# Care Homes on Connecting Care and eRed Bag Information Governance Report

## 1. Introduction

This report outlines the work and the outputs related to Information Governance from the 'design' stage of establishing Care Homes as partners within the Connecting Care Programme. The report includes input from key staff from Care Homes, NHS care providers, NHS Digital, Clinical Commissioning Groups, Patient representative groups and others. Much of this was engaged at a workshop in August 2019.

In addition to that invaluable input, documentary reviews and research work have been undertaken to produce the Data Protection Impact Assessment, to establish the legal gateways and lawful basis for recording and sharing data and set out key details of data to be recorded and shared between agencies effectively and securely. This report accompanies the Data Protection Impact Assessment (DPIA).

Back in 2016 the Care Quality Commission (CQC) noted in their report 'Safe Data, Safe Care' that many NHS organisations had widespread commitment to data security, infrastructure and staff training, but standards were not in place to support data security as much as they needed to be. This lead to the development of the Data Security & Protection Toolkit (DS&PT) with its requirements to assess leadership, information, tools and training, IT systems and unsupported technology.

Care Homes as a sector regulated by CQC are now starting to adopt the DS&P Toolkit, recognising the opportunity that provides to consider wider sharing of data for the delivery of care and how it is crucial to achieve appropriate standards to engage with shared record programmes such as Connecting Care. In addition the regulation by CQC links to legislation that both enables and requires Care Homes to share relevant data for safe care and effective transfers of care through programmes such as the Red Bag initiative.

This report addresses the Information Governance requirements related to developing an eRed Bag solution and enabling wider data sharing with Care Homes.

## 2. Data Protection Impact Assessment (DPIA)

A DPIA has been set out for this programme that covers the design stage and the requirements of the implementation stage.

The DPIA assesses the following considerations:

- The data to be shared, including where it comes from, where it is generated and who it is shared with

- How role based access will be determined for Care Home staff to access data already in Connecting Care and also which roles in Connecting Care will access the forms recorded as part of the eRed Bag development
- The scope of data to be processed including the retention requirements
- The requirements for informing data subjects and the exercise of their data protection rights
- Stakeholder consultation (which was a key part of the August workshop, including care home, health service and patient representatives)
- The legal gateways and lawful basis for processing (see section 3 for more detail)
- How data protection principles such as limitation, minimisation, accuracy and security will be applied
- Identified risks and mitigation actions either in place or required as part of implementation

The risks identified in the DPIA have all been assessed and the mitigation actions are deemed sufficient that no high risks remain.

A significant amount of the mitigation of risk is already in place in the Connecting Care solution which has been sharing data for over six years. Implementation of access for Care Homes and the eRed Bag forms will be overseen by the existing mature governance processes already in place.

## 3. Legalities of sharing data with Care Homes

### 3.1. Legal gateways and lawful basis for recording and sharing data

Detailed analysis has been conducted on the basis on which Care Homes, those providing nursing care and those that provide residential care can record and share personal data of individuals, including special categories of personal data related to their health.

From the outset it is important to be clear on whether consent is an appropriate basis to record and share data. It is a widely held belief, but also a common misconception that the sharing of data has to be based on explicit consent. The Information Commissioner's Office has provided detailed guidance on all lawful bases for processing of data. Their code of practice on data sharing notes:

*'Data protection does not prevent data sharing, as long as you approach it in a sensible and proportionate way…. Balance the risks and benefits….'*

*'Misconception – we can only share data with people's consent' – NO, you can usually share without consent if you have a good reason to do so.*

*'Consent means offering individuals real choice and control. If you cannot offer a genuine choice, consent is not appropriate… …If you make consent a precondition of a service, it is unlikely to be the most appropriate lawful basis'*

It is becoming generally accepted across all forms of care services, that where an individual agrees to receive a care service, that the processing of data which is necessary to provide that service and to document that care was delivered appropriately is NOT a choice that the individual has about the use of their data. The individual's choice is to receive the service or not to. If they choose not to receive the service, a record of their choice needs to be made, and there is then no necessity to share data.

This is as applicable to the provision of care by care homes as it is to any health or social care service.

This does not mean the individual has no say at all as they still have the right to object under article 21 of the General Data Protection Regulation. However they have to set out why their circumstances are leading them to object and the organisations processing their data can, with compelling legitimate reasons, override an objection if ultimately necessary.

