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1 Introduction

The Treatment Outcomes Profile (TOP) is a simple and short set of questions, with accompanying data fields, to be used at assessment, care plan reviews and discharge (and reported through NDTMS) to plot clients’ progress through structured drug treatment (Tiers 3 and 4). It will be available for incorporation into clinical practice from June 2007 onwards. There is an expectation that from 1 October 2007, TOP scores will be reported via NDTMS by all relevant specialist structured treatment services (both adult and young people’s services) as set out in the local Treatment System’s TOP implementation plan.

This guidance is aimed at drug service managers and data staff, to facilitate the linking of clinical and operational practice to reporting TOP data to NDTMS.

It is generally recognised\(^1\) that monitoring treatment outcomes is an important component of delivering high-quality, effective services. Over the last five years, drug treatment services have been required to report on performance, in terms of process measures such as waiting times and numbers in treatment. The NTA has a shared long-term goal with treatment providers, service users and commissioners to establish a more direct outcomes monitoring system and has now developed the TOP to meet this objective.

Drug treatment outcomes in the UK are grouped into four key domains and are applicable to all clients in structured drug treatment aged 16 or over:

- Drug and alcohol use
- Physical and psychological health
- Criminal involvement and offending
- Social functioning.

These domains are generally assessed in care planning and care plan reviews. A range of treatment outcomes monitoring instruments covering these domains already exist; however, many of these lack the sensitivity within harm reduction services to detect change, lack sufficient user involvement, or are too long and complex for routine, non-research use. Therefore, the TOP has been developed as a simple but effective, validated instrument that can be incorporated into NDTMS, and assessment and regular care plan reviews by keyworkers.

A copy of the finalised TOP v1.0 is included in section three. This guidance is concerned with clarifying the procedures that should be followed to report the new data items to NDTMS (indicated in blue on the TOP form). Software to support NDTMS submissions will be modified through the course of 2007/08 and service providers should check locally and plan their reporting of TOP around appropriate software modifications. For further information, contact your local NTA regional team\(^2\) or regional NDTMS database manager.\(^3\)

A range of guidance is available and being developed to further support the implementation of TOP (see section four).

Note: It is not expected that the form in section three will be used by all treatment agencies. Many agencies have their own more comprehensive care planning documentation – as long as the appropriate data items are captured at appropriate times during the client journey and are reported to NDTMS as required, agencies have discretion as to how they best go about this.

\(^2\) http://www.nta.nhs.uk/areas/regions/default.aspx
\(^3\) http://www.nta.nhs.uk/areas/ndtms/regional_NDTMS_contacts.aspx
2 Incorporating TOP data reporting into clinical practice

The TOP tool and supporting guidance for implementation into clinical practice will be available from the June 2007. It is anticipated that each local treatment system will incorporate TOP into clinical practice when materials are available. This will apply to every new client at the beginning of a treatment episode, or at care plan review for clients entering treatment prior to the introduction of TOP.

The NDTMS Data Entry Tool (DET), managed by the NTA, will have the capability to receive TOP data from 1 October 2007. The NTA is working with other providers of NDTMS software to ensure that as many as possible will be also be ready for the beginning of October 2007.

Note: Where an individual is simultaneously receiving Tier 3 and 4 interventions from two or more agencies, only one TOP should be administered and reported at the appropriate points in the client’s journey. It is up to local treatment systems to agree who (as the case managing agency) should administer the TOP and if or when responsibility should be passed from one agency to another as the client’s treatment journey progresses. Where there is more than one agency simultaneously providing treatment, the agency should (subject to permissions and data sharing protocols) send copies of the TOP for information to other services. Each local treatment system – with the support of their NTA and NDTMS regional teams as appropriate – should develop a plan that sets out how TOP will be introduced and developed locally. A pro forma to allow the national NTA NDTMS team to generate accurate exception reports (see section 7) is required to be submitted on behalf of all treatment systems to their local NTA regional team by Friday 31 August 2007.

The NTA will produce monthly exception reports (see section five), which will identify cases where seemingly more than one set of TOP scores has been reported on an individual client. By the same token, the exception report will also highlight individuals who have not had a single TOP score reported within a given period. If required, treatment system staff will be able to contact their local NDTMS data managers to obtain client attributors to identify the actual individuals concerned (as is currently the case with the waiting times exception reporting process).

