



South, Central and West
Commissioning Support Unit

Care and Health Information Exchange Compliance Review with General Data Protection Regulations

Document Control Sheet

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Abbreviation	Meaning
AUA	Acceptable use agreement
CHIE	Care and Health Information Exchange
CHIA	Care and Health Information Analytics
CCG	Clinical Commissioning Group
DOH	Department of Health
DSA	Data sharing agreement
DSCRO	Data Services for Commissioners Regional Offices
GP	General Practice
HCC	Hampshire County Council
HHFT	Hampshire Hospitals Foundation Trust
HHR	Hampshire Health Record
HHRA	HHR Analytics
HHRIGG	HHR Information Governance Group
PHT	Portsmouth Hospitals Trust
SCW CSU	South Central and West Commissioning support unit
SHFT	Southern Health Foundation Trust
Solent	Solent Healthcare Trust
UHS	University Hospital Southampton Foundation Trust
RBAC	Role Based Access Control

1 Purpose

This document is a review of the compliance of the Care and Health Information Exchange (CHIE) also known by its previous name, the Hampshire Health record (HHR). As of the date of this document, the process of re-branding HHR as CHIE is ongoing, and these names are used interchangeably in some documents.

This document covers two separate but related services supplied by South, Central and West (SCW) commissioning support unit:

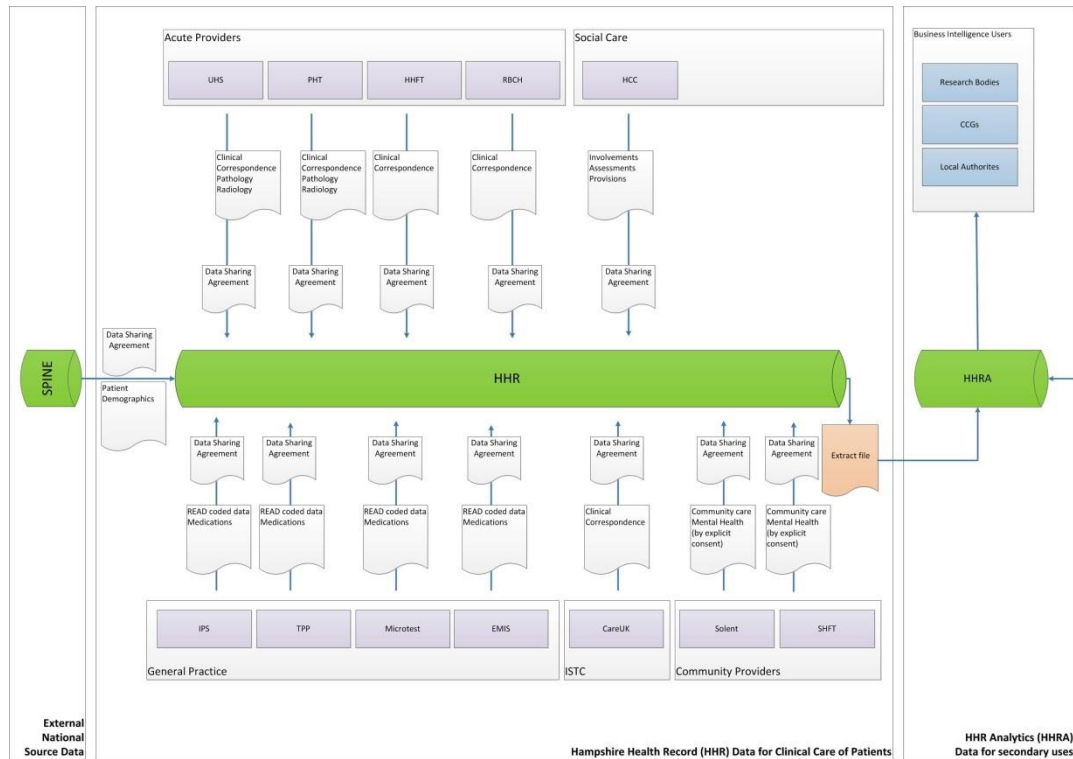
- CHIE, a clinical and care service used by doctors, nurses, pharmacists, social workers and other professionals (whether in the public, private or third sector) involved in delivering NHS or local authority commissioned services. This is designed to support direct care to patients.
- CHIE Analytics (CHIA), a service that provides business analytics and research capability using data supplied through CHIE

The processes and procedures of the CHIE are governed by the security policy which is included below as

Appendix 1: Security and Confidentiality Protocol

2 Overview of Patient Information Flows

The overall architecture is described pictorially below, with the primary data flows shown into CHIE and CHIA in terms of the types of data being processed:



Records held on CHIE are held with clear NHS numbers and other identifiers required to locate records to deliver to professionals in support of treatment and care.

For CHIA all records are pseudonymised by removing Name, NHS Number, address, postcode and date of birth from records. NHS Numbers are encrypted to provide a unique identifier (NHSNumber) and date of birth is converted to year of birth (except for infants below the age of one, where date of birth is converted to week of birth). Postcodes are converted to Super Output Area codes from which an Index of Multiple Deprivation is derived and attached to each patient record. SOAs were designed to improve the reporting of small area statistics and are built up from groups of output areas (OAs). Statistics for lower layer super output areas (LSOAs) and middle layer super output areas (MSOAs) were originally released in 2004 for England and Wales.

Extraction of data for analysis is done in response to approved requests for data by the CHIE IG Group and is supplied to CHIA in pseudonymised format. Only coded data is extracted to CHIA, no free text is supplied for analysis.

Only a subset of data in CHIE is used in CHIA for analysis. These data sets are set out in the processing manual included as Appendix 2: Data pseudonymisation for CHIA process. The only data to be analysed in CHIA is:

- GP clinical codes, without any associated free text
- Diagnostic codes which form the results of investigations for pathology and radiology from
 - University Hospitals, Southampton
 - Portsmouth Hospitals

These are likewise without any associated commentary.

CHIA does not combine or link data from CHIE to any other dataset.

