Running Major Trauma PROMs

(Patient Reported Outcome Measures)

Guidance and useful tips for an effective PROMs programme

2018
Acknowledgements

This document is a result of information received from hospitals participating in the PROMs programme and gathered from an online survey and telephone discussions.

Thank you to all who took part in this process during 2017.

Contact Address

The Trauma Audit & Research Network
Faculty of Biology, Medicine and Health
University of Manchester
3rd Floor, The Mayo Building
Salford Royal NHS Foundation Trust, Stott Lane, Salford
M6 8HD

tel: 0161 206 4397
demail: support@tarn.ac.uk
Background to this Guidance Document

TARN has historically collected patient outcome data (alive or dead) at discharge or at 30 days. However, no long-term outcome information has been gathered at patient level, so there has been little understanding of the long-term impact of Major Trauma including return to work or education.

Commissioned by NHS England, an initial 12 month feasibility project was introduced by TARN in 2014 to gather patient reported outcomes both in-hospital and 6 months after injury (MT PROMs):

- Introduced to 19 adult Major Trauma Centres (MTCs)
- A specific Children’s Major Trauma PROMs was launched in January 2015.

Since 2016, all NHS England MTCS and CMTCs have been participating in the MT PROMs programme (including one Trauma Unit and one Welsh Hospital). The MT PROMS is currently funded by TARN.

The purpose of this guidance document is to help participating hospitals with:

- patient identification
- data capture
- establishing best practice for PROMs, by learning from each other.

The Trauma Audit and Research Network (TARN) has been working with NHS Trusts across England, Wales, Republic and Northern Ireland for almost 30 years to improve healthcare systems for trauma by collating and analysing trauma patient care data within each trust/health board. TARN is a non-profit making organisation, part of the University of Manchester and provides the national trauma audit to benchmark practice through monitoring and publishing process measures, allowing on-going and continued appraisal and improvement for the system.
The PROMs Process

**PROMs are short questionnaires that are completed by patients and measure the patients’ perception of their health status or health related quality of life at a single point in time.**

The information collected provides an indication of the outcomes or quality of care delivered to the patients.

- A PROMs questionnaire (Q1) is given to patients in hospital.
- A follow-up PROMs questionnaire (Q2) is sent to patients via post at 6 months post injury.

TARN works with an **NHS England PROMs accredited supplier, Quality Health Limited.**

Quality Health will ensure that your hospital is equipped with all the materials needed to support the MT PROMs programme such as:

- Providing a dedicated PROMs Manager for each Trust
- Providing a regular supply of Q1 questionnaires and courier envelopes which your PROMs Manager can organise for you
- Leaflets and posters for patients and help sheets for members of your team
- Returns Log & Patient Declines Log
- Secure monthly collection of completed PROMs questionnaires by courier
- Advice on the PROMs process

**Quality Health support TARN by:**

- Training hospitals in administering and managing PROMs
- Send questionnaire to patients at 6 months post injury
- Validate and process the Q1 & Q2 data
- Send a monthly PROMs data file to TARN.

**TARN’s role is to:**

- Link the PROMs data with TARN submissions.
- Produce quarterly PROMs reports to help Trusts identify patients experiencing serious to extreme problems at 6 months. Trusts can then follow up these patients where appropriate.
- Provide you access to your raw PROMs data. This is accessed via a download from the secure area of the TARN website and updated quarterly.
- Provide any additional PROMs support including advice on patient inclusion, analysis requests and reporting queries
Which patients should be included?

Trusts are encouraged to include patients with Injury Severity Score (ISS) >15 in the first instance however, if resources are available, patients with an ISS >9 can be included.

50% of hospitals find it simpler to try and include all any TARN eligible patients

Survey results are shown below:

Patient groups included in PROMs

- 53% All TARN eligible
- 23% ISS>15
- 12% ISS>8
- 12% Other

‘Other’ group includes:

- “Those patients or relatives who have capacity to understand the concept of PROMS and can engage”.
- “Those that come down the Major Trauma Rehabilitation Unit pathway.”

