

Data sharing Protocol

Connect Hackney: Ageing Better Data Sharing Protocol

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1. Terminology

The wide remit of participating partners necessitates standardising terminology throughout this Protocol;
the following terms have been used:

1.1. Data Subject

The individuals who will be participating in the projects. The term 'Data Subject' replaces terms such as clients, customers, and users, and refers to individuals.

1.2. Organisations

Organisations who will be registered with the partnership and have their information stored on the shared system.

1.3. Lead Partner

Hackney CVS is the lead partner for Connect Hackney.

1.4. Delivery Agency

Organisations who have been appointed by the Lead Partner to deliver specific elements of the Connect Hackney project, including working with and supporting a Data Subject.

For the purpose of complying with the Data Protection Act 1998 every Delivery Agency involved in this partnership will act as a Data Controller and will have submitted for approval its Data Protection Protocol.

In data protection terms the Data Subject will be the Data Subject.

1.5. Worker

Any staff member who works directly with Data Subjects. The term 'worker' replaces other terms such as support workers, project workers, volunteers, outreach workers, case workers, etc.

1.6 Steering Group

The body which provides strategic leadership to the Connect Hackney programme.

1.7 Connect Hackney Database

The Ecorys and Hackney CVS monitoring database.

2. Purpose and Introduction

2.1. This Protocol provides a broad framework for secure sharing of Data Subject information across organisational and professional boundaries and is a development of information sharing protocols and Protocols that already exist within individual Organisations.

2.2. Its aim is to facilitate the appropriate and lawful sharing of information to meet the needs of Data Subjects while protecting their individual rights.

2.3. Government Protocol places a strong emphasis on partners working together, in partnership with each other and with people in contact with the services provided by those

partners, to provide a seamless service that is centred on the needs of the Data Subject. It is good practice to maximise the sharing of information in order to best meet the needs of every individual Data Subject. Government Protocol also emphasises the importance of the security and confidentiality of Data Subject information, informing Data Subjects about the use of information about them, and their rights in relation to that information

2.4. Keeping information secure and confidential should not be confused with keeping information secret. The appropriate sharing of personal information is essential to the provision of seamless support. Having all of the relevant information to hand aids the assessment process and enables informed decisions to be made, in discussion with the individual Data Subject, about the support required.

2.5. All participating organisations acknowledge the desire to work positively to contribute effectively to delivery of Connect Hackney. The professionalism of workers in all Organisations must ensure that information will be shared appropriately.

2.6. This Protocol is also complementary to other existing policies, procedures and protocols to which some Organisations are required to comply. For those Organisations that already work in compliance to other established protocols currently in force, this Protocol should be read and applied complementary to those other protocols.

2.7. Statutory sector partners - for example, general practitioners, NHS Delivery Partners, police, probation, social services - will not be given permissions to access the system.

2.8. Data Subject information will not be shared with or given to statutory partners except in exceptional circumstances – for example, if required by a court order.

2.9. Every Organisation collecting information on Data Subjects must satisfy their legal obligations as required by the Data Protection Act 1998.

2.10. It is therefore a requirement of this Protocol that all Organisations must have, and follow, a data protection Protocol, but each Organisation must comply with its own duties and obligations as a data controller. It is not the intention of this Protocol to add to or increase any Organisation's obligation in this area.

2.11. A list of participating Organisations is available on the Data Sharing Protocol - Appendix 1.

3. Aims of the Protocol

3.1. Background to Connect Hackney

Connect Hackney is one of 14 partnerships funded through the Big Lottery's Fulfilling Lives, Ageing Better Programme. The Big Lottery is investing £78million in improving the lives of older people, and our programme in Hackney is an exciting opportunity to make a real difference in this area. The overall aims of the national programme are around piloting new or joined up ways to reduce social isolation and collect better evidence of what works.

Connect Hackney is a partnership of voluntary and community groups working closely together to tackle the social isolation, loneliness and poor physical and mental health outcomes that many older people in the Hackney experience. Hackney CVS is the Connect Hackney Lead Partner and is solely responsible to the Big Lottery Fund for the delivery of the programme in accordance with Big Lottery Fund terms and conditions.