2.1 Data Sharing Architecture

Sharing of data with and by CHIE and CHIA is governed by:

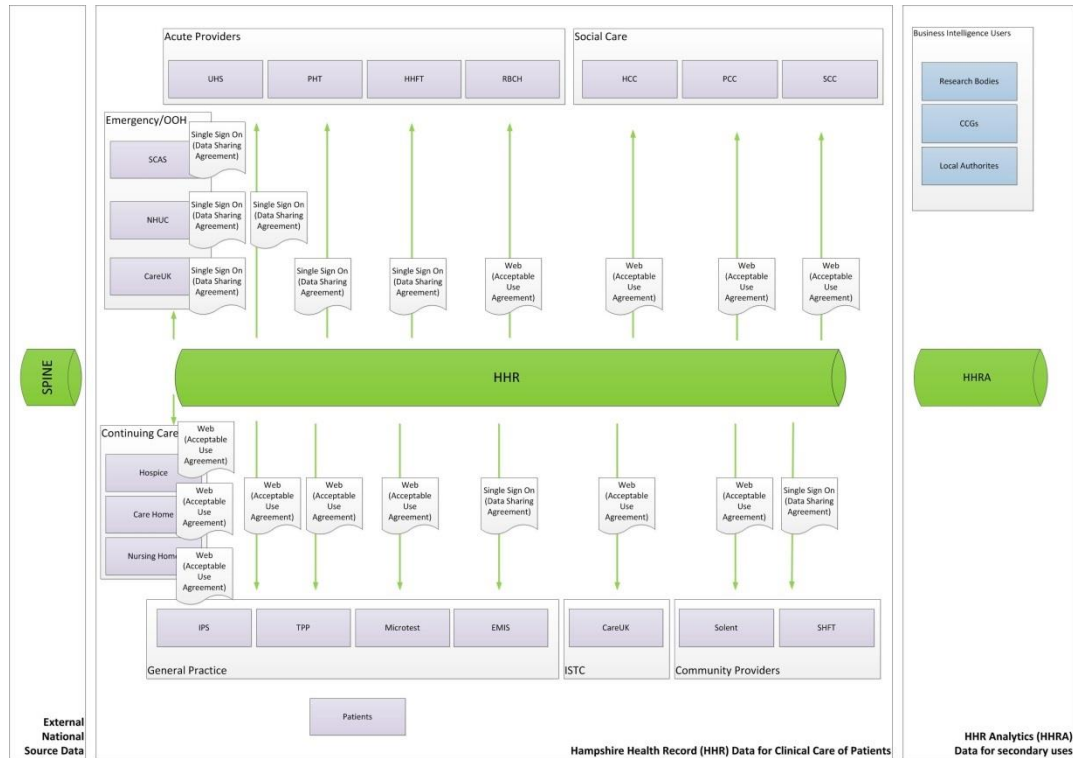
- Data Sharing Agreements (DSA) covering flows of data between organisations. This includes a requirement for the organisation to ensure acceptable usage where that organisation uses 'Single Sign On' (SSO) functionality.
- Acceptable use agreements (AUA) by individuals. These have to be accepted and returned by users prior to release of access passwords. This applies to users that log on using the web front end into CHIE. Users that log on using SSO are covered by the organisational DSA (see above)
- Where practical, consent to view at the point of use

Template examples of DSA and AUA are included as Appendix 3: Data Sharing Agreement Templates below

As well as the AUA, data is restricted using a Role Based Access Control (RBAC) model. This governs what information types are available to which staff groups based on their role. The full list of access types is included in

Appendix 1: Security and Confidentiality Protocol

This is represented below



2.2 Data Categories

- Demographics/Allergies
 - Orglinks (single tenancy)
- GP data
 - GP Extracts – Emis, INPS Vision and Microtest
 - GP Extracts - TPP
- Clinical Correspondence
 - University Hospital of Southampton (UHS) – range of clinical correspondence
 - Portsmouth Hospitals Trust (PHT) -
 - Hampshire Hospitals Trust (HHFT) – discharge summaries
 - Royal Bournemouth and Christchurch Foundation Trust (RBCH) – clinic letters/discharge summaries
 - Care UK (Southampton independent treatment centre) – discharge summaries
 - Documents uploaded by users e.g. care plans
- Mental Health and Community
 - Southern Health Foundation Trust – Rio
 - Solent Health Foundation Trust – TPP SystemOne
- Social Care
 - Hampshire County Council (HCC) – Swift

- Pathology and Radiology
 - University Hospital of Southampton (UHS)
 - Portsmouth Hospitals Trust (PHT)

2.3 Physical Architecture

The identifiable data stored in CHIE is physically located on the CSU network, in 2 secure data centres and provided to users using 128-bit secure socket layer (SSL) encryption through load balanced web servers. No data is ever physically resident on the client PC.

The CHIE servers are managed by SCW CSU staff

At a high level this architecture is comprised of:

- Virtual data base which holds the CHIE operational data.
- Virtual feed servers that receive data from external sources. This data is processed to allow it to be uploaded to CHIE-DB in the correct format, after which it is deleted from the FEED server.
- Virtual web servers that provide the data to users
- CHIA DB, which is a separate virtual server for processing secondary use requests and holds no patient identifiable data

The CHIE servers sit within a separate dedicated domain and are protected by vArmour, which delivers a distributed platform with integrated security services including software-based segmentation, micro-segmentation, application-aware monitoring, and cyber deception.

Penetration testing is carried out on a regular basis, as are windows and other security updates to the software.

2.4 Governance and Data Ownership

The data on CHIE is owned by the data controllers, which comprise:

- Individual GP practices
- Acute Trusts
- Community Trusts
- Local Authorities
- Independent treatment centres

These organisations remain as joint data controllers under the data protection act (DPA) and this is expected to continue under GDPR. Data is supplied by GP practices, acute hospital trusts, social services, community and mental health trusts and others.

Control of the data held in CHIE remains the joint responsibility of the data controllers of the organisations supplying that data. In order to facilitate decision making by the data controllers, CHIE has as part of its governance an information governance group (CHIE IG Group) which is charged with making IG decisions on behalf of the joint data controllers. Terms of reference for this group are included below as Appendix 4: CHIE IG Group Terms of Reference.

