

Suggestion for the process that must be followed in order to amend care.data/CES

We would expect that the minimum process for any expansion of collection, would be an expansion on the following:

1. NHS England publish a green paper of possible thematic additions on a particular topic. *(NHS England then has meetings with stakeholders (both existing, and those who emerge after the green paper is published) to hear initial comments within a reasonable time scale. For some areas, this step may require a formal 12 week consultation, or several iterations of a green paper if lessons of the care.data roll out were not learnt).*
2. NHS England publish a white paper with a substantive proposal for expansion, including relevant aspects of process (patient contact, opt-in/opt-out etc).
3. There is then a full 12 week public consultation process on the white paper, with an associated draft set of codes to be extracted. This includes NHSCitizen, other statutory vehicles, plus additional oversight from statistical bodies, and the Health Select Committee if it wished to take a view.

NHS England publish the consultation comments and seek process feedback from stakeholders before finalising the codes to be extracted (and how).

4. NHS England publish a full proposal, as would go to IAG etc, along with the code set being requested for extraction, as the commencement of an 8 week consultation period on the codeset for extraction.
5. Following consideration of responses, the full proposal goes into IAG etc.

This process would allow IAG constituents, and other bodies, to offer comments at an early stage, so that the formal process, which is still required to approve an extract process, should be relatively straightforward, without surprises.

For “minor” tweaks to the specification (e.g. inclusion of new derived codes where the parent is already extracted), we’d expect an biennial cleanup update to correct detected errors in the codeset. We would expect IAG guidance to be followed on the definition of “minor”. Such updates could enter straight at point 4 in that process. If necessary, at any step, the process can be reset back to stage 1, based on lessons learnt, should IAG be dissatisfied with NHS England’s process.

We also expect that this process must be promised to apply to any other datasets that could ever be considered for inclusion in the Care Episode Statistics: Maternity data, Child health, Mental Health, Pathology, Free Text, DNA, Historical data, Ambulance events, social care...

medConfidential,
September 2014