

Workshop Outcomes

“What the data tells us and how we should use it”

Presenter: Robert Cavalleri

Chair: Professor Eric Emerson

Background

Transforming Care: A national response to Winterbourne View Hospital (December 2012) included a commitment by the Department of Health to “commission an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay.”

Health and Social Care Information Centre (HSCIC) was commissioned to undertake the Learning Disability Census collecting data from NHS and independent sector hospital providers on 30 September 2013 & 30 September 2014. NHS England has also collected data since December 2013 from NHS commissioners in England.

The longer term plans are to collect and combine the Learning Disability Census and NHS England’s data through the Mental Health and Learning Services Disability Data Set at HSCIC.

Presentation & Discussion

The workshop began with a presentation from Robert Cavalleri (HSCIC) highlighting some of the findings from the 2014 census initial report. Including:

- How many people were in hospital
- What kind of hospital people were in
- Why people were in hospital
- Experience of care (including incidents self-harm, physical assaults, restraint, seclusion and use of antipsychotic medication)
- Advocacy
- Length of stay
- Distance from home
- Cost

Further analysis of the 2014 census will be published on 30th April 2015.

HSCIC’s future work in this area was discussed and Robert Cavalleri explained plans to compare and reconcile the Learning Disability Census and NHS England data by considering responses from commissioners and providers on those questions that appear incongruent. . It was asked if the Learning Disability Census would be held again, since the group felt it unlikely that the ‘reconciling’ would be

complete in time. HSCIC thought they might be asked but that it had not been confirmed yet.

HSCIC will build a tool “tableau” so people can self-serve and interact with the data, it would have the capacity to inform local area decision making and commissioning practice.

Moving forward, the point was raised that we need to compare ‘like with like’. Robert responded that assuming we get the go ahead for the census 2015, we will engage with the Royal College, Learning Disability Professional Senate etc. to work out if we need to change things, especially since we don’t want to lose comparability with year 1 and year 2. If it is simple mapping, the analyst can do that but serious shifts will need more thought. Consulting and engagement will occur if the census is given the go ahead.

CB-NSG members commented that:

- We need to be clear about why people are in ATUs, is it because they have nowhere to go back to? Is there actually assessment and treatment going on? Is a 3 month stay a reasonable standard?
- A big problem we have is that length of stay disguises two phases – how long it takes to assess and treat, and the time it then takes to set something up. Could this be shown separately – it artificially extends stays and should be segmented. Step-down services are also unhelpful as it is simply another hospital environment with less skilled staff.
- An issue that worries me is that if there are less than 5 people somewhere, you couldn’t disclose but one of the issues is one or two women in a unit on their own, ethnicity. This kind of risk needs to be flagged.
 - HSCIC explained that the regulators get to know, so in terms of our publication we don’t disclose and suppress appropriately, but the regulator can see that level of detail.
- If we look closely at the placement of women in the 2013 census, more women are in a mixed setting, but we can’t see any association with adverse settings in single vs mixed sets settings.
- One of the flaws of the data, thinking of the Mansell report is that you are measuring the tip of the iceberg, and if it changes shape, which is useful to have but beneath the surface we need to know what’s going on. That tip might disappear, but what is going on beneath the surface might be as bad and this needs to be acknowledged.
- Reclassification is an issue – hospitals reclassifying themselves as residential care, so they’re not declared by CCGs but the situation for patients has not changed. Various authorities declare just hospitals, others include residential nursing homes, we need to unpack all of that to get the whole picture.
 - CQC are aware of the issue and are looking into it.
- There needs to be a move towards outcome focused data
 - That is what the HSCIC Mental Health Services Data Set (MHSDS) aims to achieve.
 - It ought to be able to provide longitudinal data e.g. each person in hospital now, where are they in each dataset subsequently (not just hospital settings), working out how many people are coming in and

admitted multiple times etc. as well as measures of quality of life and quality of care (but it may be difficult to get measures of these agreed nationally).

- There would need to be a process of consultations and partnership working, where do we go from here?
- Outcome measures – no one agrees to anything, we need to start with measures that are already collected e.g. safety data. Clinical outcomes need to be simple and easy to use or else it won't be useful. But we need some that get into the MHSDS soon to generate comparability – we have to measure something.
- There needs to be a consultative development process to allow different stakeholders, professionals, family carers etc. to contribute to. Some initial scoping work will be carried out but what will be the method to get agreement/gain input. Needs to be a partnership to catalyse the process and gather views.
- Potential for the CB-NSG to have as one of its days a focus on outcomes, to allow the incorporation of social care outcomes, since it important not just to have health results monitored.
- Wales want to develop a live register that can be used for commissioning – Robert Cavalleri would share how they do it, via website and contact.
- Scotland and Ireland both have national databases
- Families are very aware of the importance of measuring outcomes but what I want might be different, there is a need to ask families what their outcomes would be.

Actions

Action	Who/how to take it forward
Continue the broader discussion through learning disability professional senate and with the Royal College	To be included as part of the planning process for the action below.
HSCIC to develop a plan to consult on collecting outcome focused data & share with CB NSG <ul style="list-style-type: none"> ● Including a potential CB-NSG meeting focused on what outcomes should be collected and used 	CBF to approach NHSE Robert Cavalleri to input.
Write up recommendations from this discussion and formally write to HSCIC	CBF
HSCIC to note support for continuation of census & update CB NSG about 'Census 2015'	Robert Cavalleri