views
- d. Ensure that the Select Committee Inquiry is publicised widely and that stakeholders who wish to be involved are able to do so
- e. Publish relevant material as the Inquiry progresses eg aims, timescales, members' names, progress updates, transcriptions of evidence, findings
- f. Ensure the analysis of the evidence is incisive and the findings reflect the balance of opinion
- g. Produce the Stage 1 Interim Review report by the end of April which will include the decision on whether or not to continue to Stage 2

(3) Scope

Inclusions

- a. The Inquiry will investigate the sharing of patient identifiable data for the purposes of direct patient care only
- b. The Inquiry will assess the main barriers to sharing based on evidence-based requirements, opinions and concerns received from committee members and witnesses.

Exclusions

The Inquiry will exclude issues associated with the sharing of data for secondary and commissioning purposes

(4) Key Success Criteria and Milestones

- a. The committee shall meet three times during Stage 1 in February and March
- b. The Inquiry will make reasonable endeavours to ensure that stakeholders are aware of the Inquiry and of the opportunity to submit evidence
- c. A high level of engagement and interest is achieved
- d. The Inquiry adheres to the Select Committee process
- e. The Inquiry is seen to be balanced and credible
- f. The analysis of the evidence will be independent and quality assured (by the Academic Health Sciences Network) if necessary
- g. Recommendations will be deliverable
- h. The Interim Review report and presentation will be delivered by the end of April

(5) Membership

The list of Select Committee members is attached

(6) Governance

The Select Committee will be accountable to the CCG SRO

The CSU will provide senior project oversight and a route of escalation for the Inquiry Manager and SRO

The Inquiry Manager will be accountable to the select Committee and, along with administrative support, will provide a full project management and project support service

(7) Process and Support

The Government/Lord's Select Committee process will be followed wherever practical.

The Select Committee will receive evidence in oral and written form and will have the opportunity to ask all relevant questions.

An Inquiry Manager will manage the whole process, ensuring it meets time, cost and quality requirements.

The Inquiry Manager will

- ensure the existence of the Inquiry is widely publicised
- invite members and witnesses
- ensure evidence is submitted from stakeholders in an organised manner
- facilitate meetings
- ensure progress is publicised
- undertake the analysis
- write the interim review report

It is intended that all oral evidence will be recorded and/or transcribed and, along with written evidence, made available on the CCG website

(8) Risks

The following risks (High & Medium only) will need to be managed:

No	Risk	Likelihood	Impact		Mitigating Actions
R1	The findings are not accepted by all members of the Select Committee	M	M	Difficult to take forward recommendations	Ensure full engagement and seek common ground & ensure all views are appropriately published in the final report
R2	The findings do not feed into policy and guidelines	M	H	Unlikely to see changes on the ground	Ensure Board and policy makers are fully engaged
R3	There is insufficient time to deliver full project scope and all deliverables	M	M	Reputational damage to Inquiry if not agreed early on	Reduce scope and deliverables early on. Consider reduction in quality
R4	The 'secondary uses' issue may distract attention from the main objective of sharing data for the purpose of direct patient care	M	M	Main objectives not delivered. Recommendations reduced and not delivered fully	Raise at separate forum eg Clinical Reference Group

(9) Quorum Level

A SCI meeting will be deemed inquorate if less than 75% of members are present

APPENDIX B. COMMITTEE MEMBERS

The list of members of the Select Committee is given in the table below.

Primary Role	Member Name	Organisation
Chair	Dr Charles Heatley	CCG/GP
Senior Responsible Owner	Idris Griffiths	CCG
GP1	Dr Chris Bronsdon	CCG/GP
GP2	Dr Jo Buchanon	CCG/GP
Consultant in Medicine for the Elderly	Vincent Clubb	Sheffield Teaching Hospital
Social Care/Local Authority	Richard Parrott/John Curtis	Sheffield City Council
Patient Representative	David Chapman	
Public/patient champion	Vicky Cooper	Sheffield Healthwatch
Medical Educationalist	Pirashanthie Vivekananda-Schmidt	Sheffield University
Supplier1	John Connolly	TPP
Supplier 2	Matt Sweeney	EMIS

