

# MTN-11: Rehabilitation Event

## 3<sup>rd</sup> February 2016

# PROMs and TARN

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*Deputy to the Executive Director*

# The Trauma Audit & Research Network (TARN)

- National Clinical Audit for trauma care - *25 years old!*
  - *Report on standards of care and rates of survival*
- Data submitted by all hospitals across England, Wales, ROI
- Based at Salford Royal Hospital, University of Manchester & Manchester Academic Health Sciences Centre (MAHSC)
- Largest European trauma registry >500,000 injured patients

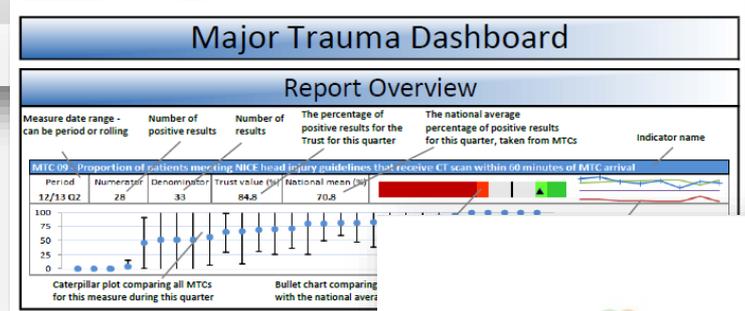
# The role of TARN

- Monitors the effectiveness of Major Trauma Networks
- Compare processes of care using clinically-defined standards  
*Provide regular and informative feedback*
- Ensure quality data coordination
- Review outlier patients and hospitals  
*Unexpected survivors/deaths – what went right/wrong?*

***Drive improvements in trauma care***

# The role of TARN

- Rates of Survival
- Standards of Care
  - Clinical Reports
  - Dashboards
    - Adult & Children MTCs, Trauma Units
  - National Reports
    - Severe Injury in Children
    - Under development:*
    - Major Injury in Older People*
    - Head Injury*
- Measure patient outcome at 30 days or discharge



# Long term patient outcomes (PROMs)

# Long Term Outcomes

- Little understanding of the impact of major injury
- No national measure in major trauma on how patients rate their outcome
- Current national PROMs Programs (elective surgery)
  - *Knee & Hip replacement, Hernia repair, Varicose Vein Surgery*
- PROMs - important extension to national clinical audit

# PROMs Development

## ➤ Approached by Department of Health

- **12 month feasibility (Oct 14-Dec 2015)**
  - Include Major Trauma Centres (19)
  - Focus on ISS > 15 – If resources ISS 9+
- **1<sup>st</sup> Questionnaire** administered in-hospital  
*when patient stable enough to be approached*
- **2<sup>nd</sup> Questionnaire** at 6 months post injury – postal
- Accredited PROMs Supplier **Quality Health Limited**



# Major Trauma PROMs Pilot Sites

- ▶ **Greater Manchester**  
Salford Royal NHS Foundation Trust  
Central Manchester University Hospital  
**(MRI & Royal Manchester Children's Hospital)**  
University Hospital of South Manchester
- ▶ **Cheshire & Mersey**  
Walton Centre for Neurology & Neurosurgery  
Royal Liverpool University Hospital  
University Hospital Aintree  
**Alder Hey Children's Hospital**
- ▶ **South West**  
Southmead Hospital, Bristol  
Derriford Hospital, Plymouth
- ▶ **South East London**  
Kings College
- ▶ **Sussex**  
Royal Sussex County Hospital
- ▶ **Thames Valley**  
John Radcliffe Hospital
- ▶ **East of England**  
Addenbrooke's Hospital
- ▶ **East Midlands**  
Queens Medical Centre, Nottingham
- ▶ **West Midlands**  
University Hospital Coventry & Warwickshire  
**Birmingham Children's Hospital**
- ▶ **Yorkshire & Humber**  
Leeds General Infirmary  
**Sheffield Children's Hospital**

**NHS-E funded (2015)**

# Trauma Questionnaire

After your initial treatment



## 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 Batch 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.

## Questionnaire 1 (Q1)

- Administered in hospital
- Same format as national PROMs
- By completing, patient is giving consent to be part of PROMs & to be followed up with Q2
- ***Sent to hospitals and collected for processing by QH***

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

**Q8. Mobility**

- I have no problems in walking about  1
- I have slight problems in walking about  2
- I have moderate problems in walking about  3
- I have severe problems in walking about  4
- I am unable to walk about  5

**Q9. Self-Care**

- I have no problems with washing or dressing myself  1
- I have slight problems washing or dressing myself  2
- I have moderate problems washing or dressing myself  3
- I have severe problems washing or dressing myself  4
- I am unable to wash or dress myself  5

**Q10. Usual Activities** (*work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities  1
- I have slight problems doing my usual activities  2
- I have moderate problems doing my usual activities  3
- I have severe problems doing my usual activities  4
- I am unable to do my usual activities  5