Where the exception reports highlight multiple or zero returns, it is the responsibility of local commissioners to co-ordinate and oversee how these problems will be eradicated. Local NTA regional teams or regional NDTMS database managers will be able to offer practical support where required.

2.1 Collecting and reporting TOP data at the beginning of a treatment journey

As mentioned previously, clients starting completely new treatment episodes, at agencies within a treatment system that can report TOP data, should have a TOP administered relating to the 28 days prior to them commencing treatment. A new treatment episode is defined as an individual not having been in any structured treatment within the partnership area’s treatment system during the preceding 21 days.

If clients have already started treatment journeys with other agencies within the local treatment system and are being referred on, then a new TOP should not be administered at the start of a subsequent modality or intervention by the agency receiving the referral.

When the first TOP is administered for a new treatment journey, clients should be asked to think about the month prior to their modality start dates (as recorded in NDTMS).

---

4 A local treatment system is defined as the structured treatment services (Tier 3 and 4 as defined by Models of Care for Treatment of Adult Drug Misusers: Update 2006) that DAT partnership areas commission for their residents. This can include services outside the physical boundaries of the partnership if they are specifically commissioned for DAT partnership residents to access (e.g. Tier 4 services).
2.2 Collecting and reporting TOP data at the care plan review stage

Reporting of TOP scores through NDTMS will be required at regular quarterly intervals for clients (typically at care plan review stage) over their entire treatment journeys. Clients should be asked to think about the last month when answering questions. Again, in cases where individuals are simultaneously the clients of more than one treatment service, agreement should be secured locally as to which agency should submit the single TOP score. This is because the focus is on the outcome for clients across the course of their treatment journeys, not specific agencies.

It is acknowledged that TOP scores will not be collected three months to the day from the previous one and consequently there will be a two-week window either side for the submission of TOP data. Therefore, the exception reports will only flag up a zero return for individuals who do not have a discharge date and do not have TOP scores submitted for a given four-month period. In other words, exception reports will operate on a rolling basis, based on the assumption that every client remaining in treatment over a 12-month period should have at least three TOP scores submitted within that timeframe.

2.3 Collecting and reporting TOP data in areas operating a “gateway system”

Some partnership areas use a "gateway" model for admitting clients into treatment; commonly a duty system where staff from a range of local providers see new referrals and signpost clients to the appropriate local treatment agency. In these cases, the agency to which the modality or intervention start date is attributed (at the start of a new treatment journey) should report the initial TOP data.

2.4 Collecting and reporting TOP data at the end of a treatment journey

When an individual is discharged from all structured services commissioned within the local treatment system, a TOP should be completed. This should be done face-to-face between the keyworker and client where possible, but can be done over the telephone if there is no other option – for example, in the case of unplanned discharges. No other options for data collection are appropriate (such as the keyworker using their knowledge of the client’s situation to complete the TOP independently, without speaking directly to the client).

TOP discharge data should be reported in all cases where possible, even if the discharge date is less than three months from the last date when TOP data was reported. Data should be collected with reference to the 28 days prior to the discharge date (as reported through NDTMS).

Note: If individuals move to new partnership areas, they should be given a discharge date in NDTMS and a discharge TOP submitted for the area that they are leaving. For the receiving area, a new TOP assessment should be completed, because referrals between DATs are not tracked via NDTMS (because the attributor data is not comprehensive enough to guarantee two people with similar attributors in different parts of the country will not be mistakenly assumed to be the same individual). See section 6.4.

2.5 Collecting and reporting TOP data in Tier 4 services

Many Tier 4 services take referrals from multiple partnership areas. In these cases, the referring Tier 3 agency should agree with the Tier 4 agency that they take responsibility for reporting TOP (as part of the ongoing care plan review schedule) for the duration of the time that the client is a resident of the service. The only exception to this is where the residential treatment component is due to start and finish before the next care plan review date is due. (In practice this would apply almost exclusively to standalone inpatient assisted withdrawal as opposed to residential rehabilitation treatment services.)
In most cases, clients leaving Tier 4 services will continue in structured treatment (community support and aftercare) and TOPs will continue to be done by the appropriate care manager or community service. In cases where a client is leaving structured treatment on discharge from residential rehabilitation, the residential service should conduct discharge and, if feasible, post-discharge TOPs as described in the next section. See section 6.3.