SCW operate this product acting as data processors on behalf of the joint data controllers and are represented on the CHIE IG group. GPs are represented on the group by the Wessex local medical committee (LMC) of the British Medical Association (BMA).

Data is processed by SCW CSU. In order to comply with the wishes of the data controllers:

- all requests to CHIA and
- any new developments to CHIE

are subject to approval by the CHIE information governance group (CHIE IG Group). All development projects require a privacy impact assessment to be approved both by the CSU as data processor and by the CHIE IG Group.

Terms of reference for this group are included as Appendix 4: CHIE IG Group Terms of Reference

2.5 Contractual Ownership

The contract with Graphnet Health is owned jointly by the 7 CCGs that fund CHIE:

- North Hants
- North East Hants and Farnham
- Southampton City
- Portsmouth
- South East Hants
- Fareham and Gosport
- West Hants
- Isle of Wight

These organisations hold the contract, but do not act as data controllers or data processors. The contract covers standard licensing and support term and conditions with the software supplier (Graphnet). In addition the funding CCGs hold a variation agreement with South Central and West CSU, Data Processor, for the provision of:

- Hardware support
- Supplier management
- Training
- Project management
- Application support
- Testing

And other necessary functions to support and develop the CHIE service.

3 GDPR Principles

CHIE has always taken its commitment under the DPA seriously and has been set up following the principles set out in that legislation. GDPR refines those principles. Article 5 of the GDPR requires that personal data shall be:

- (a) processed lawfully, fairly and in a transparent manner in relation to individuals;
- (b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall not be considered to be incompatible with the initial purposes;
- (c) adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;
- (d) accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay;
- (e) kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the GDPR in order to safeguard the rights and freedoms of individuals;
- (f) processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.

3.1 processed lawfully, fairly and in a transparent manner in relation to individuals

CHIE contains health and care data and is used to support treatment and care of patients and care recipients, as well as for planning and research purposes. CHIE makes the following statement publically on its website at www.chie.org.uk:

Care And Health Information Exchange

The primary purpose of the CHIE is to provide clinical and care professionals with complete, accurate and up-to-date information when caring for patients. This information comes from a variety of sources including GP practices, community providers, acute hospitals and (shortly) social care providers. CHIE is used by GP out of hours, acute hospital doctors, ambulance service, GPs and others in caring for patients.

CHIE Analytics

In addition to this your information can help in improving the way we care for you. CHIE analytics (or CHIA) is a database used for analysing trends in population health in order to identify better ways of treating patients. This is called 'Secondary Processing'. CHIA is a physically separate database, which receives some data from CHIE.

During the process of transfer from CHIE to CHIA patient identifiers are removed from the data. This includes names, initials, addresses, dates of birth and postcodes. NHS numbers are encrypted in the extract and cannot be read. This process is called 'pseudonymisation'. This subset of data does not include information typed in by hand,

so there is no possibility of it containing references to family members or other people. It contains only coded entries for things like allergies and prescribed drugs.

It is not possible to identify any patient by looking at the 'pseudonymised' data on the CHIA database. People who have access to CHIA do not have access to CHIE

Who Uses CHIA?

Data in CHIA is used to plan how health and care services will be delivered in future, based on what types of diseases are being recorded and how many are being referred to hospital etc.

Data is also used to help research into new treatments for diseases. Examples of how this has helped patients with diabetes, acute kidney injury etc. can be found at <http://www.hantshealthrecord.nhs.uk/news/publications>

Data in CHIA is never shared with commercial companies like drug manufacturers

CHIE supplies posters for use in health and care settings and patient leaflets and also carries out regular advertising in local press to ensure that data subjects are aware of the service and if required, how to opt out of that service. Copies of the leaflet are included as Appendix 5: Fair Processing materials below.

Article 5(2) requires that

“the controller shall be responsible for, and be able to demonstrate, compliance with the principles.”

Article 5(2) also introduces the concept of 'accountability' into GDPR, requiring organisations (including data processors) to demonstrate compliance with these principles e.g. documenting the decisions taken about a processing activity

In order to comply with this requirement, the following must be communicated transparently through fair processing notices (FPNs):

Information to be supplied	Required for CHIE/CHIA service	Compliance
Identity and contact details of the controller and where applicable, the controller's representative) and the data protection officer	Required	Contained in all fair processing materials (see Appendix 5: Fair Processing materials) In the case of CHIE/CHIA it is expected that the SCW team will act as the data controllers representative
Purpose of the processing and the	Required	For CHIE/CHIA this is summarised in fair processing materials and described in

Information to be supplied	Required for CHIE/CHIA service	Compliance
legal basis for the processing		detail on website The legal bases for CHIE and CHIA are set out in on page 10
The legitimate interests of the controller or third party, where applicable	Required	Not applicable Public Authorities can no longer use 'Legitimate Interests' under GDPR as a lawful basis for processing
Categories of personal data	Required	Categories would require an explanation of Personal Data and 'Special Categories' (sensitive under DPA) data under GDPR which are not currently on the website To be summarised in fair processing materials and described in detail on website
Any recipient or categories of recipients of the personal data	Required	Summarised in fair processing materials and described in detail on website
Details of transfers to third country and safeguards	Not Required	Not applicable
Retention period or criteria used to determine the retention period	Required	To be added to website
The existence of each of data subject's rights	Required	Stated in fair processing materials and on website
The right to withdraw consent at any time, where relevant	Required	Stated in fair processing materials and on website
The right to lodge a complaint with a supervisory authority	Required	Stated in fair processing materials and on website
The source the personal data originates from and whether it came	Required	Summarised in fair processing materials and described in detail on website

Information to be supplied	Required for CHIE/CHIA service	Compliance
from publicly accessible sources		
Whether the provision of personal data part of a statutory or contractual requirement or obligation and possible consequences of failing to provide the personal data	Not Required	Not applicable
The existence of automated decision making, including profiling and information about how decisions are made, the significance and the consequences.	Required	Not applicable

3.2 Article 6: Lawfulness

Under GDPR section 6 (1), the following are given as lawful processing conditions. Processing may be legal if one or more of these criteria are met

6(1)(a) – Consent of the data subject

6(1)(b) – Processing is necessary for the performance of a contract with the data subject or to take steps to enter into a contract

6(1)(c) – Processing is necessary for compliance with a legal obligation

6(1)(d) – Processing is necessary to protect the vital interests of a data subject or another person

6(1)(e) – Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

6(1)(f) – Necessary for the purposes of legitimate interests pursued by the controller or a third party, except where such interests are overridden by the interests, rights or freedoms of the data subject.

