

Response from the RCGP Substance Misuse Unit in relation to the Treatment Outcome Profile criminal justice question

**Dr Linda Harris
March 2009**

Background

The Treatment Outcome Profile tool (TOP) was launched in 2007 by the National Treatment Agency (NTA) and is a national substance misuse specific outcome monitoring methodology. TOP measures outcomes across the four key domains of substance misuse treatment and care and includes the measurement of impact of substance misuse treatment on criminal activity through the self reporting by the individual service user. The TOP is designed to be collected electronically through clinical IT systems (e.g. SystemOne).

Given that all GP data is warehoused by the Strategic Health Authority (SHA) for 30 years, the Department of Health's Digital Policy Unit (DPU) have expressed concerns that a record of crime will be retained in the clinical record after the criminal conviction is spent with the criminal justice authorities, thereby potentially damaging the doctor patient relationship.

My understanding is that the preferred solution of the NTA would be to permit the recording of the criminal involvement on the TOP on NHS clinical systems, but for this data to be excluded from the Care Records Service data warehouse, and therefore subject to deletion after 8 years (the records retention period for National Drug Treatment Monitoring System [NDTMS] data).

The Royal College of General Practitioners (RCGP) Substance Misuse Unit (SMU) was approached by the NTA to provide a response on the issue of the ethics of recording of criminal activity on GP systems. The RCGP Substance Misuse Unit (SMU) provides education training and support to primary care professionals in the management of substance misuse in primary care. The SMU coordinates and provides a suite of educational products linked to the skills escalator of primary care professionals working with substance misuse in community and secure environments. The request was made for views from primary care regarding the criminal justice questions on TOP forms prior to a planned meeting between the DPU and the NTA in December 2008. In order to provide a response the SMU regional network of clinical leads and tutors were consulted with, as well as members of the SMU Clinical Executive Team. The consultation provided the basis for a response that makes a number of key points in relation to TOP.

Response

1. The RCGP acknowledges and understands the importance of working with patients to ensure a shared understanding of their progress in treatment.
2. The measurement of clinical outcomes is a core element of the work of any primary care professional and takes many guises including practice based clinical audit, lessons learnt from significant events, and the nationally

coordinated Quality Outcome Framework (QOF). GPs and nurses are enthusiastic about measuring and sharing health outcomes and see this as a way of improving quality of care year on year for their patients.

3. Substance misuse management is a complex area often involving a number of health and social care agencies working together. In the majority of cases primary care professionals will be managing physical, psychological, social and community dimensions of care.
4. Primary care welcomes the opportunity to support and participate in specific substance misuse outcome monitoring and appreciates the importance of conducting this throughout an individual's journey of care.
5. Whilst there is overwhelming support for a treatment outcome profile tool in the substance misuse field questions have been raised regarding certain elements of the TOP data collection itself, notably the questions relating to criminal activity.
6. It is important to note that primary care professionals, and in particular GPs, have always recorded information indirectly in relation to an individual's criminal activities, for example, where there is a need to acknowledge a prison sentence in a clinical assessment and in routine required information sharing with other healthcare professionals (e.g. safeguarding children, health visitors, shared care, forensic medical services etc).
7. It could be argued that reviewing the involvement or otherwise of a patient's criminal behaviours is an appropriate outcome monitoring indicator for substance misuse as part of harm reduction or any other treatment intervention and forms part of the public health role of the GP who has a significant role in tackling health inequalities and improving an individual's health and well being in the broader sense.
8. Clinicians have questioned whether data should be collected on any of the areas covered by TOP if it is not directly relevant for ongoing care and the need to take into account valid concerns shared around data quality, and what is happening to data once it has been collected.
9. Clinicians are concerned that confidential information is being collected from people who are highly vulnerable and do not realise or enquire as to what use this information can be put. Nor are they in a strong position to refuse to participate.
10. Clinicians report how frontline practitioners regularly completing TOP forms have questioned the quality of the information being reported back from patients in relation to the crime question, with evidence emerging in some localities of a complete cessation of criminal activity recorded through TOP and of individuals reporting no criminal activity even where their route into treatment is through the criminal justice system itself. This may reflect a problem regarding how TOP is being completed by clinicians who, rather than recording n/a in the crime section, are recording '0'.

11. Concerns and “unease” regarding the reliability of the data collected in relation to crime was regularly cited and this appears to have sowed the seeds in some clinicians’ minds of data reliability in relation to *other* parts of the form. For example, some feel that the scaling questions are very dependent on how patients feel on the day of asking and question their validity.
12. Members of the RCGP SMU note the importance of conducting research to evidence crime reduction in treated drug users and cite papers previously published in this area using research methods informed by regulatory standards for data protection and informed patient consent.
13. There are already examples where services have been threatened with reduction in funding if TOP are not completed and given our understanding that the substance misuse team/workers’ performance could be in some way managed by TOP in the future, clinicians have questioned the bias that may result from this i.e. is a worker likely to encourage a patient to complete TOP in a way that demonstrates improvements in their health and well being.
14. Almost all clinicians have expressed anxieties regarding care being potentially compromised by time being taken up by the questioning itself.
15. One GP felt that the completed TOP including the crime question should be an integral part of the clinical record provided the information was for clinical care but was uncomfortable that the form was being used for monitoring and research purposes.
16. The concept of any dual data entry in relation to certain aspects of the form was not welcomed by some GPs as it is unlikely to be completed.
17. In terms of the doctor patient relationship, clinicians reported the “intrusiveness” of the questions relating to crime and a potentially negative impact on the Dr/Patient relationship.
18. One GP wondered about the feasibility of the crime question being optional.
19. One GP questioned where the collection of data of the TOP forms fitted with legislation regarding the Data Protection Act and confidentiality

Summary

The overwhelming view of professionals consulted suggests serious concerns with the TOP forms and particularly.

The majority of clinicians consulted do not wish to see the criminal record being tied to the medical record stating that “the statute of limitations should apply i.e. there should be no ongoing record of spent convictions and thus allegations or records of criminal activity on records beyond the usual period when they are deleted according to law”.

Concerns regarding data reliability in relation to the crime question have in many areas called into question the veracity of other data collected by the system

Many at The RCGP SMU would support consideration be given any *outcome monitoring question* relating to criminal activity be separated from the TOP data collection within the clinical record, and indeed from the whole clinical consultation.

In sharing this view with the NTA the RCGP SMU acknowledge that discussion of crime related issues will in certain patients cases be necessary and will still take place as part of routine substance misuse clinical work, but that the recording of it will be filtered by the clinician's judgement based on what is necessary and relevant.

Dr Linda Harris, Clinical Director, RCGP Substance Misuse Unit