



Care.data involvement

Healthwatch Involvement

In 2014 a quarter of the local Healthwatch network raised concerns over NHS England's attempts to explain the care.data programme.

Residents throughout the country reported to Healthwatch that they felt unable to make an informed decision about whether to opt out of the programme.

Healthwatch England research indicates that many adults would be happy to donate their personal health data to help research if it was anonymous.

Healthwatch is currently neutral on the project, and our involvement at this stage is to enable local residents to make an informed decision.

Following the pathfinders Healthwatch England will review the reports from the 4 local Healthwatch involved, and continue to evaluate the program using their 10 principles of information sharing.



10 principles of information sharing

1. People can **access their own health and social care data** and records to see what the system has collected and who they are sharing it with
2. Data is collected and shared in a manner that **does not unjustifiably compromise people's anonymity, safety or treatment.**
3. Collecting and sharing data **cannot be used to justify treating people on an unequal basis** with others.
4. Data collection and sharing will **not have impact on a person's wellbeing** by, for example, causing them additional anxiety or distress.
5. **People are provided with all the information they require** about Care.data or any other data sharing initiative, to make an informed choice about whether they want to opt in or out.
6. Frontline **professionals are upfront and honest about the benefits and dis-benefits** of opting in or out of Care.data or any other similar programme.
7. **If an opt out is offered, it must be a genuine option** (i.e. not overly burdensome) and people must be informed about the restrictions and limitations of this option.
8. **If someone raises a concern** or makes a complaint about the collection or sharing of their records, **this must be taken seriously** and staff must take immediate action to address the concern and, if it relates to a breach of confidentiality, put safeguards in place to restore the person's anonymity.
9. People should be **able to opt out of Care.data later if they change their mind** about the programme in future.
10. People should be **offered an opportunity to get involved in local decisions** at their GP surgeries about whether or not records are shared with the Care.data programme.

Local Involvement

Healthwatch BwD has been commissioned to provide additional engagement around the care.data program in Blackburn with Darwen.

Aim: increase the awareness within the local population to ensure they're able to make an informed decision regarding sharing their data.

Method: Engage with members of the public who may not engage with local community groups or other services.

The engagement completed by Healthwatch BwD will be additional to the engagement from provider organisations, and will aim to reach additional communities and residents within the Borough.



Healthwatch BwD work plan

Community Access Point

Asda
Blackburn Job Centre
Blackburn Market
Darwen Leisure Centre
Darwen Health Centre
Barbara Castle Health Centre

Targeted Engagement

Asylum Seekers and Refugees
Blackburn College

Report Back

Report to review Healthwatch engagement, feedback received from residents, and frequently asked questions



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