Further information about TARN eligibility or ISS can be found in the Procedures Manual under the Resources section of www.tarn.ac.uk or from TARN support.
The Questionnaires

Q1 questionnaire

This is completed in hospital, as soon as possible after injury when the situation is stable enough for the patient (or relative) to be approached.

The questionnaire must be completed prior to discharge.

The questionnaire includes:

- Patient Experience in hospital.
- EQ5D-5L: A standardised generic measure of health status.
- VAS (Visual Analogue Scale) where patients rank how they’re feeling on a scale of 0 (worse health imaginable) to 100 (best health imaginable).
- Employment/education status prior to injury.
- Details about as why the information is being collected, how it will stored and how it will be used:
  - Ability for patients to specify that their information should not be shared with professionals involved in their care
  - By completing the questionnaire, the patient is providing explicit agreement to be followed up in the future

The patient can receive help to complete the questionnaire and it can also be completed by a family member or carer if it is difficult for the patient to express their views. This is indicated on the questionnaire.

The questionnaire must be completed whilst in hospital and cannot be taken home to complete.
Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don’t worry if you make a mistake, simply cross out the mistake and put a tick in the correct box.

IMPORTANT INFORMATION TO READ BEFORE COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is to collect information about the quality of healthcare services. The information collected will be used to produce statistics about the quality of healthcare services offered by different healthcare providers (hospitals) across the NHS. These statistics will be used to measure and improve the quality of healthcare services.

With your permission, the personal details that you provide and other information held about you in other NHS databases will be used to analyse and interpret the information collected.

By completing this questionnaire you are giving your consent for the information provided to be used for the purposes set out above. You are agreeing that:
- Your personal details and other relevant health information related to your treatment will be held and used by the Trauma Audit and Research Network (TARN), including relevant information held about you by the Demographics and Birth Service, and other NHS databases.
- Your personal details can be used to send you related follow-up questionnaires in the future.
- Your personal details and health information can be held and used by contractors, working on behalf of TARN and NHS England for this project.

Your personal information will be handled securely and anonymised after analysis and before any publication. TARN, NHS England and contractor(s) working on their behalf will not release your personal information unless required by law or where there is a clear overriding public interest. They will hold your personal information for no longer than 24 months for checking the accuracy of the information.

Your personal information may be shared with healthcare professionals involved in your care if you do not wish for your information to be shared with healthcare professionals involved in your care please tick the box below.

☐ I do not want the information I give here to be shared with healthcare professionals involved in my care.

Your participation is voluntary. If you do not want to take part, do not fill in the questionnaire. You may withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about this information or the questionnaire please call the FREEPHONE helpline on xxxx xxx xxx.

EQ5D-5L example

Trauma Questionnaire – After your Initial treatment

Under each heading, please tick the ONE box that best describes your health TODAY

G8. Mobility

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about
Q11.

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = [ ]
Q2 questionnaire

Q2 is administered by Quality Health and sent directly to the patient at 6 months post injury and includes:

- GOSE (Glasgow Outcome Scale Extended) where patients can provide more detail about how the injury has impacted on their day-to-day lives
- Changes to employment/education status post injury.
- Patient experience after leaving hospital.

![Trauma questionnaire - During your recovery](image)
Electronic questionnaires

TARN has licence to collect via paper & e-format and electronic questionnaires are available for Q1 and Q2.

Quality Health is currently working with one Trust to pilot this data capture system.

If you are interested in finding out more about this format, please contact TARN or your Quality Health PROMs Manager.

Children’s PROMs

Different questionnaires are available for children of varying ages: 1-12 months, 13-24 months, 2-4, 5-7, 8-12 and 13-15.

They can be completed by parents or carers for younger children, but children of 5 and over may complete the questionnaire themselves if desired.

These questionnaires still include Health related quality of life measurements but are more specific to children and the language is child friendly.
Who is asking the questions?
We are called TARN - the Trauma Audit and Research Network.

We are an organisation which is a part of the NHS - the National Health Service. We are interested in helping hospitals that treat people who have had an injury. We want to make sure that everyone gets the best care so that they can get better as quickly as possible.

