



## CHC Response to Findings from Citizens' Jury

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### Citizens' Jury Findings

The findings from the citizens' juries showed that people tended to move in their general attitudes in favour of greater sharing of patient data for public benefit. They were more supportive in principle, but this depended entirely on how they perceived the specific use under consideration. As a consequence, some citizens became more cautious about information sharing for certain uses and less cautious for other uses.

All of the *planned* uses (i.e. the exemplar care pathway projects) were considered appropriate by most, but not all, of the jurors. The arguments that the jurors found most compelling for these planned uses were that they have the potential of benefitting the public through improving care and saving lives and are likely to have multiple benefits and ultimately improve the quality of life of many patients. Overall, jurors found plans that produced positive health outcomes to be more acceptable than those that 'only' improved efficiency of services.

It is no surprise that both juries were concerned about the risks of data being accessed inappropriately or about having breaches of patient confidentiality. However, the Manchester jurors were *more* concerned about the uses to which the results from the data analysis would be put. They were particularly concerned about two key areas: whether improving efficiency would lead to inequitable distribution or closure of services and whether the lack of funding or political will to implement new services would lead to increased public dissatisfaction due to expectations having been falsely raised.

The two juries' conclusions about the *potential* uses (i.e. the exemplar commercial use projects) were similar. The arguments as to why some of the potential uses were appropriate included that the potential uses clearly communicated the possibility for improvements in drugs, treatments, and other healthcare as well as how these improvements could lower costs for the NHS. Some jurors changed their minds and became more accepting of commercial uses as they understood them better. Commercial uses that did not produce actual health benefits were unacceptable, regardless of any safeguards for the data, even if the data were aggregated. Jurors were deeply concerned about using patient data for reasons that prioritised generating profit for private organisations over public benefit. Commercial gain should be secondary to public benefit. Whereas most jurors found the information governance safeguards planned by CHC to be acceptable for the planned uses of data, they were split on whether the safeguards were sufficient for commercial uses.

Jurors brought their existing understanding about how the NHS currently runs to the table. For example, beliefs that accident and emergency departments were routinely being closed due to the need for efficiency meant that some jurors objected to uses of data for the

purposes of efficiency, which they thought might further this objective. CHC was seen by some as a government initiative and therefore at risk of furthering the Government's perceived initiative of "carving up the NHS".

## Response by CHC

As a result of the findings above, CHC will commit to continue and improve in two broad areas of engagement:

- Putting systems in place to ensure that any data use initiatives will be for public benefit above all other considerations.
- Refining the content of its communication about what it is doing or planning to do (both in terms of why data will be used and how data will be protected).

This work will be the responsibility of, among others, the Public Engagement Working Group, the Communications Working Group and the public forums from the city regions and the hub.

## Ensuring the public benefit

Initiatives to ensure public benefit will include those focussing on improving care and those likely to improve the quality of life of many patients. The CHC hub will constitute an Independent Assessment Panel, which will be responsible for giving advice to the Senior Management Team of the CHC hub and the Directors of the city regions. Membership of this Panel will be drawn from, amongst others, members of the public with experience in audit or governance in other sectors. The Panel will write a Citizen's Charter, which will outline what the citizens of the North of England can expect CHC to do and not to do.

Responsibilities of the Panel will include:

- Making recommendations as to the types of future data uses (including projects with commercial partners) that should be approved because of the likely public benefit.
- Auditing whether existing data uses (such as the care pathway projects) have been conducted in accordance with agreed standards and, overall, have been for the public benefit.

This is in addition to the work being done by the public forums in each city region to ensure that the ongoing work of that region is for the public benefit.

## Communicating the public benefit

There are two interrelated concepts that need to be clearly articulated about any proposed data use initiative – that there will be clear public benefit and that the privacy of the individual is protected. The first of these is probably more important, as evidenced by the fact that one potential use where privacy was protected by using aggregate data was not acceptable because the use was considered to be *only* for commercial benefit.

As a general point, we must recognise that many members of the public do not understand how or why NHS services are managed in the way that they are currently. Therefore, their understanding of why changes need to be made to the care pathways may be based on false assumption. We should work with our public panels, both in each city region and in the hub, to ensure that the information that we provide will be appropriately understood by a broad range of the public.

Where possible we should provide layered information, with brief outlines accompanied by links to longer information sources for those people who are interested. This may, and probably should, include providing external links to basic information about the NHS.

### **The public benefit of the care pathway projects**

On our websites and in any public-facing communications, we will explain the following points about each of our pathways:

- What currently happens and why the care pathway runs that way. There was a strong message coming through from the jurors that, although they believed that existing care may be inadequate or unavailable, they did not believe that the results of data analysis would change that. Information needs to be provided to persuade people that this is not the case.
- Why changes are needed to the pathway to deliver the desired outcomes. The arguments need to be articulated about the importance of introducing system changes instead of introducing better training for existing staff (which was the first thing thought of by some members of the juries) and explaining.
- What kinds of things might happen differently to the pathway as a result of what CHC proposes to do?
- What benefit will accrue as a result of what CHC proposes to do, in a way that is well substantiated and persuasive to diverse patient groups, including those who are sceptical about uses of data for improving health care."
- Will the NHS commit to acting on these results in the future and, if so, how? In addition to reassuring the public that data about them are safe (see below), they need to be reassured that the NHS is safe from any consequences from the data usage.

### **The public benefit of projects with commercial partners**

On our websites and in any public-facing communications, we will explain the following points about any project that involves commercial partners:

- What currently happens and why changes are needed, as described above, will be provided for these projects also.
- What are the potential health benefits expected from the project?
- Who each commercial partner is and what their role will be in data handling and/or analysis.
- Why collaborating with each commercial partner adds additional benefits over and above what would be possible with CHC staff alone.

- Transparency about beneficiaries (e.g. whether any profits were retained by the company or shared with the NHS).

### What we inform the public about our governance

In addition to the above reassurances about the reasons why data are being used, there needs to be clear explanations given as to how the risks of data breaches are being mitigated. This applies both to when data are in the hands of CHC and when in the hands of their partners, when delivering the projects described above. This is particularly the case regarding safeguards that are put in place for any data use that involves commercial companies. Much of this information is required by the Data Protection Act. However, we should be seen to go over and beyond that

On our websites and in any public-facing communications, we will explain the following:

- How we will process and share information, in an easily accessible Fair Processing Notice, as required by the Data Protection Act.
- More detailed information about our security procedures for those members of the public who have additional interest.
- More detailed information about any procedures or restrictions about “sharing on” data that we receive.
- Our governance procedures as to how we will ensure the public benefit of the future projects that we propose (i.e. the Independent Assessment Panel described above).
- Our governance procedures as to how we will audit whether we have delivered projects that are for public benefit (i.e. the Independent Assessment Panel described above), with the agreed safeguards for the data used.
- The deliberations of the Independent Assessment Panel will be published on the website as fully as possible, whilst recognising that CHC will be in receipt of information that is ‘commercial in confidence’.