Note that this condition is not available to processing carried out by public authorities in the performance of their tasks.

3.3 Article 9: Processing of special categories of personal data

GDPR makes special provision for processing of certain categories of data, specifically:

Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited [unless certain specific conditions set out in the regulations apply].

GDPR sets out a number of situations where it is legal to use data of this kind for specified purposes. The relevant conditions in regard to CHIE and CHIA are set out below.

3.4 Legal Basis for processing data for clinical care (CHIE)

3.4.1 GDPR Section 6

CHIE does not rely on the consent of the data subject to process data for direct care, although as good practice users are asked to seek the consent of the patient at the point where the data is accessed for clinical use. The advice given to users in the acceptable use agreement is:

Where practical users should ask the patient before accessing CHIE. If the patient is unconscious or not present but would benefit from use of CHIE, users should exercise their professional judgement.

This is in line with ICO guidance following their public consultation¹.

CHIE does rely on the following criteria for the legal basis for sharing data, in respect of direct care to patients:

6(1)(d) – Processing is necessary to protect the vital interests of a data subject or another person

The vital interest being that safe treatment of patients requires knowledge of the medical history of the patient. This would apply only in certain emergency situations, for example if a patient was unconscious in A&E

In normal situations, the health and care community which uses CHIE are governed by legislation requiring the sharing of data appropriately, under the condition:

6(1)(c) – Processing is necessary for compliance with a legal obligation

The following pieces of legislation contain requirements which apply to the sharing of data for patient care:

- Health and Social Care (Quality & Safety) Act 2015
- Health & Social Care Act 2012
- Care Act 2014
- The Children Act 1989

¹ <https://ico.org.uk/media/about-the-ico/consultations/2013551/draft-gdpr-consent-guidance-for-consultation-201703.pdf>

- The Children Act 2004
- Childcare Act 2006
- Children (Leaving Care) Act 2000
- Children and Families Act 2014
- National Health Service Act 1977
- National Health Service Act 2006
- Education Act 2002
- Special Education Needs and Disability Regulations 2014
- Localism Act 2011
- Immigration and Asylum Act 1999
- Crime and Disorder Act 1998

The specific sections of these pieces of legislation requiring health data to be shared in circumstances are set out in Appendix 6: Legislative Framework below

In addition, as statutory bodies, Health and Care organisations are under a duty to provide Health and Care services to patients and citizens. As such they are entitled to use the legal basis:

Article 6(1)(e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

3.4.2 GDPR Section 9 Special Categories of Data

CHIE processes data of a type specified in section 9 of GDPR and therefore require a reason for processing this data. Legitimate reasons are set out in Article 9 (2) of the GDPR. SCW consider the following reason apply to the direct care activities of CHIE.

9(2)(h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3;

Article 9(2)(h) will cover the majority of individual care uses of CHIE. In addition in some circumstances article 9(2)(c) may also apply

9(2)(c) processing is necessary to protect the vital interests of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent;

This condition can be justified in potential life threatening situations where access to key information in CHIE would be vital to protect the life of an individual.

As with the personal data processing conditions, the 'member state laws' are set out in Appendix 6: Legislative Framework.

If access is needed to defend a legal claim then article 9(2)(f) 'legal claims' may well apply on a case by case basis, although to date this has not been invoked.

3.5 Legal Basis for processing data for Analysis (CHIA)

3.5.1 GDPR Section 6

In addition, the health and care community which uses CHIA are governed by legislation requiring the sharing of data appropriately, under the conditions:

- In respect of CCGs and Local Authorities this condition applies:
6(1)(c) – Processing is necessary for compliance with a legal obligation
- In respect of Research Bodies, and only in relation to those requests specifically authorised by the CHIE IG group, this condition also applies:
6(1)(e) – Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

The ICO guidance mentioned above specifically states that:

A public task: If you need to process personal data to carry out your official functions or a task in the public interest – and you have a legal basis for the processing under UK law – you can. If you are a UK public authority, our view is that this is likely to give you a lawful basis for many if not all of your activities.

The following pieces of legislation contain requirements which apply to CCGs and Local Authorities in carrying out their statutory duties, which require data analysis:

- Health and Social Care (Quality & Safety) Act 2015
- Health & Social Care Act 2012

Under this legislation, legal duties are placed on CCGs and Local Authorities to perform a number of functions. These are outlined in the document below and at

<https://www.england.nhs.uk/wp-content/uploads/2013/03/a-functions-ccgs.pdf>



CHIA provides information to CCGs and Local Authorities in support of these functions. The data provided is in fully anonymised form.

3.5.2 GDPR Section 9 Special Categories of Data

CHIA processes patient-level but de-identified data for this purpose. This is legal under the section 9 stipulations:

- (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy

- (h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3;

Both of these apply to the processing activities carried out by CHIA for its support for public health and management respectively. The data processed by CHIA is de-identified (pseudonymised) and therefore it is not possible to identify individual patients using this information. SCW consider that this therefore meets the safeguards in respect of the rights and freedoms set out in the paragraph above.

This has been reviewed in line with the advice in GDPR Recital 45 and SCW consider activities in CHIA to be in compliance with that advice.²

3.5.3 “Section 251”

This is a short-hand term, and refers to section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002. The powers of Section 251 are to permit processing that without approval would breach the common law of confidentiality without this approval

In order to require a “section 251 derogation” the requested information must also be identifiable, for example where common identifiers include NHS Number, name, address and date of birth, or where, for example, the activity requires information on rare illnesses that could potentially identify a patient. ‘Confidential patient information’ also covers information related to deceased persons.