APPENDIX C WITNESSES CALLED

Hearing No. 1 – 5th March

Dr Yonatan Shemmer	Academic Ethicist, Department of Philosophy, University of Sheffield
Adrian Scott	Clinical Director for Endocrinology and Diabetes, Sheffield Teaching Hospital
Dr Patricia Edney	GP/CCG Commissioning Executive Team
Helen Rowe & Geoff Pick	Patients

Hearing No. 2 – 12th March

Rebecca Pierce & John Wilshaw	Data Sharing Experts, W&SYB Commissioning Support Unit
Helen Rowe & Geoff Pick	Patients
Dr Anil Gill	GP
Dr Jonathan Mitchell	Consultant Psychiatrist, Sheffield Health and Social Care Trust
Sarah Withers	Consultant Physiotherapist, Sheffield Teaching Hospital

Hearing No. 3 – 19th March

Dr Jo Buchanon	GP
Dr Chris Bronsdon	GP
Jacque Stubbs	Patient
Dr William Lumb	NHS Cumbria Chief Clinical Information Officer

APPENDIX D DETAILED FINDINGS

The detailed findings have been categorised for ease of reference and are based solely on the oral and written evidence submitted to the committee

General

- a. Appropriate and safe patient data sharing for the purposes of direct care is in the best interests of the patient.
- b. No further opinion is required that sharing potentially improves care.
- c. There are risks in sharing - and the risks need managing - but the benefits outweigh the risks.

Impact on the quality and safety of care

- a. Lack of sharing information on the more complex cases usually has the greatest impact. In these cases, access to the whole patient record is of particular importance.
- b. Safeguarding reviews cite poorly co-ordinated working arrangements between agencies and lack of information sharing as key factors in failing the individuals concerned. Care for children and vulnerable families were impacted by the lack of sharing between GPs and A&E Departments.
- c. Lack of sharing of information on the needs of people with cognitive impairments (learning disabilities, etc) affects providers' abilities to put in place the 'reasonable adjustments' required under the Equalities Act
- d. Out of Hours services, A&E, Ambulance are other care settings where the patient may not be able to provide information and where ready access to patient data would reduce clinical risk
- e. The introduction of the Sunquest ICE system allowed the immediate access to blood and other test results for all Sheffield healthcare organisations and led to a 'transformation' in the level of care

Impact on efficiency of care

- a. If a practitioner does not have access to a patient's information, they have to undertake a time-consuming and onerous process of contacting other health professionals involved in the care pathway. This can also lead to errors and incomplete information.
- b. Occasionally, secondary care patients need to go back to their GP for the information needed by their consultants which leads to delays in diagnosis and treatment.

Privacy and security

- a. Privacy is of great importance and breaching privacy should be done only when absolutely necessary and when the cost of breaching privacy is commensurate with the gain of doing so.
- b. Using existing IT systems, a patient can keep parts of their medical record private and inaccessible to selected people or groups. This requires a good understanding of how the systems work. Restricting access in this way however risks the care professional missing certain relevant information and not being able to take a holistic approach. It would be better for the patient to leave the decision on access to their judgement noting that they have to abide by a professional code of conduct which confers a duty on them not to inappropriately share or misuse data in any way.

- c. Improving access to electronic patient data gives rise to the fear of privacy breaches and that the information may be opened up to organisations (such as insurance companies) who will use it for purposes not envisaged today. The precedent has been set with the electoral roll data.
- d. Not all GPs understand the security features of their IT systems and more training and ongoing support would be useful