The programme will be delivered by a number of Delivery Partners appointed to deliver the specific workstreams within the project. Each Delivery Agency will sign up to this Protocol.

3.2. Aims

- 3.2.1. To manage the collection, storage and transfer of information on all Data Subjects and Delivery Partners in the Connect Hackney Project.
- 3.2.2. The data will be collated and anonymised to be used in the monitoring and evaluation of the Connect Hackney Project

3.3. Secondary aim

- 3.3.1. The aim of the Project is to develop a pool of shared information for the benefit of Data Subjects and to assist Delivery Partners and other Organisations participating in Connect Hackney. It is not the intention of the Protocol to establish any formal organisation or association. The Protocol is not intended to create any legal relationship between Organisations or Delivery Partners and will not operate so as to create any partnership or joint venture of any kind or be construed as to constitute one partner to be the agent of any other or to authorise any partner to enter into any engagement or make any representations or warranties on behalf of any other. Nor does the Protocol establish any association or other organisation of the partners. A commitment to the principles of the Protocol does not entitle any Organisation to participate and any participation does not guarantee future participation. Organisations may be excluded from the Protocol at the discretion of the strategic partnership from time to time.

4. Protocol

Data Subjects

- 4.1. Every Data Subject has the right to privacy and to expect that any personal information stored about her/him will be handled sensitively and confidentially.
- 4.2. This Protocol acknowledges that responsibility for the sensitive handling of all information lies with every worker within the associated Organisations and that the tenets of confidentiality govern every aspect of the workers' contact with Data Subjects.
- 4.3. The Protocol also acknowledges that only information that is relevant is recorded. Information is therefore used to inform participating Delivery Partners how to best meet the needs and aspirations of each individual Data Subject and for no other purpose and in accordance with the Data Subject's rights.

4.4. Information held about Data Subjects may include the following:

- *Name/Initials*
- *Date of birth (DOB)*
- *Address and Postcode*
- *Gender*
- *Ethnicity*
- *Faith*
- *NHS number*
- *Living arrangements*
- *Caring responsibilities*
- *Project activity*
- *Mental and physical wellbeing*
- *Data from outcome measures (e.g., Social isolation and loneliness)*

4.5. The following information will be held in relation to a Data Subjects' support needs:

- *General support needs*
- *Referrals/signposting*
- *Outcomes associated with activity undertaken including relating to Connect Hackney's Key Performance Indicators*

4.6. Additionally, aggregated data will be used as a programme-wide resource for statistical information. All statistical information will be anonymised and will not contain any identifiable information. Adherence to this Protocol should in no way undermine the usual organisational responsibilities of any Organisation. This Protocol acknowledges the very difficult nature of aligning procedures between bodies in order to provide Data Subjects and Workers alike with a more streamlined way of working.

4.7. Organisations agree that they will ensure that they have policies and procedures in place, which establish and maintain good security standards for information systems containing personal information. It is the responsibility of each Organisation to ensure that workers are aware of their responsibilities in respect of these policies and procedures

4.8. By law, every Organisation collecting and storing details on Data Subjects *in any way* is required to comply with the Data Protection Act and have an adequate Data Protection Protocol.

4.9. Keeping records private

4.9.1. Delivery agencies will be able to access limited information on other data subjects for the purpose of finding out whether that individual has already been entered onto the database by another delivery agency.

4.9.2. The lead partner will be able to access all information entered onto the database

5. Maintaining the Protocol

5.1. Compliance with this Protocol

All Organisations must comply with the Connect Hackney Data Sharing Protocol. To ensure all Delivery Partners are maintaining Data Subject details correctly, the Lead Partner will carry out regular checks on information held.

5.2. Monitoring the Protocol

Regular monitoring and review of the Protocol will be undertaken by the Lead Partner.

Problems arising from operational use of the Protocol by Delivery Partners must be logged and reported to the Lead Partner.

5.3. Breach of the Protocol

Reported breaches of the Protocol will be considered by the Lead Partner. Confirmed breaches may result in an Organisation's permission to participate being withdrawn.

5.4. Reviewing the Data Sharing Protocol

The first formal review of this Protocol will take place in 2018.

Thereafter, reviews will take place annually unless legislative changes or other changes require immediate action.