As set out in Section 2 above the data held in CHIA is **not** patient identifiable and therefore “section 251” derogation is **not** required for its continued operation. This is because of the removal of all patient identifiers and restriction of access to this data to only specific individuals.

Information about “Section 251” can be found below, and at

<https://www.hra.nhs.uk/documents/223/cag-frequently-asked-questions-1.pdf>



4 Individual's Rights under GDPR

The GDPR provides the following rights for individuals:

1. The right to be informed

² <https://gdpr-info.eu/recitals/no-45/>

2. The right of access
3. The right to rectification
4. The right to erasure
5. The right to restrict processing
6. The right to data portability
7. The right to object
8. Rights in relation to automated decision making and profiling.

4.1 The right to be informed

Data subjects are informed about the remit of CHIE in 3 ways:

- through the fair processing materials distributed to data controllers
- on the website
- in local media campaigns at regular intervals

The content of these are given in Appendix 5: Fair Processing materials

4.2 The right of access

Data subjects have a standing right to the audit report on who has accessed CHIE through Audit reports. This is operated through the standard operating procedure in Appendix 7: Standard Operating Procedures

As the CHIE record is collated from a summary of data provided by individual data controllers, it is not appropriate for CHIE to provide Subject Access Request data directly, but CHIE does, on request, provide data subjects with an indication of which organisations hold relevant data for them.

4.3 The right to rectification

As CHIE is a record collated from data supplied by external data controllers, data is not rectified directly within CHIE. To do so would create a dis-join between data held on CHIE and the originating system, e.g. hospital or GP record. This could be clinically dangerous.

If CHIE are alerted to incorrect data, the relevant data controller is contacted and a rectification plan put in place on the source system. This action also rectifies the data on CHIE once the source has been updated

4.4 The right to erasure

The right to erasure is also known as 'the right to be forgotten'. The broad principle underpinning this right is to enable an individual to request the deletion or removal of personal data whether there is no compelling reason for its continued processing

In common with many IT systems, CHIE does not currently have facility to fully erase data and is also bound by other legislation about retention of medical records including The Access to Health Records Act 1990 and The Medical Reports Act 1998. These set retention periods for

medical records, which vary depending on the type of data in question (maternity, mental and physical health, paediatric etc.)

However, CHIE do recognise the rights of data subjects in this regard. CHIE operate a system of functional erasure, where access to records is restricted from any user. At the time of writing SCW do not have a technical mechanism to meet this requirement. In respect of CHIA, this data is no longer considered 'personal' for the reasons given in section 2 above.

In considering requests for erasure, it is also necessary to look at the circumstances under GDPR where the right to erasure does not apply. Article 17(3) needs to be considered. Specifically:

17(3)(b) '... or in the exercise of official authority vested in the controller'. As highlighted earlier a key basis for processing data in CHIE is this condition. Where that is the case in a specific situation, then the right to erasure would not apply and the reasons for this need to be put to the individual.

17(3)(c) 'for reasons of public interest in the area of public health in accordance with points (h) and (i) of Article 9(2). This refers back to the condition to process for the 'provision of health or social care or treatment.... Article 9(2)(h)'. There is a need for clarity over the reference to 'public health' and 'public interest', however if a request for erasure is made, these need to be explored in relation to the specifics of the request.

17(3)(e) 'for the establishment, exercise or defence of legal claims'. It is conceivable that data on CHIE particularly that which provides evidence of access to information in the system could be key evidence in a legal claim such as negligence in care. This also relates to the minimum legal retention periods for data, where these have not expired, then this element carries some weight with regard to refusal to erase. However if the retention periods for the data in question have expired, then this goes straight back to the first erasure scenario 'data is no longer necessary' and erasure should happen

4.5 The right to restrict processing

Under the DPA, individuals have a right to 'block' or suppress processing of personal data. The restriction of processing under the GDPR is similar.

When processing is restricted, organisations are permitted to store the personal data, but not further process it. CHIE can retain just enough information about the individual to ensure that the restriction is respected in future. The operation of this right is the same as the right to object (see section 4.7 below). Data subjects can restrict processing to direct care (data not transferred to CHIA) only or completely (data not visible in CHIE or CHIA)

4.6 The right to data portability

The right to data portability allows individuals to obtain and reuse their personal data for their own purposes across different services.

It allows them to move, copy or transfer personal data easily from one IT environment to another in a safe and secure way, without hindrance to usability.

As CHIE is a collated record, it is not practice to port data directly from CHIE. However, the originating systems do have facility to do this, and these are in regular use at least as far as primary care and diagnostic data is concerned. GP data for example is moved between systems using the GP2GP service operated by NHS Digital and radiology data via Image Exchange Portal.

4.7 The right to object

CHIE complies with the right to object by operating an opt-out facility in 3 ways:

- 1) If a patient records their dissent with the GP practice and that GP is uploading data, then the code is sent to CHIE. This has the effect of preventing access to ANY of the information held on CHIE, whether that data originated with the GP or other provider
- 2) If the practice is not sending data, patients can fill out a dissent form and provide directly to CHIE, where it is processed with the same effect
- 3) Specific opt-out for secondary use