Patient consent

- a. There are a number of ways in which consent is obtained and recorded – this can be with or without a conversation with the GP.
- b. If consent is not gained through a process that is sufficiently thorough, and if information is seen to be used in a way that is not good for the patient, the relationship and trust between the care professional and patient may be lost.
- c. A loss of trust may lead to a failure to reveal information or to reveal incomplete information – the consequences of such loss of trust will outweigh the cost of not sharing information.
- d. Explicit “Informed Consent” has four elements: Full information, Voluntariness, Capacity and Consent. The assessment of alternative consent options should satisfy these four criteria.
- e. Consent to share the patient’s data is obtained by GPs from the patient, guardian or advocate
- f. Patient consent was felt to be the most significant single barrier to sharing. The number of patients from whom consent has been successfully obtained ranged from 2% to 88% in a survey of 27 Sheffield practices.
- g. Over 60% of patients have not been asked for their consent (based on information gained from GP users of SystmOne - 80% of Sheffield practices)
- h. Some practices felt that they did not have sufficient time to explain consent to patients (“it takes half an hour”)
- i. Gaining prior consent can be problematic. It is difficult to predict a patient’s future healthcare interventions and for the GP to decide with whom to share.
- j. Other ways of gaining consent need to be considered to simplify the process at the GP practice eg gaining consent at the point of care.

Patients’ information and understanding

- a. There are concerns about patients being properly informed and whether they are actually giving informed consent
- b. Reasons that patients may not be sufficiently informed range from:
 - not given the opportunity to consent/dissent
 - not reading the additional information that was available
 - given the opportunity to consent/read information but didn’t pay attention to it
 - paid attention but didn’t understand (eg too complex, language barrier, cognitive impairment, elderly, confused, depressed)
 - some limited understanding but did not appreciate advantages and disadvantages
- c. Some patients want detailed information but want to be informed and reassured that data is being held safely and accessed appropriately. Some are satisfied with a brief request to share from the care professional.

- d. Information for patients should be written in plain English
- e. Patients are informed in different ways of what data is being shared, why and with whom.
- f. Lessons need to be learnt from the publicising of care.data
- g. Patients do believe that GPs have integrity and will share their personal data safely, appropriately and in their best interests.
- h. Patients concerns include the risk of misinterpretation and their data being accessed by organisations who will use it for profit or in their own self-interest.
- i. Many patients want more information about their care in order to be equal partners in the planning and delivery of their care (“I am the expert on me” in the words of one witness).
- j. Few patients are aware that they can access their medical records and very few actually do so.

Patient Record Ownership

- a. Many GPs assumed that they were the custodians and owners of the patient’s data.
- b. The Committee however took the view that the record belonged to the patient to which a range of care professionals contributed. However, a custodian role will still be needed (for example, in the cases of vulnerable patients or those with a mental impairment).
- c. There could be multiple custodians of the patient’s record which could, for example, be each organisation’s Caldicott Guardian. The custodian(s) however should receive comprehensive training to ensure they understand the benefits and risks of sharing or of not sharing the patient’s data. Access to the data should not be restricted if there is a possibility that it will prevent the patient receiving the best treatment from any health and social care professional involved in the patient’s care.

Accessing Patient Data and the Record Sharing Model

- a. The patient record should be available at the point of care on the patient’s pathway. However, the GP element of the record, can only be accessed if the patient has consented and the GP has set their preferences on their IT systems.
- b. Those involved in a patient’s care can only access data held in GP systems if the GP has set the preferences (for sharing GP-input data) made by patients and has opened up sharing to others (‘sharing out’). However, often GPs did not obtain patient consent or set the patient’s preferences (see section 4.1 for reasons why) and this frustrated other care professionals involved in a patient’s care who needed to access GP-input data. The Committee felt that there should be no requirement for GPs to set preferences for sharing prior to access by other care professionals (who would explicitly request consent from the patient).
- c. The IT suppliers confirmed that it was not possible to change the record sharing models. It was felt that, alternatively, improved use of both the consent process and the record sharing process was best achieved through better awareness, support and guidance.
- d. Sharing within primary/community care was variable with some community nurses being given access to patient data by the GP and others not.
- e. Real time access to key patient data items can be justified.
- f. Both the TPP and EMIS systems have a ‘consent override’ facility which can be used if it is in the best interests of the patient. This facility could be utilised in, for example, cases of unconscious patients, children at risk

- g. The lack of sharing of non-health data with care professionals and vice versa should not be overlooked

Checks and Balances

- a. Systems used by GPs ie SystmOne, EMIS PCS and EMIS Web, have good audit trail facilities which monitor access to the patient's record
- b. GPs are concerned about the lack of audit trail functionality in external systems which would hold shared GP data, especially hospital systems.
- c. Audit trails need to be used more comprehensively by Caldicott Guardians to reassure GPs and patients that any inappropriate access is being picked up and firm corrective action is being taken (including suspension and dismissal).