Prior to the review date, Delivery Partners subscribing to the Protocol are invited to submit views and opinions on the operational use of the Protocol and propose options for addressing problems or amending procedures.

6. Data Subjects' Rights of Confidentiality

6.1. When a Data Subject whose details are not already recorded with Connect Hackney approaches a Delivery Agency, it is the responsibility of that Agency to explain to the Data Subject the procedures involved in the process of recording information on the Database.

6.2. Data Subjects should be made aware that any information stored on the Connect Hackney Database will only be used to assist in providing an activity or service as part of Connect Hackney. All Data Subjects taking part in evaluation will be asked to complete a User Consent Form.

6.3. A Data Subject's right of confidentiality is protected by:

- *the Common Law Duty of Confidentiality*
- *the Data Protection Act 1998*
- *the Data Protection Act*
- *the Human Rights Act 1998*

6.4. The fundamental principle rooted in professional, ethical and legal requirements is that the use of information that a Data Subject provides in confidence is supported by their ***explicit informed consent***.

Informed consent (consent) is when a Data Subject understands why their information is needed, who it will be shared with, the possible consequences of them agreeing or not to that proposed use, and gives consent.

In law, consent may be *explicit* or *implied*. In relation to the Connect Hackney Database only the *explicit* consent of the Data Subject is permissible.

'Explicit consent' is a freely-given, specific and informed indication of a Data Subject's Protocol to a course of action where information is given to that Data Subject about the proposed course of action.

'Explicit consent' can be either written (written consent at the point of initial registration is mandatory) or verbal, or provided online, but in any case it must be *absolutely clear*.

Validity of consent: 'explicit consent' must comply with all the following conditions to be valid. The Data Subject giving consent must:

- be 'competent' to give consent;
- have received sufficient information on which to properly base a decision to give consent; and
- not be acting under duress.

A Data Subject is 'competent' if he/she:

- *understands what is being proposed and why;*
- *understands the benefits, risks and possible alternatives; and*
- *can retain sufficient understanding of what is being said to make an effective decision based on it.*

6.5. For the purposes of this Protocol, Organisations are required to obtain consent rather than rely upon any other permission which may be available. A permission which may be available for one Organisation may not be available to another and since the purpose of this Protocol is to assist in the sharing of information, explicit consent is to be preferred as it is applicable to all partners.

6.6. *Withheld consent.* A Data Subject may not want her/his information to be shared with other Organisations and therefore not give consent. The Data Subject's wishes must be respected. Whilst every effort should be made to explain to the Data Subject the possible consequences for their care and the management and planning of the service provided, care should be taken to avoid the application of any undue pressure. The final decision should rest with the Data Subject.

6.7. *Withdrawn consent.* Confirmation of withdrawal must be provided to the Lead Partner, and the Data Subject's personal data removed from the Connect Hackney Database.

6.8. *Sharing of information without consent.* In circumstances which are the exception rather than the rule, wherever Data Subject information is stored there may be circumstances when it is necessary to share information even though the Data Subject has not consented.

6.9. Obviously such rare occasions are recognised as legitimate breaches of confidentiality and should be contained within the information-sharing Protocol of each participating Organisation. Where an Organisation has some evidence to suggest that there may be an issue requiring such disclosure, but the information stored on the Connect Hackney Database is incomplete, before acting it will be appropriate to consult and discuss with the Lead Partner to take legal advice. We cannot envisage a circumstance where this would arise, but that doesn't mean that this would not happen.

6.10. Information can be shared without the consent of the relevant Data Subject where it is:

- *in the Data Subject's vital interest to do so;*
- *in the substantial public interest and necessary for the prevention or detection of crime or to protect members of the public; or*
- *a requirement under a court order.*

6.11. The decision to release information in the public interest requires a judgement to be made. The worker making this judgement should be at an appropriate level within the Organisation in question. What is considered an 'appropriate level' will differ across Organisations according to individual policies. It may be necessary to take legal or other specific advice.

6.12. *Retention of details on the Connect Hackney Database.* The details stored on the Connect Hackney Database relating to a Data Subject will be stored for a maximum of seven years following the end of the programme to enable monitoring and reporting on Data Subject information, and in line with funding requirements. Following this period the data will be deleted.