2.6 Collecting and TOP data post-discharge

If required, the TOP can also be used to follow up clients and assess their progress post-discharge – after they have left the structured treatment system. This information can be used for local outcome monitoring purposes, provided that informed consent to be contacted post-discharge had been obtained from the client prior to them leaving the treatment system and any required local approval for this aspect of the monitoring protocol has been secured. Post-discharge data can be reported to NDTMS, but will not be part of the NTA’s exception report framework. This applies equally to clients who stop contact with all drug agencies and those who remain in contact with Tier 2 services.

Note: It is possible that when a client is contacted for post-discharge follow-up they may have reengaged with a treatment agency. In these cases, TOP post-discharge data should not be reported – even if it is unclear whether the treatment that the individual is receiving is not structured (i.e. tier 2). In other words, any TOP post-discharge data that is submitted to NDTMS will be assumed to be about individuals who are not in contact with specialist drug services.

2.7 TOP and confidentiality

TOP data submitted via NDTMS will have the same safeguards in relation to confidentiality as any other item within the NDTMS core dataset. This should be carefully explained to the client and local confidentiality agreements should be modified as appropriate to take into account the introduction of TOP into clinical and reporting systems. Service managers should take care to ensure that clinical staff fully understand the complexities and importance of taking time to explain and reassure clients about the confidential nature and how this data will be used.

Where the TOP form itself is used (see section 3) to record information, keyworkers can – if the client prefers – write a standard service client reference number on the top of the form instead of the actual name of the individual.

2.8 Dealing with missing data

While every effort should be made to get information from clients on each data item (see TOP keyworker guidance for further information), there may be some rare instances where a client is unable or unwilling to answer a particular question. In these cases, “NA” (indicating that data is not available) should be entered in the appropriate field within NDTMS.

Note: Every data item on each TOP should be completed, even if the answer is “NA”.

2.9 TOP and alcohol

TOP has been validated for individuals with a primary alcohol problem and agencies are free to use the TOP in the same way in the care plan review process as they would with primary drug users. As no data is required to be reported to NDTMS for individuals with a primary alcohol problem, there is no expectation for the submission of TOP scores for this client group. NDTMS will accept alcohol data (for example, in the cases of joint alcohol and drug services), but no analysis will be fed back on primary alcohol users.
The exception to this is young people’s services that are required to report primary alcohol users to NDTMS. In these cases, TOP scores should be submitted in the same manner as any other client who is eligible for their activity data to be reported to NDTMS.
## Treatment Outcomes Profile (TOP)

### Section 1: Substance use

Record the average amount on a using day and number of days substances used in each of past four weeks

<table>
<thead>
<tr>
<th>Substance</th>
<th>Average</th>
<th>Week 4</th>
<th>Week 3</th>
<th>Week 2</th>
<th>Week 1</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Opiates</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Crack</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Cocaine</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Amphetamines</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Cannabis</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Other problem substance?</td>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
</tbody>
</table>

### Section 2: Injecting risk behaviour

Record number of days client injected non-prescribed drugs in past four weeks (if no, enter zero and go to section 3)

<table>
<thead>
<tr>
<th>Injected</th>
<th>Week 4</th>
<th>Week 3</th>
<th>Week 2</th>
<th>Week 1</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
</tbody>
</table>

### Section 3: Crime

Record days of shoplifting, drug selling and other categories committed in past four weeks

<table>
<thead>
<tr>
<th>Crime</th>
<th>Week 4</th>
<th>Week 3</th>
<th>Week 2</th>
<th>Week 1</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoplifting</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Drug selling</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-7</td>
<td>0-28</td>
</tr>
<tr>
<td>Theft from or of a vehicle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other property theft or burglary</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Enter &quot;Y&quot; if any yes, otherwise 'N'</td>
</tr>
<tr>
<td>Fraud, forgery and handling stolen goods</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Enter &quot;Y&quot; if any yes, otherwise 'N'</td>
</tr>
<tr>
<td>Committing assault or violence</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Enter &quot;Y&quot; or 'N'</td>
</tr>
</tbody>
</table>

### Section 4: Health and social functioning

a. Client's rating of psychological health status (anxiety, depression and problem emotions and feelings)