Culture, Attitude and Practice

- a. GPs are independent practitioners and usually do not work in multidisciplinary environments. Unlike, for example, secondary care or community services they do not have a history of working in teams and sharing the necessary information
- b. GPs felt that any changes to their workload (arising from the consent process) needed to be simple, quick and manageable within the allotted time of an individual patient consultation
- c. Some groups of GPs were resistant to change.
- d. Any changes to the behaviour and practice of care professionals need to be undertaken with caution and with appropriate support and guidance
- e. Patients' data is not always accessed by care professionals even though consent and sharing has been granted by the patient. This is a missed opportunity to improve care.
- f. There is a misunderstanding that once consent has been obtained that patient data is available to a wide number of people rather than only to those care professionals who have a legitimate relationship with the patient

GPs' Understanding

- a. The adverse impact of inadequate data sharing or of variable data quality on a patient's care provided in other parts of their care pathway was not well understood by GPs
- b. GPs were often unclear as to what patient data they could and could not legally share
- c. GPs wanted clear unambiguous guidance from a single source
- d. GPs' understanding of the use of IT systems was limited in some cases leading to sub-optimal use

Information Governance, Caldicott and the Law

- a. Each organisation should be responsible for its own information governance
- b. Caldicott Guardians in GP practices do not generally understand their role as agents of safe sharing practice and do not understand the risks of not sharing.
- c. There is a legal duty to share children's records
- d. Caldicott states that sharing should happen unless there is a good reason not to
- e. The GMC Guidelines recommend data sharing as good practice – 'there is a duty to share'

Information Sharing Agreement

- a. Sharing agreements should be at an organisational not team level
- b. GPs wanted a simple 'Consensus Statement' agreed by all care organisations across the patch
- c. Such a universal agreement along with access to a single source of relevant patient information would avoid the onerous and time-consuming task of collecting data from every care professional which inherently could lead to incomplete information
- d. Cumbria has a single global information sharing agreement across the health community. There is consensus among health and social care organisations that current information agreements in Sheffield need updating and multiple groups are undertaking reviews. These reviews need coordinating and need to include consideration of wider agreements covering South and West Yorkshire.

Data Quality and Relevance

- a. New data added from sources other than the GP were felt to clutter up the GP database making it more difficult to find the relevant information and deterring GPs from allowing others to add to the patient record. However, this should not mean the idea of a single record that is accessible, and changeable, by any care professional legitimately involved in a patient's care is compromised.
- b. GPs were anxious about maintaining the quality and integrity of the patient data. This required all care professionals contributing to the patient record to understand that their data would be accessed by others and to ensure the data was relevant and of appropriate quality. The integrity of the single record needs to be maintained through training for all users in both data quality and systems use.

Record Keeping and Information Sharing Awareness for Care Professionals

- a. It would be useful to regularly refresh care professionals' understanding of record keeping, data sharing and the optimum use of IT systems. Poor record keeping can affect patient care (eg incorrect Read codes)
- b. There exists an Information Sharing Toolkit, endorsed by the Information Commissioner's Office.

IT and Systems Interoperability

- a. The lack of interoperability among systems in Sheffield health and social care organisations hinders the effective flow of information.
- b. Many systems can hold the NHS number but it is not used for sharing.
- c. It would be useful to visualise the ideal system of sharing without the restrictions of technology or cost. Describing the ideal and differentiating between it and what is actually implemented will allow future goals for improving the system to be set and to consider ways to reaching these goals.
- d. Refresher training and ongoing support for GP practices was necessary to ensure safe optimal use of systems

Finance

- a. The deployment of further IT across the health community in order to improve sharing will incur extra costs

Commitment and Leadership

- a. Commitment and leadership from senior clinicians and management across the health community was vital if change was to be successfully communicated, delivered throughout the workforce and sufficiently funded.