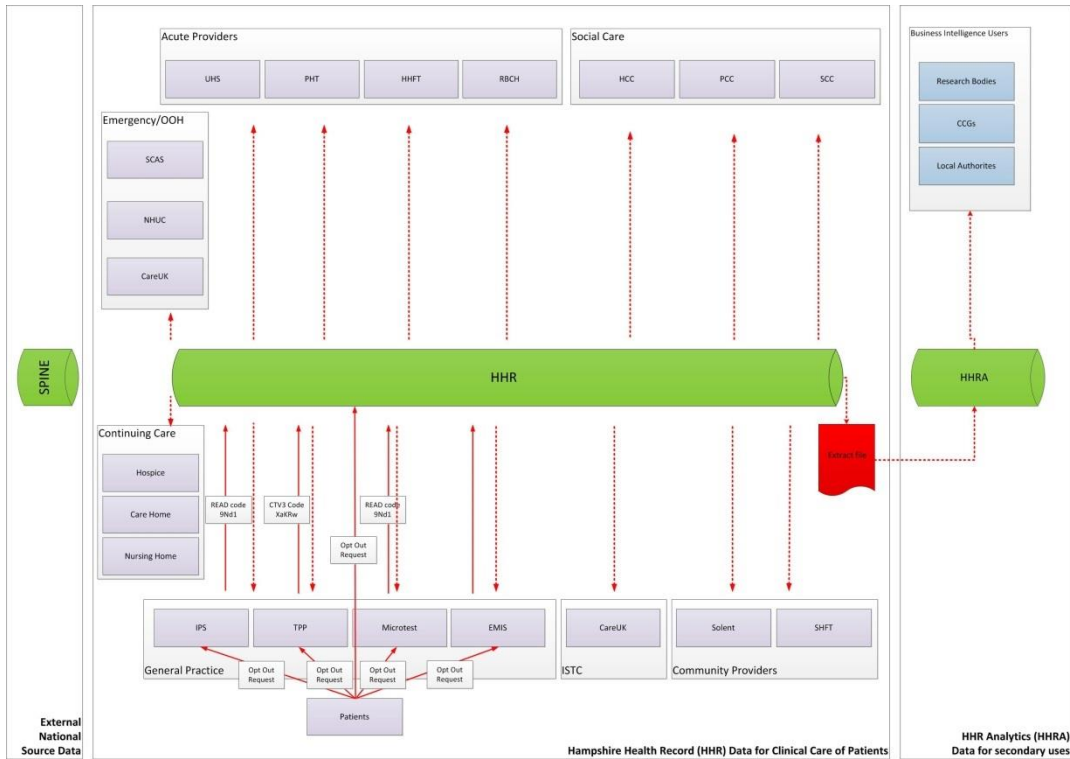
The full list of dissent codes and the way they are implemented in the CHIE software is included in Appendix 8: Opt-Out code implementation

Dissent from sharing for secondary use is recorded as a separate code. Recording this code allows clinical users to access data on CHIE, but prevents data being transferred to CHIA

Dissent codes and the direct CHIE dissent are subject to a 'double lock'. This means that the presence of a dissent code:

- 1) Stops data being processed onto CHIE through the feed servers
- 2) Prevents users from accessing data via the CHIE user interface, so if there was to be any data present from prior to the dissent code, then this will not be accessible by users.

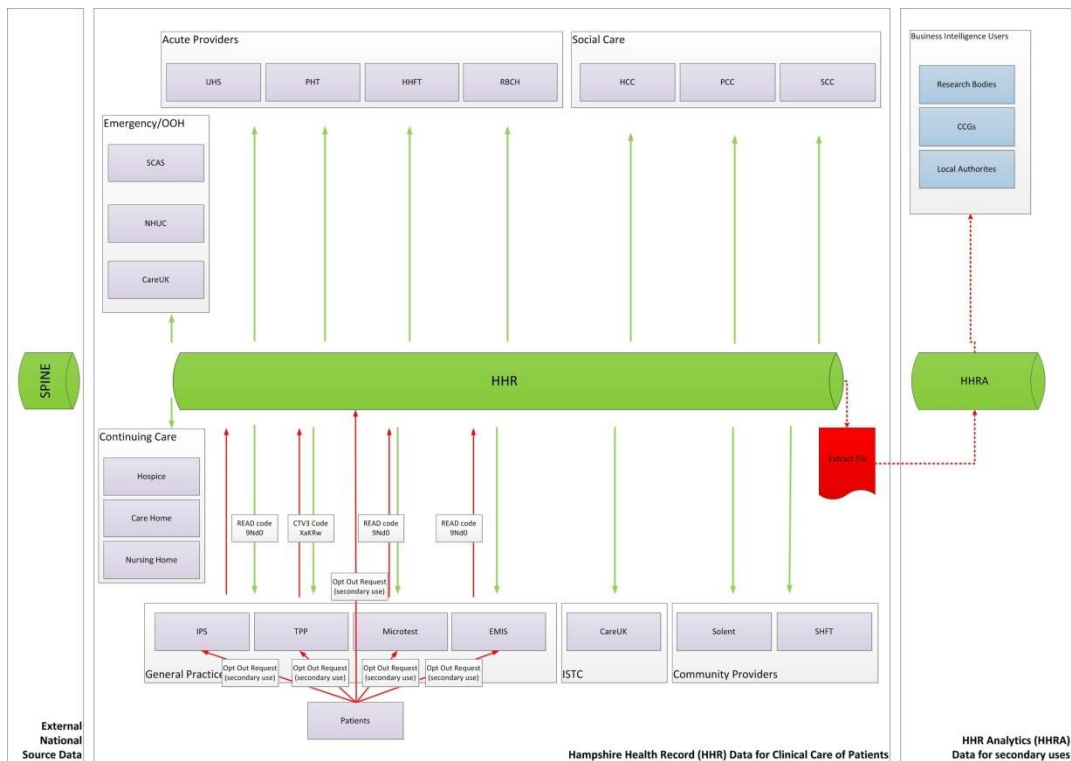
This is represented below



4.7.1 Dissent from Secondary use

If a patient dissents from secondary use, then their data continues to be processed and accessible on CHIE, but is not included in the anonymised extract to CHIA. The extraction/anonymisation of data from CHIE to CHIA is carried out by CSU staff acting under the DSCRO.

The opt out for secondary use only is represented as below



In addition to dissent, sensitive codes (HIV status, termination of pregnancy etc.) are not uploaded to CHIE or CHIA for any patient. The list of these codes is included as Appendix 9: Exclusion Codes.

As the opt-out model is operated via the GP practice, GPs are provided with an explicit set of instructions on how to operate the opt outs for both direct care and secondary processing. These instructions can be found in Appendix 8: Opt-Out code implementation

4.7.2 Explicit consent

As stated above and in FPNs the sharing and processing of data does not require consent as its legal basis. However, as good practice users are encouraged to ask consent where practical.