**It is on this basis that consent is not being proposed as the legal basis for processing data.**

Therefore other legal bases that are compliant with current data protection legislation need to be identified. There is need to check what categories of data need to be recorded and shared, to identify if legal bases need to be identified for both personal data and special categories of personal data.

All care organisations will have personal data. Whilst residential homes will have limited data related to health of their residents, they will still have some basic details that relate to an individual's health and therefore we can confirm all care providers will also have 'special categories of personal data'.

**Explaining 'legal gateways'**

Public sector organisations can only undertake tasks that they have been legally established to do, unlike private organisations that can do what they want, so long as their actions do not break any laws. So a public authority needs to identify it's legal gateway to act when performing a task and in doing so record and share personal data related to the task it is undertaking. The public sector can commission private organisations to undertake the tasks they are established to do and thereby delegate the 'legal gateway' to perform the task.

Further to that, specific elements of current data protection legislation only permit the processing of data where it is related to a piece of legislation that enables an organisation to perform the overall task. For example data related to health and social care can be processed (article 9(2)(h)) but has to be linked to either a (European) Union or Member state law that enables the organisation to do the overall task they need to use the data for. For example, Clinical Commissioning Groups have wide ranging legal powers to plan and develop services for the population they cover and the laws providing those powers are the ones they need to link to their potential use of data for managing health and care services.

So where any organisation is claiming processing is based on 'the exercise of official authority' or the processing has to be linked to a 'member state law' then it is necessary to identify the relevant statutes that give the authority for those organisations to act.

To add complexity, in the care home sector it is important to note the difference between care commissioned by a public authority (including individuals given control over their own budgets) and self-funding individuals as the bases for processing are different.

The following tables set out the bases for processing for both the recording and sharing of data by care homes and residential homes, developed by researching the relevant laws.

Recording of Personal data – Article 6

| NHS or Local Authority funded | Self funding |
|---|---|
| 6(1)(e) – necessary for the exercise of official authority. *This is delegated from the body that is commissioning the care* | 6(1)(b) – necessary for the performance of a contract to which the data subject is a party (includes establishing the contract) |

These would be the same for Nursing Homes & Residential Homes

Legislation giving the 'official authority' includes:

- NHS legal gateway - NHS Act 2006, S3 (Duty to provide accommodation)
- LA Legal gateway - Care Act 2014, S18 (Duty to meet needs for care & support)
- The H&SC Act 2008 (Regulated Activities) Regulations 2014 - s12(2)(a,b & i) - Safe care & treatment

Recording of Special Category Personal data related to health – Article 9

| NHS or Local Authority funded | Self funding |
|---|---|
| 9(2)(h) – necessary for the provision of health and social care services, on the basis of **'member' state laws** or a pursuant to a contract with a health professional | |
| **NHS/LA funded – relevant laws:** | **Self funding – relevant laws:** |
| • NHS Act 2006, S3 (duty to provide accommodation)<br>• Care Act 2014, S18 (duty to meet needs for care & support<br>• Health & Social Care Act 2008 (Regulated Activities) Regulations 2014 – S12 (a, b & i) – safe care & treatment | • Health & Social Care Act 2008 (Regulated Activities) Regulations 2014 – S12 (a, b & i) – safe care & treatment |

These would be the same for Nursing Homes & Residential Homes

Sharing of Personal data – Article 6

| NHS or Local Authority funded | Self funding |
|---|---|
| 6(1)(c) – Necessary for compliance with a legal obligation to which the controller is subject.<br><br>The legal obligation comes from Health & Social Care (Safety & Quality) Act 2015, **Section 3 – Duty to share information**<br>This is between providers of health and adult social care and they must ensure that the information is disclosed to other relevant health or adult social care providers where it is likely to facilitate the provision of services to the individual and is in their best interests.<br><br>The duty does not apply if the individual objects, or is likely to. | |

These would be the same for Nursing Homes & Residential Homes

Sharing of Special Category Personal data related to health – Article 9

| NHS or Local Authority funded | Self funding |
|---|---|
| 9(2)(h)– Necessary for provision of health or social care services, on the basis of member state laws<br><br>The legal obligation comes from Health & Social Care (Safety & Quality) Act 2015, **Section 3 – Duty to share information (see previous slide).**<br><br>Also – Health & Social Care Act 2008 (regulated activities) Regulations 2014, S12 (i) - where responsibility for the care and treatment of service users is shared with, or transferred to, other persons, working with such other persons, service users and other appropriate persons to ensure that timely care planning takes place to ensure the health, safety and welfare of the service users | |

These would be the same for Nursing Homes & Residential Homes

So in summary the above tables set out the data protection legislation justifications (lawful basis) for recording and sharing data and where appropriate link to the legislation that enables and/or requires the organisations to perform those tasks.