Lessons from Elsewhere

Cumbria is a national information sharing exemplar community and the CCG's Chief Clinical Information Officer attended the Inquiry as the final witness of Stage 1

- a. Widespread viewing of data collected through the Message Interoperability Gateway takes place across the Cumbria community.
- b. 79 of the 82 practices share 'meaningfully'.
- c. Sharing is still not universal eg social care and all secondary care not yet on board.
- d. There is a risk that GPs feel isolated – sharing applies to all care professionals and must be implemented as a whole community
- e. The main enabler was the single global Information Sharing Agreement across the community. Encourages everyone to think beyond their own boundaries and reduces overheads.
- f. Considerable information governance training and awareness has been undertaken. The time taken to visit every IG Lead was a worthwhile investment. If the IG issues are not understood, then it is easier and safer not to share.
- g. The opt out approach has been taken in Cumbria and the rate has been very low. A large amount of publicity was undertaken: mailshots to each household, PR events, local media etc
- h. Patient participation groups have been created who have run a patient engagement campaign
- i. A number of minimum datasets (mds) have been created for the purposes of sharing. To date these include EOL, Ambulance, OOH, A&E, Medical Assessment Unit. Each individual care group has agreed that the mds should only comprise clinically relevant data.
- j. Sensitive data is filtered out before creating the mds and sharing

APPENDIX E EVIDENCE FROM DR YONATAN SHEMMER, PHILOSOPHER AND ACADEMIC ETHICIST, UNIVERSITY OF SHEFFIELD

It was felt that the evidence provided by Dr Shemmer got to the heart of the privacy and consent debate. When considering future changes it would be valuable to return to the points and issues he raised to constantly remind ourselves of our principles and objectives and assess the risks and benefits of any changes to sharing models from the perspective of the patient as well as the care professional. The evidence has therefore been reproduced in full below.

Dr Yonatan suggested there were at least two more questions supplementary to the main question about inherent rights of privacy he was asked to address.

Inherent and instrumental rights

There is a debate among philosophers about whether privacy has an inherent value or an instrumental value or both. There is also a debate about whether the best framework for understanding the value of privacy is in terms of rights, or happiness, or wellbeing, or virtue.... But all this is of little importance. Whether the value of privacy is inherent or instrumental (indeed many things that we would protect at all cost have only instrumental value: for example locks on doors) and whatever the right way of understanding this value is, most philosophers agree that privacy is of great importance and that breaching privacy should be done only when absolutely necessary and when the cost of breaching privacy is commensurate with the gain of doing so. Polls in the general population suggest that most people share this view about the importance of privacy and about the importance of not breaching it unless it is done for reasons that are of greater importance. In particular some philosophers emphasize that a breach of privacy should be considered only when there are direct benefits to the person whose privacy is being breached and in any case not simply as a time saving or money saving measure.

These considerations have direct implication for the decision that your committee faces since some of the arguments for breaching privacy that you have considered seem to suggest that the benefits are not always directly to all the patients whose privacy might be breached as a result of the implementation of the suggested changes and some of these benefits are financial benefits to the system.

*There are 4 important aspects of **inherent** value of privacy:*

- 1 Autonomy to have control over how the world sees me through the information available*
- 2 Self ownership of the information*
- 3 Intimacy, there are different levels of relationship and some imply different levels of access to information, so having control over the release of information allows the individual to determine the level of intimacy*
- 4 Dignity which is complicated and hard to define. Being a human being is of itself of value and so one should be treated as having that value. An example would be to have to kneel on the floor to lick food off, and that some philosophers would argue that the inherent right to dignity would be present even if there were substantial instrumental value in carrying out this action.*

Instrumental value of privacy

Autonomy can be hard to protect if others have information about us that is private.

A person can be abused by others using the information in a number of ways.

Leakage of information might therefore lead to abuse.

We have to assess the dangers should this information be leaked, or in case it is used not in accordance with its intended purpose by people inside the system.

This last consideration is extremely important since on the suggested proposal the system will include all NHS employees as well as many social workers and other people in the care system and possibly other health suppliers such as employees of insurance company.

Finally there is a very important aspect of privacy, relating to consent

We must aim to maintain a high level of trust in the system. This is a concern for medical ethicists.

If consent is not gained through a process that is sufficiently thorough, and if information is seen to be used in a way that is not good for the patient, this trust may be lost.