<table>
<thead>
<tr>
<th>Poor</th>
<th>Good</th>
</tr>
</thead>
</table>

Record days worked and at college or school for the past four weeks

<table>
<thead>
<tr>
<th>Work</th>
<th>College or School</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-7</td>
</tr>
</tbody>
</table>

Record accommodation items for the past four weeks

<table>
<thead>
<tr>
<th>Item</th>
<th>Enter &quot;Y&quot; or &quot;N&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute housing problem</td>
<td></td>
</tr>
<tr>
<td>At risk of eviction</td>
<td></td>
</tr>
<tr>
<td>Client's rating of overall quality of life</td>
<td>Enter &quot;Y&quot; or 'N'</td>
</tr>
</tbody>
</table>

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Treatment Outcomes Profile (TOP)

About the TOP
The Treatment Outcomes Profile (TOP) is a new drug treatment outcome monitoring tool that has been developed by the NTA in partnership with drug treatment providers in over 70 sites across England. It is applicable for use in all of the structured treatment modalities as defined by Models of Care for Treatment of Adult Drug Misusers: Update 2006. For the first time, service users, clinicians, service managers and commissioners will be able to obtain objective and comparable data about real improvements in service users' lives that will be able to inform and improve practice on both an individual and strategic level.

The TOP is a simple set of questions that will improve clinical practice by enhancing assessment and care plan reviews for clients. The data it provides will improve performance monitoring. Data will be reported into the National Drug Treatment Monitoring System (NDTMS) from October 2007 and results fed back to providers and commissioners from March 2008. There will also be monthly exception reports from NDTMS on non-returns and multiple submissions.

The TOP should be completed at the start of each client's treatment journey to record a baseline of behaviour in the month leading up to starting a new treatment journey. Follow up scores should be recorded every three months during treatment (usually at the same time as a care plan review) to capture changes in behaviour. It should also be completed at discharge and may be used by some services to measure post-discharge outcomes. Note: when services are introducing TOP, existing clients (as well as new presentations) should also have TOP forms completed with them as part of the care plan review process.

How to complete the TOP
Start by entering:
- Name and identifiers of your client (date of birth and gender)
- Your name
- Date of assessment
- The stage at which the TOP is being completed – modality start, care plan review, discharge or post-discharge.

Types of responses:
- Timeline – invite the client to recall the number of days in each of the past four weeks on which they did something – for example, the number of days they used heroin. You then add these to create a total for the past four weeks in the blue NDTMS box.
- Yes and no – a simple tick for yes or no, then a ‘Y’ or ‘N’ in the blue NDTMS box.
- Rating scale – a 20-point scale from poor to good. Together with the client, mark the scale in an appropriate place and then write the equivalent score in the blue NDTMS box.

You should aim to ask and complete every question. Do not leave any of the blue boxes blank. Enter "NA" if the client refuses to answer a question or, after prompting, cannot recall.

(See TOP keyworker guidance for more detailed information: www.nta.nhs.uk/TOP)

Alcohol units converter

<table>
<thead>
<tr>
<th>Drink</th>
<th>%ABV</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pint ordinary strength lager, beer or cider</td>
<td>3.5</td>
<td>2</td>
</tr>
<tr>
<td>Pint strong lager, beer or cider</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>440ml can ordinary strength lager</td>
<td>3.5</td>
<td>1.5</td>
</tr>
<tr>
<td>440ml can strong lager, beer or cider</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>440ml can super strength lager or cider</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>1 litre bottle ordinary strength cider</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>1 litre bottle strong cider</td>
<td>9</td>
<td>9</td>
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</tbody>
</table>

Thank you for your contribution to the TOP
## 4 TOP guidance and supporting documentation

<table>
<thead>
<tr>
<th>Document</th>
<th>Availability</th>
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</thead>
<tbody>
<tr>
<td>TOP form</td>
<td>Available June 2007</td>
</tr>
<tr>
<td>NDTMS business definitions</td>
<td>Available June 2007</td>
</tr>
<tr>
<td>TOP guide for service users</td>
<td>Available June 2007</td>
</tr>
<tr>
<td>Revised eCare Planning Guide</td>
<td>Release date TBC</td>
</tr>
<tr>
<td>Training pack and manual</td>
<td>Available June 2007</td>
</tr>
<tr>
<td>Implementation guide for managers</td>
<td>Available June 2007</td>
</tr>
<tr>
<td>Guide for keyworkers</td>
<td>Available June 2007</td>
</tr>
</tbody>
</table>
5  NTA exception report formats for TOP reporting

