

Meeting between NTA and GMC - 25/01/08

Present

Malcolm Roxburgh - NTA Information Manager
Colin Bradbury - NTA Treatment Delivery Manager
Michael Farrell - Consultant Psychiatrist, Institute of Psychiatry
Suzanne Wood - GMC, Policy Advisor, Standards and Ethics Team
Michael Keegan - GMC, Policy Advisor

The meeting began by discussing the contents of the SW's letter to Dr Verner dated 30/08/07. There were several clarifications regarding the TOP guidance on anonymity that were referred to in the letter. The NTA explained that guidance that related to the data collection prior to September referred to a research exercise to validate an outcomes questionnaire. The NTA explained that all client data collected during this research was anonymised.

The NTA explained that once the results of the research were known, the data items that could be validated were then implemented on the National Drug Treatment Monitoring System (NDTMS). The NTA explained that the NDTMS was a collected patient identifiable data with full consent. Guidance relating to the completion of NDTMS is distributed via regional NDTMS teams, mainly housed within Public Health Observatories (PHOs) within SHAs. The NTA performance manage the distribution of this guidance through Service Level Agreements with the PHO's.

The NTA agreed to ensure that the GMC could see a copy of this guidance. An example of the information provided by regional teams can be found here <http://www.erpho.org.uk/ViewResource.aspx?id=16129>

The GMC stated that they thought that the Guidance to Key workers document available on the NTA website as part of the TOP documentation had been misleading as it promised clients full anonymity. The NTA explained that the text in the guidance had been a cut and paste from the TOP validation exercise (which did afford participants anonymity). It was unhelpful to include this form of words in the guidance for key workers once the TOP has been rolled out; precisely because TOP data in practice is to be submitted to the NTA via NDTMS. A corrected version of the key worker guidance has been placed on the NTA website, and existing hard copies of any guidance containing this version have been pulped.

It was stressed by the NTA that participation in the data collection was voluntary on the part of the client, and that the NTA had issued guidance that participation should not have any impact on a client's access to treatment.

The NDTMS system uses the client's initials, date of birth and gender as an identifier. It was explained that this was required because the role of the system was to support the PSA target that measured the number of individuals in treatment. As clients can be treated more than once, there is a need to de-duplicate clients to monitor this figure, and that the initials, DoB

and Sex was considered as the minimum required for purpose. The NTA explained that NHS number is not a viable alternative, and about half the activity is taking place outside the NHS, and these providers were unable to submit NHS numbers.

The GMC suggested the use of one way encryption for data submitted to the NDTMS. The NTA agreed that this would be an ideal solution, but that it was considered impractical to expect over 1700 submitting agencies to have the one way encryption algorithm embedded into their clinical information systems.

There was a discussion relating to the criminal justice data on the form. The NTA's understanding is that the data recorded on the form could not be used as incriminating evidence. However, guidance issued by the NTA on TOP stresses throughout the importance of ensuring that the local confidentiality policy is fully explained and understood by the client at the outset of treatment with the provider. This is because the boundaries of confidentiality will vary depending on circumstance or type of service (for example treatment being sought as part of a court order supervised by the Probation Service).

In summary, it was agreed at the meeting that:

- The NTA do not believe it is currently practical to fully anonymise data given the nature and purpose of NDTMS (the system by which TOP scores are reported)
- Guidance issued by the NTA to accompany the national launch of TOP makes it clear that the information contained within NDTMS is not anonymised
- NTA guidance clearly states that informed client consent is required before any information is submitted via NDTMS
- If a client withholds consent for any or all of their data being reported to NDTMS then this should in no way affect their right to access appropriate treatment.

The NTA and the GMC agreed that minutes of this meeting may be made available to the field by the NTA once they have been agreed.