The advice given to patients on when it is appropriate for clinical staff to access their record is as below:

“Where practical care professionals will ask you before accessing CHIE for your care

If you are unconscious or not present but it would benefit your care, professionals will use their judgement about accessing your information”

This is supported by the following statement in the Acceptable Use Agreement (see Appendix 3: Data Sharing Agreement Templates and Acceptable use agreement):

I will ensure that where practical, as a care professional, I will ask the patient before accessing the CHIE for patient care. If the patient is unconscious or not present but would

benefit from my care, I may use my judgement about accessing the information and will record my reason for doing so

Users are required to acknowledge this on entry into the system as below and are also able to access the acceptable use agreement as well as advice from the CHIE team from this log in page if in any doubt about the appropriateness of the access:

Graphnet
CARE SOLUTIONS

CHIE
Care and Health Information Exchange

By clicking 'OK', I confirm that I am accessing this system in accordance with the [Acceptable Usage Agreement](#)

Where practical users should ask the patient before accessing CHIE. If the patient is unconscious or not present but would benefit from use of CHIE, users should exercise their professional judgement.

Your access to CHIE will be logged showing your name, date/time of access, the patient's name. In the line with legislation, this log may be audited by your employer and/or made available to the patient. Unauthorised, illegal or improper use may result in disciplinary action, civil or criminal prosecution and/or risk your professional registration.

For further information, please visit [Care and Health Information Exchange](#)

OK

Only proceed if you have the authority to proceed, otherwise please exit.
DATA CONFIDENTIALITY AND SYSTEM SECURITY
The Data Protection Act 1998 protects data contained in this system. You must not pass the data to anyone who does not have a proper need to use it. You must follow the NHS Trust standard procedures to ensure that:
- The data items are safe from deliberate or accidental additions, alterations or deletions by unauthorised persons.
- No unauthorised persons have or have access to the data.
Failure to comply with the Trust standard procedures will make you personally liable to a criminal prosecution. If you have any doubts or queries about the meaning of this message, please contact your Caldicott Guardian.

4.8 Rights in relation to automated decision making and profiling

The GDPR provides safeguards for individuals against the risk that a potentially damaging decision is taken without human intervention. These rights work in a similar way to existing rights under the DPA. Currently, CHIE and CHIA do not carry out this activity.

Appendix 1: Security and Confidentiality Protocol



Microsoft Word 97 -
2003 Document

Appendix 2: Data pseudonymisation for CHIA process



HHRA Manual
v10.3.docx

Appendix 3: Data Sharing Agreement Templates and Acceptable use agreement



Microsoft Word
Document



CHIE request for
new account form.pdf

Appendix 4: CHIE IG Group Terms of Reference



Microsoft Word 97 -
2003 Document

Appendix 5: Fair Processing materials

Posters for GP and other settings



CHIE A4 poster
FINAL December 17, 201

Advert for local press



CHIE advert
128x194 FINAL Decem

Patient Leaflet



CHIE A5 Patient flyer
FINAL December 201

Appendix 6: Legislative Framework

Legislation	Legal gateway	Organisation
Health and Social Care (Quality & Safety) Act 2015	<p>Section 3(1),(2)(a)(b):</p> <p>(1) This section applies in relation to information about an individual that is held by a relevant health or adult social care commissioner or provider (“the relevant person”).</p> <p>(2) The relevant person must ensure that the information is disclosed to (a) persons working for the relevant person, and (b) any other relevant health or adult social care commissioner or provider with whom the relevant person communicates about the individual.</p>	All
Health & Social Care Act 2012	Part 5 – contains guidance about specific duties of co-operation, including creating a Health and Wellbeing Board, which must, for the purpose of advancing the health and wellbeing of the people in its area, encourage persons who arrange for the provision of any health or social care services in that area to work in an integrated manner.	All
Care Act 2014	<p>Section 1 – (1) The general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual’s well-being.</p> <p>Well-being in this Part includes:</p> <p>(b) physical and mental health and emotional well-being;</p> <p>(c) protection from abuse and neglect;</p> <p>(f) social and economic well-being;</p>	Local authorities
Care Act 2014	Section 3 – Local authorities must exercise their functions under this Part with a view to ensuring the integration of care and support provision with health provision and health-related provision where it considers that this would—	Local authorities

	<p>(a) promote the well-being of adults in its area with needs for care and support and the well-being of carers in its area,</p> <p>(b) contribute to the prevention or delay of the development by adults in its area of needs for care and support or the development by carers in its area of needs for support, or</p> <p>(c) improve the quality of care and support for adults, and of support for carers, provided in its area (including the outcomes that are achieved from such provision).</p>	
The Children Act 1989	<p>Section 47(9)(11):</p> <p>Where a local authority are conducting enquiries under this section, it shall be the duty of any person mentioned in subsection (11) to assist them with those enquiries (in particular by providing relevant information and advice).</p> <p>The persons are—</p> <p>(a) any local authority;</p> <p>(d) any Local Health Board , Special Health Authority, Primary Care Trust, National Health Service trust or NHS foundation trust; and</p> <p>(e) Any person authorised by the Secretary of State for the purposes of this section.</p>	All
The Children Act 1989	<p>A local authority may also request help from those listed above in connection with its functions under Part 3 of the Act. Part 3 of the Act, which comprises of sections 17-30 allows for local authorities to provide various types of support for children and families</p>	Local authorities
The Children Act 2004	<p>Section 10 – Co-operation to improve well-being.</p> <p>(2) The arrangements are to be made with a view to improving the well-being of children in the local authority’s area so far as relating to—</p> <p>(a) Physical and mental health and emotional well-</p>	<p>Local authorities</p> <p>CCG’s</p>

