

Public patient Involvement and engagement (PPIE) in the CDC

This is an introduction and overview of the new Civic Data Co-operative (CDC) for people who might be interested in becoming involved in the PPIE activities that are being developed.

The CDC is a Liverpool region initiative that intends to improve and better integrate existing computerised patient data. To achieve this Liverpool University along with others universities in the region will be in partnership with local NHS trusts. They will do this in collaboration with Liverpool Health Partnership set up to bring academics and the NHS closer together.

The aim within the Care and Health Informatics (CHI) theme of ARC (NWC) is to support the setup of the CDC by building links between a number of existing data sets holding health and associated records.

These links will integrate information collected and held by a large number of providers. In the short term we expect that information will come from hospitals, GPs and Social Care. This may be extended to other partners such as the Fire Service and schools.

The intention is that this linked information will form the core of the CDC. Access to it will provide research answers to key issues and improve the health and wellbeing of people living not only in the Liverpool region but the wider population.

At various times members of the public will have given their permission for their health data to be stored online. They may have been unaware at the time that this data could be brought together and linked with other known data about them.

Before we do this linking exercise we need to reassure members of the public that their details held in this linked format will be secure. Also, whichever researcher looks at their data will do so only under the strictest levels of supervision.

With privacy uppermost in mind we want to establish a forum drawn from the public to review our approach.

Initially we are turning to those people in PPIE roles for their feedback. Later on we hope to expand this to open forums to which the general public will be invited.

We would like your assistance and cooperation in getting the message across that combining research data in this manner is a valuable and essential health tool. We need your views on how happy you would be to have your own records integrated in this manner and your views on data privacy

We will be contacting people shortly looking for expressions of interest to join a review panel.