### 3.2. Informing individuals of data sharing

Given the proposed sharing of data with Care homes, both in terms of eRed Bag forms and access by care home staff to Connecting Care, at the workshop in August 2019 representatives of homes were asked to highlight how they currently inform their residents of how their data is used. This is to meet the first principle of data protection legislation to

ensure that data processing is fair and transparent. The representatives reported that they used the following methods:

- Leaflets and posters
- Privacy/Fair processing notices on websites
- Discussion with residents during the delivery of services

An example of a resident's privacy notice is available at:
https://www.stmonicatrust.org.uk/resources/files/Residents-privacy-notice-NEW.pdf

In addition to these general methods, the forms that are proposed to be developed include the 'About Me' form, much of the data for that will be gathered with the resident themselves so there is ample opportunity to discuss how such data will be used and answer any queries the resident and/or carers/next of kin may have.

In addition existing Connecting Care partners will be required to check their notices to ensure that they sufficiently cover sharing with Homes or will be amended as required. This will also apply to the core Connecting Care fair processing materials.

### 3.3. Role Based Access for those sharing data

Following detailed discussion at the August 2019 workshop and consultation with staff experienced in the services and developing access control models a set of recommended roles and data access have been developed. These are set out in Appendix 1.

This shows the categories and types of data that workshop attendees identified as being needed by these roles. These will be assessed in relation to the existing role based access matrix for Connecting Care to establish if existing roles can be used to provide the access or if new roles need to be created. Initial analysis shows that two existing roles can be used and the reference to them being used by Care Home staff will be in the notes of each individual user account.

Any changes to existing roles or new roles will be taken through the relevant change process for the Connecting Care information sharing framework, overseen by the Connecting Care Information Governance committee.

### 3.4. Proposed methods and detail of data sharing (partnership)

Staff in Care Homes will be given role based access to the data in the Connecting Care portal. Each organisation will be taken through the 'new organisation' sign up process to ensure all access is identified and authorised in an appropriate manner as well as ensuring all existing data controllers are aware of and in agreement to the expansion of use of the Connecting Care portal. These processes will be overseen by the Connecting Care Information Governance Committee.

### 3.5. Proposed methods and detail of data sharing (care homes)

As well as Care Home staff access to Connecting Care, the 'About Me' and 'SBAR'(situation, background, assessment, recommendation) forms from the eRed Bag are being established as data collection forms within the Connecting Care portal. Appropriately authorised Care Home staff will enter data into these forms which will then be visible to appropriately authorised Connecting Care viewers at other settings, for example within the Ambulance Trust or at the Acute hospitals across the region.

This document includes examples of the forms that were developed at the workshop with Care Home staff in August 2019 in Appendix 2. This was a facilitated process reviewing data on existing paperwork and determining which items are required and how they ought to be laid out so that key information is clear. The process reviewed the necessity of each data item for inclusion on the forms therefore taking account of the data protection principles of minimisation and necessity.

These forms will be available to other users of the Connecting Care portal via the Role Based Access matrix. Determination of which roles will see these forms will be based on the 'need to know' principle. Connecting Care offers a greater opportunity to share these forms with a wider group of users who 'need to know' compared to the physical transfer of such data via the Red Bag.

## 4. Summary / Conclusion

Information valuable for the provision of safe and effective care to care home residents can and should be enabled to be shared via Connecting Care. Within the report and DPIA all the key Information Governance concerns have been identified and addressed and whilst no information sharing is entirely risk free, the benefits to care home residents from sharing data are clear to see. Utilising a mature system such as Connecting Care, with proven governance mechanisms to identify and mitigate risk as far as possible can achieve real benefit but also ensure data shared is protected as far as possible.

It is recognised there is some work required to ensure Care Homes' approaches to the recording and use of data meet the required (DS&P Toolkit) standards. It should be noted that is not because of a lack of commitment to data protection by Care Homes, but up to this point less drivers to formally assess compliance. The drive to connectivity and sharing electronically is also the driver to ensure all organisations meet the same baseline security standards.