5.1  Initial TOP scores

<table>
<thead>
<tr>
<th>Region</th>
<th>DAT</th>
<th>Number of new treatment journeys (individuals)</th>
<th>Number of completed TOP forms (individuals)</th>
<th>Number of individuals with &gt;1 form in the month</th>
<th>% data quality</th>
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<tbody>
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</table>

5.2  Subsequent TOP scores

<table>
<thead>
<tr>
<th>Region</th>
<th>DAT</th>
<th>Number of new treatment journeys (individuals)</th>
<th>Number of completed TOP forms (individuals)</th>
<th>Number of individuals with &gt;1 form in the month</th>
<th>% data quality</th>
</tr>
</thead>
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</tbody>
</table>
6 Scenarios for TOP completion during client journey

6.1 Client moves from one treatment agency to another

1) Client enters treatment system
Triage date: 1.10.07

Local treatment system

Agency A → Agency B

2) Client starts modality with agency A on 15.10.07, which submits initial TOP data

3) Agency A discharges client and refers client to agency B, which takes over TOP reporting (every three months)

4) Client discharged 31.3.08. Agency B reports discharge TOP

Note: Further post-discharge TOPs can be completed as required

EXIT
6.2 Client receives treatment from more than one agency simultaneously

1) Client enters treatment system
   Triage date: 1.10.07

2) Client starts modality with agency A 15.10.07, which submits initial TOP data

3) Agency A refers client to agency B, but also continues to provide a treatment intervention. Agreement between agencies A and B as to who reports TOP every three months as part of care co-ordination package.

4) Client discharged 31.3.08. Agency B reports discharge TOP
6.3 Client receives treatment from a Tier 4 agency outside of area

1) Client enters treatment system
   Triage date: 1.10.07

Local treatment system

Agency A

2) Client starts modality
   with agency A 15.10.07,
   which submits initial
   TOP data

Tier 4 agency

3) Client referred out of area
   to Tier 4 agency 31.3.08
   (which reports TOP while
   client resident at service).

4a) Client discharged from
    all structured treatment on
    30.06.08. Tier 4 agency
    reports discharge TOP

4b) Client referred back to agency A on
    30.6.08, which takes
    back responsibility
    for TOP reporting
    every three months.
6.4 Client moves to another area and is transferred to an agency within their new locality

1) Client enters treatment system
Triage date: 1.10.07

2) Client starts modality with agency A on 15.10.07, who submits initial TOP data and subsequent data every three months

Local treatment system 1

Agency A

Local treatment system 2

Agency B

3) Client moves areas and is transferred from agency A to agency B on 31.3.08. TOP discharge submitted by agency A and initial TOP data submitted by agency B. NB: These should be the same scores.
### NDTMS TOP pro forma

**Partnership name: ________________________________**

<table>
<thead>
<tr>
<th>Agency name</th>
<th>Agency code</th>
<th>Will the agency provide initial TOP assessment to NDTMS (Y/N) (1)</th>
<th>Will agency provide subsequent interventions after initial modality start? (Y/N) (2)</th>
<th>Will the agency provide care plan review(s) and provide subsequent TOP forms to NDTMS (Y/N) (3)</th>
<th>Likely referring agencies and codes – Tier 3/4 only (4)</th>
<th>What date will a TOP compliant data collection system be in place? And / or any foreseen issues. (5)</th>
<th>Does agency currently use an outcome tool? Does it collect all the TOP data items? (6)</th>
</tr>
</thead>
<tbody>
<tr>
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This form should be completed for all agencies that provide Tier 3/4 interventions to partnership residents and that report to NDTMS including residential rehab agencies.

1. Initial TOP assessment refers to where clients enter the treatment system – the first modality intervention in their treatment journey.
2. Subsequent interventions refer to modalities / interventions provided after the initial intervention in a client’s treatment journey.
3. Even though an agency might be providing subsequent interventions, they might not be expected to provide the care plan review as defined in the care coordination process.
4. Which other agencies would likely to be referring clients to this agency should be recorded here.
5. The expectation is that software systems should be in place before 1 October.
6. While agencies can continue to use existing outcome tools, they will need to be able to ask and report the TOP data items.