Will my answers be kept private?
Yes. All of the answers that you give, as well as the ones that your mum, dad or carer give about you, will be carefully looked after and kept private.

There are lots of rules about how the answers you give us should be looked after and we will follow all of these rules.

If you want to ask any more questions, or if your mum, dad or carer wants to know more about this questionnaire - you can call our helpline and we will do everything we can to help you. The FREEPHONE number is:

0800 917 1163

How are you today?
We want to know how you are feeling after your injury.
Administering the Q1 questionnaire

A recent online survey has shown that the Trauma Nurse Coordinators (TNCs) are responsible for administering the Q1 questionnaire in a quarter of hospitals.

A further half of all hospitals use a combination of the following personnel:

- TNC
- Rehabilitation coordinators
- Physiotherapists
- Trauma Ward receptions
- Volunteers
- Others

Others include: Therapy team, TARN coordinators, Major Trauma Support coordinators, Non-Clinical Doctors assistants, Admin staff and Major Trauma Managers.

Survey results are shown below:
Methods of patient identification

Below is an example of a patient identification process employed by one hospital:

- **Patient Identification**
  - **1. Commence RP**
  - **2. Add patient to Major Trauma database**

- **Screen patients for PROMs suitability**

- **Recruit patients on wards**

- **Questionnaire completion & documented on EPR**

- **Performed by MT Coordinators**
  - Each morning:
    - Check all new admission in last 24 hrs & check notes for any trauma
    - Review any triage positive patients that came through ED

- **Once patients have:**
  - Commenced Acute Care Bundle
  - Deemed ready for discharge/Discharge being planned
  - Patients with head injuries may not be ready until emerged from cognitive impairment
  - Therapy teams on those wards consult with patient and recruit should they wish to take part
  - MT Support Coordinator largely assists with recruitment

- **MT Support Coordinator stores completed questionnaires securely, coordinates collection & delivery of materials.**

Other useful patient identification methods developed by hospitals include:

- **Database queries** set up to identify predicted ISS>15 patients (databases such as Access).

- **Trauma Nurse or TARN coordinators** identify PROMs patients at the same time as identifying their TARN eligible patients.

- **Rehabilitation teams** can often help with identification as they will be aware of MT ward admissions that require a Rehabilitation Prescription.

- **Neurosurgical, Spinal, Cardiothoracic and Orthopaedic ward staff** can notify their PROMs contact of direct admissions to the wards and help identify Transfers in who may bypass ED.
PROMs administration

Patient support

- Ensure all patients have a copy of the PROMs leaflet.
- Plan where you are going to administer Q1, choose the most appropriate and effective time, place and method bearing in mind the specific circumstances of the patient.
- Ensure that patients are given as much support and information as they need to complete the Q1 questionnaire.
- Put up posters in all the places where PROMs are going to be administered.
- Use the language posters and language leaflets if appropriate.

Preparation

- Keep your stocks of PROMs materials in a secure place close to hand.
- Make sure you have everything ready before you give the Q1 questionnaire to the patient:
  - The questionnaire
  - Patient information leaflets and language leaflets
  - Pens for patients to use to complete the questionnaires

Collecting the questionnaires

- Once the questionnaire is completed, ensure the patient has filled in their name and address.
- If you are using identification labels on the back of the questionnaires make sure the correct label is put on the patient’s questionnaire.
- Try to ensure that patients do not take the questionnaires home with them; the questionnaire should be completed in hospital.
- The completed questionnaires should then be put into the labelled envelope provided for safe keeping.

Storing and returning the completed questionnaires

- The number of questionnaires being returned must be recorded on the label on the envelope and on the Returns Log to ensure that all questionnaires arrive safely at the Quality Health scanning depot.
- Ensure that the sealed envelope containing the questionnaires is delivered to your Trust’s designated secure location to await collection by the courier.
- The questionnaires will be collected at a pre-arranged time by courier.
- There is a secure pre-addressed UPS pouch to put your envelopes in.
- The completed questionnaires must not be put in the post.
## The Declines log

There will be instances where it is not possible to include a patient or a patient/family member declines a questionnaire.