**Q11. Pain / Discomfort**

- I have no pain or discomfort  1
- I have slight pain or discomfort  2
- I have moderate pain or discomfort  3
- I have severe pain or discomfort  4
- I have extreme pain or discomfort  5

**Q12. Anxiety / Depression**

- I am not anxious or depressed  1
- I am slightly anxious or depressed  2
- I am moderately anxious or depressed  3
- I am severely anxious or depressed  4
- I am extremely anxious or depressed  5

## EQ5D-5L

- Quality of Life Tool
- Used in current national PROMs
- Simple to complete

  - 5 health dimensions
  - 5 levels health status

## Other questions

- PREMS
- Return to work/education

# Trauma questionnaire

During your recovery

About six months ago you received your initial treatment following your injury. You may remember that you agreed that we could send you a *During your recovery* questionnaire. Please can you fill in this questionnaire and return it using the provided pre-paid envelope. Thank you for your help.

Q1. Is anyone helping you fill in this questionnaire?

Yes      No  
<sub>1</sub>      <sub>2</sub>

Q2. Are you filling in this questionnaire on behalf of someone else who can't express their own view?

Yes      No  
<sub>1</sub>      <sub>2</sub>



## Questionnaire 2 (Q2)

- Administered 6 months
- Sent via post
- **Electronic version**
  
- Includes:
  - EQ5D-5L
  - GOS-E Postal
  - PREMS
  - Return to work/education

## Infant's Trauma Questionnaire Ages 1-12 months After the initial treatment

NHS

## Infant's Trauma Questionnaire Ages 13-24 months After the initial treatment

NHS

## Toddler's Trauma Questionnaire Ages 2-4 After the initial treatment

NHS

**How to fill in this questionnaire**  
This questionnaire is in two sections:

1. A section for your child's personal details;
2. Questions for you (parent / guardian / carer);

For each question please tick clearly in the box that is most close to your views. Use a black or blue pen. If you can't answer a question just leave it blank and move to the next. Don't worry if you make a mistake; cross out the mistake and put a tick in the correct box.

### IMPORTANT INFORMATION TO READ BEFORE FILLING IN THIS QUESTIONNAIRE

The information collected in this questionnaire will be used to help make hospital services better.

If you agree, the personal details that you give us and other information that the NHS has about your child (because of other visits or illnesses) will be used to help make sense of the information that we collect.

If you fill in this questionnaire you are agreeing that we can use the answers you give us in this way. You are agreeing that:

- Your child's personal details and other important health information related to their treatment will be stored and used by the Trauma Audit and Research Network (TARN), including important information held about your child by the Demographics Batch Service and other NHS databases.
- Your child's personal details can be used to send related follow-up questionnaires in the future.
- Your child's personal details and health information can be stored and used by other organisations, which are working with TARN and NHS England for this project.

Your child's personal information will be carefully looked after and your child will not be able to be identified in any results that are published. TARN, NHS England and other organisations they work with will not give your child's personal information to anyone else unless there is an important reason for this. There might be times when the law says that this should happen. Your child's personal information will not be stored for any longer than 2 years.

Your child's personal information may be shared with doctors or nurses who look after them. If you do not want this, please tick the box below.

I do not want the information I give here to be shared with doctors and nurses looking after my child.

You do not have to fill in the questionnaire if you do not want to. If you fill it in, and then change your mind, you can ask to have your answers deleted up until the time that your answers have been saved and personal details taken out.

If you have any more questions please call the FREEPHONE helpline on 0800 917 1163.

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## Children's Trauma Questionnaire Ages 5-7 After the initial treatment

NHS

## Children's Trauma Questionnaire Ages 8-12 After the initial treatment

NHS

## Teenager's Trauma Questionnaire Ages 13-18 After the initial treatment

NHS

**How to fill in this questionnaire**  
This questionnaire is in three sections:

1. A section for your teenager's personal details;
2. Questions for you (parent / guardian / carer);
3. Questions for your teenager.

For each question please tick clearly in the box that is most close to your views. Use a black or blue pen. If you can't answer a question just leave it blank and move to the next. Don't worry if you make a mistake; cross out the mistake and put a tick in the correct box.

### IMPORTANT INFORMATION TO READ BEFORE FILLING IN THIS QUESTIONNAIRE

The information collected in this questionnaire will be used to help make hospital services better.

If you agree, the personal details that you give us and other information that the NHS has about your teenager (because of other visits or illnesses) will be used to help make sense of the information that we collect.

If you fill in this questionnaire you are agreeing that we can use the answers you give us in this way. You are agreeing that:

- Your teenager's personal details and other important health information related to their treatment will be stored and used by the Trauma Audit and Research Network (TARN), including important information held about your teenager by the Demographics Batch Service and other NHS databases.
- Your teenager's personal details can be used to send related follow-up questionnaires in the future.
- Your teenager's personal details and health information can be stored and used by other organisations, which are working with TARN and NHS England for this project.