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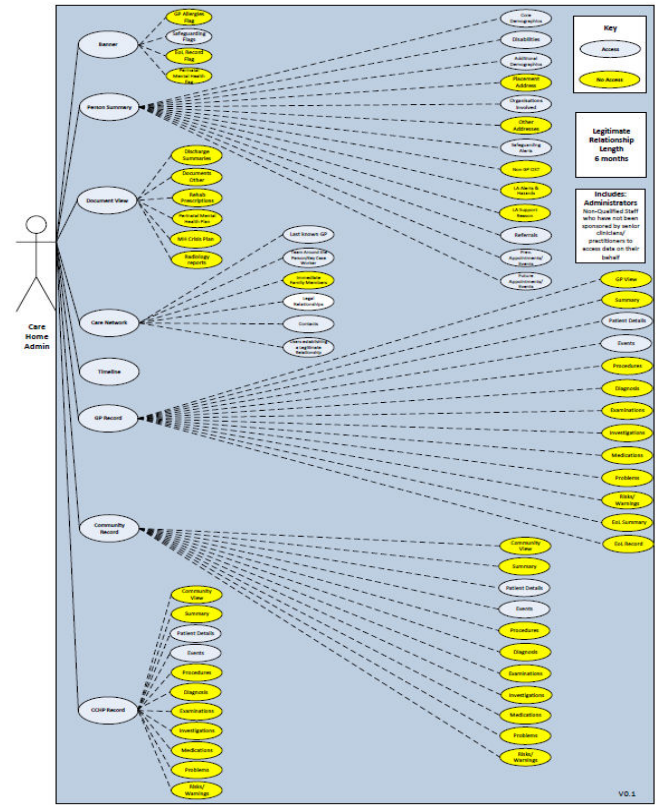
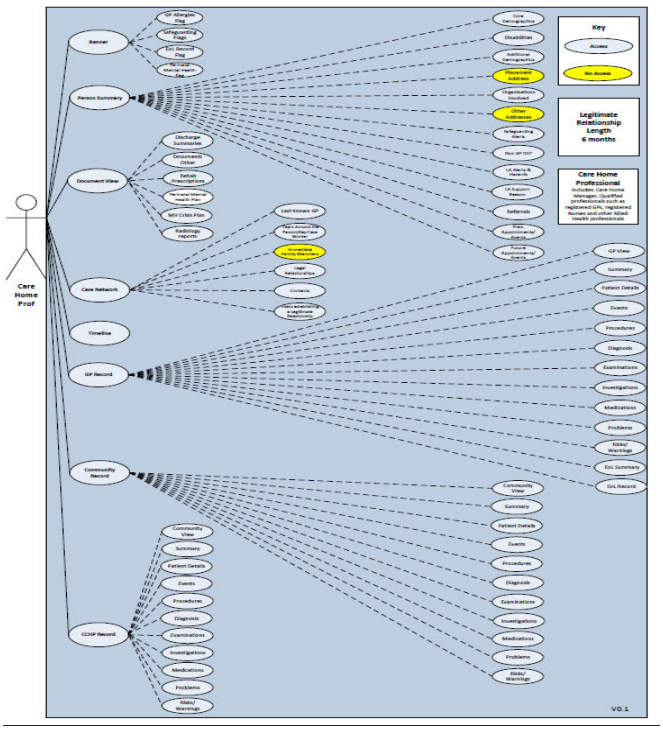
**October 2019**

