

**ISCG Open House, 21 January 2014**

**Workshop 3 report**

**COMPARATIVE DATA – INTRODUCING CARE.DATA**

**What we heard from people at the event**

**Workshop 1**

* Will care.data give information to insurance companies etc who may use the data to identify us?
* Care.data should have been opt in for patients and not opt out.
* Sharing of data is vital to improve services.
* Could leaflet/video have come in different formats? Use of sign language etc so all groups can make an informed decision about whether their data is shared.
* IT literacy/Digital Divide - lots of people may not understand or be able to use this service. How do we make sure they are not left behind?
* Quality of data - who will be making sure it is correct and 100% fulfilled? Will gaps in data cause problems?
* How easy will it be to access your medical record?
* Health prevention – how will data sharing benefit this ideal?

**Workshop 2**

* Poor quality of information - who will make this information more robust?
* How does care.data fit into the Government’s policy of open data?
* How do we get different systems talking to each other?
* How do we educate patients about the implications of opting out?
* Timeline – how often will the data be submitted to the HSCIC? How long in between when a clinical event takes place and it being available to be used?
* Can the IT cope?
* How does your Summary Care Record relate to care.data?
* Got to be clear on the different ways you can block your data going or leaving the HSCIC.
* Make it clear what the data is going to be used for. People are worried it may end up in the wrong hands.
* Accessibility – what data is published? Can I view my own data?
* If too many patients opt out, how will this affect the richness of the data?
* How quickly will charities be able to view this new source of data?
* How do researchers link their data to data being held by the HSCIC?

**Key Issues**

* Potential for public confusion - how do we get the correct message across to the public?
* Who has access to the information?
* How is the information going to be used?
* Data quality – missing and inaccurate data.
* How do patients control their information?

**Our reflections on this are**

* We need to maintain our communication and engagement activities with patients, patient groups and clinicians
* We need to continue to re-enforce the positive reasons for extracting these data.
* We are aware that the quality of data may be an issue

**Our next steps as a result are**

* We will continue with our engagement activities and have bid for resources to expand this function significantly both at nationally and regional level.
* We will ensure that our planning includes activities aimed at encouraging an increase in the quality of the data.