A loss of trust may lead to a failure to reveal information or to reveal complete information – the consequences of such loss of trust will far outweigh the cost of not sharing information.

Overall there is an acceptance by philosophers and the public that privacy is valuable. So one question is whether the cost of preserving privacy is greater than the cost of breaching it.

In case the committee decides to adopt an information sharing scheme the second ethical question is how consent is going to be acquired.

Consent

Caldicot makes it very clear that implicit consent is not the relevant kind of consent for changing the rules about information sharing.

Such change will therefore require receiving explicit consent from patients. The question the committee will be facing is what measures are required in order to acquire explicit consent.

- a. Explicit “Informed Consent” has four elements: Consent; Full information, Voluntariness, Capacity. The crucial question is whether the kind of ‘Opt Out’ consent that is considered by the committee satisfies these four elements.*

There are serious worries about a. People being properly informed b. about whether people are actually giving their consent

If:

- People didn't see the letter and additional info.*
- Saw but didn't pay attention to it.*
- Paid attention but didn't understand.*
- Weren't aware – even after reading all the literature – of the advantages and disadvantages of the scheme.*
- Didn't understand that not replying will be taken to be an explicit consent.*
- Wanted to dissent but felt that the burden of taking the necessary steps was too big (elderly, confused, or depressed patient will see what normally seems like a small hurdle as a very big hurdle).*
- Tried but failed to dissent (their letter to the practice got lost; their request wasn't properly filed...)*

There are also minor worries about capacity and voluntariness:

- In an opt-out system the doctor cannot verify that the patient who is giving the consent is competent or is not pressured by family and friend to do so.*

Most importantly there has to be a public understanding that by, e.g. not replying to the letter, they are consenting.

Factual concerns

We have to balance the value of sharing against the value of privacy and keeping the trust in the system. There are two questions, one about evidence and another about systems.

There appears to be lots of evidence about communication regarding the sharing of information but not much evidence that sharing actually improves care, much of this is anecdotal and not scientific or statistical. There is not much statistical evidence about sharing and harm.

In terms of how systems are developed, restrictions take place in technical terms, directed by cost.

He suggested that we should characterize the ideal system for sharing, and make explicit the way in which the proposal deviates from what is ideal. We can do that by imagining what we would do without limitations of cost or technology. Describing the ideal and differentiating between it and what is actually implemented will allow the committee to set future goals for improving the system and to think of ways to reaching these goals.

In some health systems sharing takes place using a card, such as in the French system. This is where a patient carries the card with them by placing it in the machine or in the hands of the doctor, consent is expressedly given then. This could be an example to aspire to.

Other things that could be improved if more money or other computer systems were available:

- What parts of the medical record should be shown?
- Which part are shown to what health teams (do social workers need to see everything that is available to doctors?)

Your Electronic Patient Record & the Sharing of Information

- A Patient's Guide

Please read this leaflet carefully. It will give you information about the sharing of your electronic patient record and the choices you need to make

Today, electronic records are kept in all the places where you receive healthcare. These NHS Care Services can usually only share information from your records by letter email, fax or phone. At times, this can slow down your treatment and mean information is hard to access.

Your GP practice uses a computer system called SystemOne that allows the sharing of full electronic records across different NHS Care Services. We are telling you about this as a patient at this practice as you have a choice to make about how your practice shares information about your care from your electronic patient record. This form is not about your Summary Care Record (SCR), it is asking your sharing preferences regarding your full electronic GP record. You can choose to share or not to share your electronic GP record with other NHS Care Services.

How is my decision recorded?

Your GPs computer system has two settings to allow you to control how your medical information is shared:

Sharing Out – This controls whether your full GP electronic patient record can be shared with other NHS Care Services where you are treated. Please record your preference:

Please tick: Sharing Out **Yes** (shared) or **No** (not shared)

Sharing In – This controls whether you agree for this practice to view information you've agreed to share at other NHS Care Services. Please record your preference:

Please tick: Sharing In **Yes** (viewable) or **No** (not viewable)

Patient Name (Print Name): _____

Date of Birth: ____ / ____ / ____

Patient Signature: _____ Date: ____ / ____ / ____