## 5. Appendix 1: Care home role diagrams

### i) Care Home Administrator role based access proposal

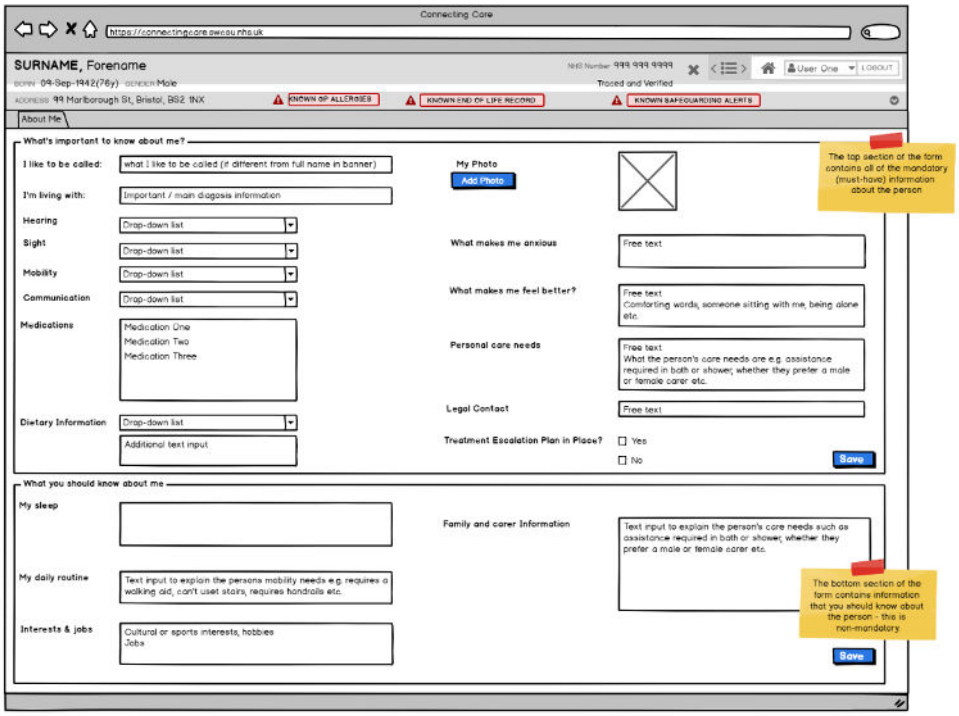



### ii) Care Home Professional role based access proposal

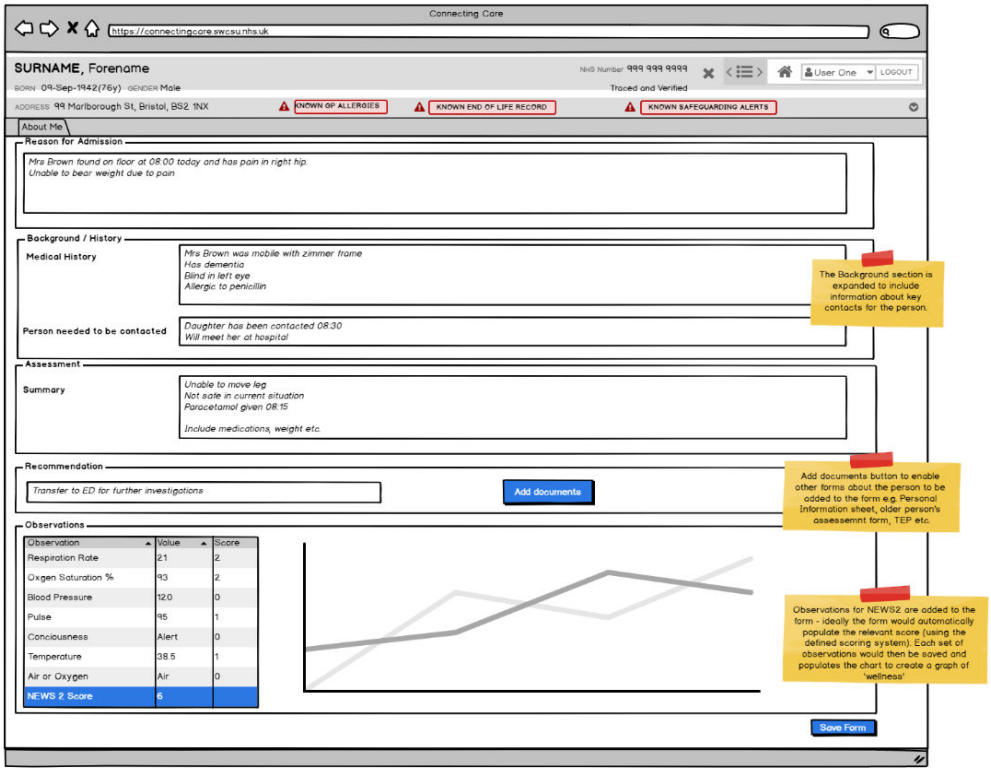


## 6. Appendix 2: Co-designed forms ‘About me’ and ‘SBAR’ (preferred versions)

### i) ‘About Me’ e form Version 3




### ii) ‘SBAR’ e form Version 2



## 7. Version Control

| Document Version | Date | Contributing Authors | Detail |
|---|---|---|---|
| FINAL 1.0 | 15/10/2019 | Author:<br>Adam Horton- Tucket Information Governance Consultancy Lead SCW<br><br>Reviewed by:<br>Fran Draper SCW<br>Tracey O'Brien SCW | FINAL RELEASE |