Please complete the declines log with the following details for every decline:

- Month
- Patients NHS Number
- Injury Type
- Reason for Decline

Some of the reasons why a patient/family member should be included on the ‘Declines’ Log:

<table>
<thead>
<tr>
<th>Patient unable to complete due to health state</th>
<th>Clinical judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient took questionnaire home</td>
<td>Patient died</td>
</tr>
<tr>
<td>Language issues</td>
<td>Patient/Family member declined</td>
</tr>
<tr>
<td>Patient transferred or discharged before questionnaire completed</td>
<td>Did not have relevant form to hand</td>
</tr>
<tr>
<td>Safeguarding</td>
<td>Questionnaire given but not returned</td>
</tr>
</tbody>
</table>

- The NHS number is particularly important as it assists with analysing data.

- Please give your completed declines log back to your dedicated PROMs Manager on a monthly basis.

- It is vital to keep Declines log up to date, as these patients are then removed from the Case ascertainment denominator in the TARN published PROMs reports.
Tips from hospitals: Improving the PROMs process and patient involvement

At some hospitals, at least 60% of MT PROMs eligible patients are asked to complete a questionnaire however; it can be as low as 20% at other hospitals.

To offer guidance on improving the MT PROMs process, feedback has been gathered from a number of hospitals where good practice was evident. Furthermore, we have taken advice from hospitals that have experienced difficulties and what they had done to overcome these (or the plans they were about to put in place).

Recommendations are:

- One nominated person must take ownership of PROMs to ensure its success

- Involving Volunteers was beneficial at some sites
  Time and resource can be an issue for a number of hospitals. Volunteers may have more time to spend with the patient. It means that they can explain what the MT PROMs programme means. They can also assist the patient if needed.

- Involving the Major Trauma Ward Receptionists/Managers
  or those who complete the ‘Friends and family’ questionnaires.

- Administer Q1 at the same time as the completing a Rehabilitation Prescription

- Administer Q1 as part of the discharge plan from the Ward.

- ‘Declines Log’
  It’s vital to keep this up to date as this will impact on your case ascertainment percentage.
Case Study

By implementing some of the above suggestions, one hospital has shown a 4-5 fold increase in data capture during June-November 2017 as compared to the same period in 2016.

Resource was a key issue for the hospital, so with agreement, the responsibility of the MT PROMs programme was handed to the Major Trauma Ward Receptionist who was already administering some of the national and local patient reported questionnaires.

Number of cases captured per month:

<table>
<thead>
<tr>
<th></th>
<th>Jun-16</th>
<th>Jul-16</th>
<th>Aug-16</th>
<th>Sep-16</th>
<th>Oct-16</th>
<th>Nov-16</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jun-16</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>22</td>
<td>20</td>
<td>0</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jun-17</td>
<td>28</td>
<td>40</td>
<td>39</td>
<td>46</td>
<td>49</td>
<td>43</td>
<td>245</td>
</tr>
</tbody>
</table>

Not all PROMs eligible patients are identified across the trust; however the change in the process has made a significant difference.
Major Trauma PROMs
(Patient Reported Outcome Measures)
Reporting
PROMs reports are published quarterly by TARN and emailed to the nominated PROMs contacts at each Trust. They contain information about both the in-hospital (Q1) phase alongside the 6 month post discharge (Q2) phase.

Q1 information includes:

- Response rate summary: See example below. 
  How many PROMs questionnaires have been validated and used in the report.
- Case ascertainment % by month. 
  The % of patients who have completed a questionnaire & are matched with an eligible TARN submission.
- Number of declines. 
  Number of patients unwilling or unable to participate in PROMs.
- Case ascertainment by ISS, Transfer type and body area: See example below. 
  Data capture rates that highlight to Trusts which patient groups they are/are not capturing.
Q2 phase reporting

Q2 information includes:

- Q2 (6 month) completion rates
- Change in ability to work at 6 months: See example below.
- Patients reporting Severe to Extreme problems at 6 months, along with the problematic category.
- Patient experience in hospital: See example below:

![Change in ability to work as a result of injury at 6 months (Q2)](image)

![Change in ability to work 6 months after injury](image)

![Patient experience - 6 months after injury](image)
Interpreting the EQ5D-5L graph

The EQ5D-5L is a standardised generic measure of health status and includes 5 health domains: Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety/Depression.