	<p>being;</p> <p>(b) Protection from harm and neglect; (e) Social and economic well-being.</p> <p>(4) For the purposes of this section each of the following is a relevant partner:</p> <p>District councils</p> <p>The police</p> <p>The probation service</p> <p>Youth offending teams (YOTs)</p> <p>Health and Wellbeing Board.</p> <p>Any clinical commissioning group for an area any part of which falls within the area of the authority</p>	
The Children Act 2004	<p>Section 11 – Arrangements to safeguard and promote welfare. The section applies to</p> <p>(a) a local authority in England</p> <p>(b) a district council which is not such an authority;</p> <p>(c) a Strategic Health Authority;</p> <p>(d) a Special Health Authority, so far as exercising functions in relation to England, designated by order made by the Secretary of State for the purposes of this section;</p> <p>(e) a Primary Care Trust;</p> <p>(f) an NHS trust all or most of whose hospitals, establishments and facilities are situated in England;</p> <p>(g) an NHS foundation trust;</p>	All
Childcare Act 2006	<p>Section 1 - General duties of local authority in relation to well-being of young children.</p> <p>(1) An English local authority must—</p> <p>(a) improve the well-being of young children in their area, and</p> <p>(2) In this Act “well-being”, in relation to children,</p>	Local authorities

	<p>means their well-being so far as relating to—.</p> <p>(a) Physical and mental health and emotional well-being;</p> <p>(b) Protection from harm and neglect;</p> <p>(e) Social and economic well-being.</p>	
Children (Leaving Care) Act 2000	<p>The main purpose of the Act is to help young people who have been looked after by a local authority, move from care into living independently in as stable a fashion as possible. To do this it amends the Children Act 1989 (c.41) to place a duty on local authorities to assess and meet need.</p> <p>The responsible local authority is under a duty to assess and meet the care and support needs of eligible and relevant children and young people and to assist former relevant children, in particular in respect of their employment, education and training.</p> <p>Sharing information with other agencies will enable the local authority to fulfil the statutory duty to provide after care services to young people leaving public care.</p>	Local authorities
Children and Families Act 2014	Section 23 - places a duty on health bodies to bring certain children to local authority's attention, where the health body has formed the opinion that the child has (or probably has) special educational needs or a disability	All
Children and Families Act 2014	<p>Section 25 - places a duty on a local authority to exercise its functions with a view to ensuring the integration of educational provision, training provision with health care and social care provision where it thinks that this would –</p> <p>(a) promote the well-being of children or young people in its area who have special education needs or a disability, or</p> <p>(b) improve the quality of special educational provision in its area or outside its area for children</p>	Local authorities

	it is responsible for who have special educational needs	
National Health Service Act 1977	<p>Section 22 - Co-operation between health authorities and local authorities.E+W+S</p> <p>(1)In exercising their respective functions NHS bodies (on the one hand) and local authorities (on the other) shall co-operate with one another in order to secure and advance the health and welfare of the people of England and Wales.</p>	All
National Health Service Act 2006	Section 82 – Places a duty on NHS bodies and local authorities to co-operate with one another in order to secure and advance the health and welfare of the people of England and Wales.	All
Education Act 2002	<p>The duty laid out in section 11 of the Children Act 2004 mirrors the duty imposed by section 175 of the Education Act 2002 on LEAs and the governing bodies of both maintained schools and further education institutions. This duty is to make arrangements to carry out their functions with a view to safeguarding and promoting the welfare of children and follow the guidance in <i>Safeguarding Children in Education</i> (DfES 2004).</p> <p>The guidance applies to proprietors of independent schools by virtue of section 157 of the Education Act 2002 and the Education (Independent Schools Standards) Regulations 2003.</p> <p>Section 21 of the Act, as amended by section 38 of the Education and Inspections Act 2006, places a duty on the governing body of a maintained school to promote the well-being of pupils at the school. Well-being in this section is defined with reference to section 10 of the Children Act 2004 (see paragraph 5.5 above). The Act adds that this duty has to be considered with regard to any relevant children and young person's plan.</p> <p>This duty extends the responsibility of the governing body and maintained schools beyond that of educational achievement and highlights the role of a school in all aspects of the child's life. Involvement of other services may be required in order to fulfil this duty so there may be an implied power to work collaboratively and share information for this purpose.</p>	All
Special Education Needs and Disability Regulations 2014	Section 6 states, where the local authority secures an EHC needs assessment for a child or young person, it must seek the advice and information in	All

	<p>relation to educational, medical needs, psychological needs and advice and information relating to Social Care from the named authorities. The Regulations also requires the local authority to seek advice and information from any other person the local authority thinks is appropriate.</p> <p>Section 7 states: "When securing an EHC needs assessment a local authority must consult (a) the child and the child's parent, or the young person and take into account their views, wishes and feelings" and (d) "engage the child and the child's parent, or the young person and ensure they are able to participate in decisions.</p>	
Localism Act 2011	<p>Section 1 - This has repealed the wellbeing powers of the Local Government Act 2000 (but not for Welsh Authorities). The general power of competence is a new power available to local authorities in England that will allow them to do "anything that individuals generally may do".</p>	Local authorities
Immigration and Asylum Act 1999	<p>Section 20 - provides for a range of information sharing for the purposes of the Secretary of State:</p> <p>To undertake the administration of immigration controls to detect or prevent criminal offences under the Immigration Act;</p> <p>To undertake the provision of support for asylum seekers and their dependents</p>	All
Crime and Disorder Act 1998	<p>Section 17 - Duty to consider crime and disorder implications.</p> <p>(1) Without prejudice to any other obligation imposed on it, it shall be the duty of each authority to which this section applies to exercise its various functions with due regard to the likely effect of the exercise of those functions on, and the need to do all that it reasonably can to prevent, crime and disorder in its area.</p> <p>(2) This section applies to a local authority, a joint</p>	Local authorities

	authority, [F1the London Fire and Emergency Planning Authority,] a police authority, a National Park authority and the Broads Authority.	
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Appendix 7: Standard Operating Procedures



SOP2- HHR Subject
Data Access and Aud

Appendix 8: Opt-Out code implementation



TechNote23-OptInO
ptOut.pdf



CHIE A5 GP Flyer
December 2017.pdf

Appendix 9: Exclusion Codes



Microsoft Excel 95
Worksheet