This graph below uses this information to demonstrate whether there has been an improvement in the way patients rate their health at 2 time points (in-hospital and 6 months after injury).

The graph contains 2 boxes plots—see below.
- The green box plot represents the range of how patients have rated their health in-hospital (Q1).
- The orange box plot represents this at 6 months after injury (Q2).

**Median**
- The line within each box represents the average health rating recorded by your patients in each period.

**Whiskers**
- Indicate the health rating range in each period. This is considered the typical response range.

**Green and orange Box plots**
- Show the Interquartile Range (IQR) of responses, i.e. the middle 50% and represents the response Trend.
- In this example the middle range of responses is far narrower at Q2 (orange box) than Q1 (green box), so these patients (in general) are rating their health a lot better at 6 months.
Highlighting patients for review

A red diamond on the ED5D-5L graph highlights any patient who is experiencing severe to extreme problems at 6 months and therefore falls outside the typical range of responses.

The patient’s TARN submission ID is shown in the report and the area/s they are experiencing problems with.

In the example below patient 999990009504 is having problems with both Mobility and Usual activities at 6 months.

Trusts may wish to follow up these patients

![Table showing patients for review](image)

Submission IDs shown in grey have already been flagged for review in a previous report.

Following up patients

A recent online survey of PROMs participants showed that almost half of Trusts are now regularly following up patients still experiencing severe to extreme problems at 6 months, and are doing so via the following means:

- Major Trauma Clinics
- Nominated clinical volunteers who review the patient notes
- Outpatient follow-up
- Telephone
- Review of notes, phone call to identify issues, discussion with relevant professionals, onwards referral if required
- Review case history, look for any outliers, unexpected cases or any patterns.

Report Publication dates

Reports are published quarterly.

Publication dates are shown in the Reporting & Training Calendar on the secure area of the TARN website: www.tarn.ac.uk
Data download

Following receipt of the monthly data file from Quality Heath, the data is linked (where possible) to TARN data using patient’s NHS number, DOB and Arrival and Discharge dates.

A complete/linked excel file is then uploaded onto the TARN website once a month.

This Excel file contains all the fields completed for Q1 and (where applicable) Q2, along with patient details including: NHS no. & TARN submission ID.

Example below:

This file can be accessed using your secure username and password via the AUDIT section of the TARN website: www.tarn.ac.uk

In keeping with existing national PROMs governance, only two nominated people per Trust can have access to this raw data file: the MT PROMs Managerial lead and another nominated person. Please contact TARN support if you wish for more information about this.
INCLUSION CRITERIA
Ensure patients meet the TARN inclusion criteria. Involve your TARN coordinator in this process.

IDENTIFY PATIENTS
Trusts are encouraged to include TARN eligible patients with ISS >8 or >15. However, some Trusts prefer to include all patients. Whichever you choose, you should agree on a method of patient identification.

QUESTIONNAIRE (Q1)
Q1 questionnaire is completed in hospital as soon as the patient is stable. Children's questionnaires are also available.

WHO ISSUES Q1?
Trauma Nurse coordinators, Physiotherapists, Rehabilitation coordinators, volunteers or you may consider using Ward staff to administer the questionnaire.

RETURNING Q1
Ensure Returns & Declines logs are kept up to date. Keep completed Q1 in designated secure location until collection. Questionnaire collection is via courier. Do not put questionnaires in the post!

PROMS REPORTING
Monthly data download is available via TARN website using secure log in. Reports published quarterly by TARN list patients experiencing severe to extreme problems at 6 months.

TIP:
CONSIDER USING LISTS IN OP REVIEWS.

TARN contact details:
0161 206 4397
support@tarn.ac.uk
For queries & collection, contact your regional manager at Quality Health: 01246 856263