Your teenager's personal information will be carefully looked after and your teenager will not be able to be identified in any results that are published. TARN, NHS England and other organisations they work with will not give your teenager's personal information to anyone else unless there is an important reason for this. There might be times when the law says that this should happen. Your teenager's personal information will not be stored for any longer than 2 years.

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➤ Children's PROMs – launched January 2015 across 4 CMTC's  
➤ PEDsQL

**Initial findings:**  
***6 month patient follow-up***

# PROMS – Response & match rates

## Adult PROMs (16yrs and above) – 19<sup>th</sup> January 2016

### In hospital questionnaire - Q1

Completed questionnaires	<b>2760</b>
Processed by Quality Health & returned to TARN	2515
<b>Matched to patients on TARN*</b>	<b>2113 (84%)</b>

\* *Missing NHS No/patients yet to be submitted/LOS inclusion*

## Adult PROMs – at 6 months (16yrs and above)

<b>Data sample received</b> (19 <sup>th</sup> January 2016) <i>Last questionnaires expected July 2016</i>	<b>597</b>
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## Age and gender (in-hospital responses)

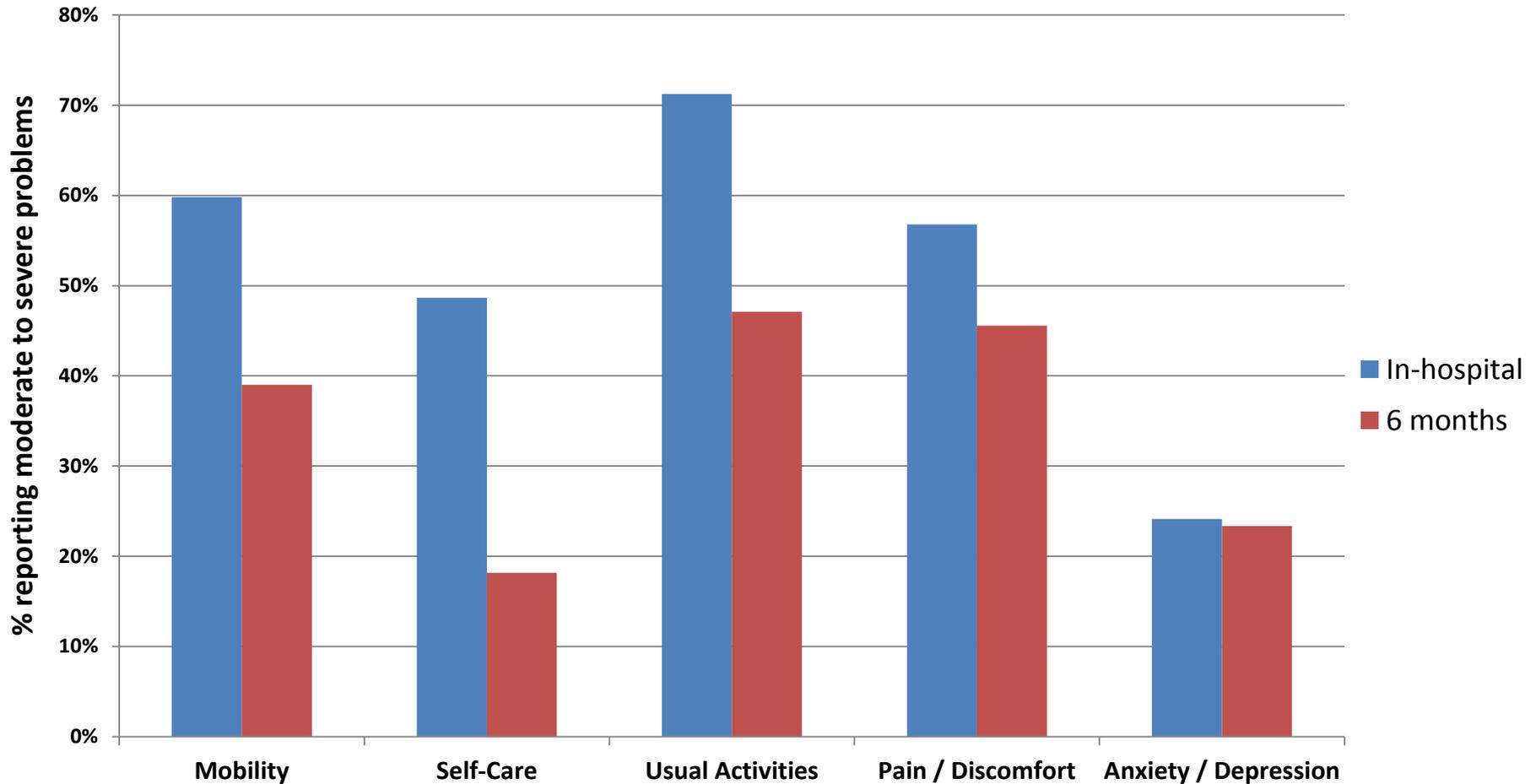
	<b>Age</b>	<b>Male</b>
	<b>%</b>	<b>%</b>
16 – 25 years	15%	76%
26 – 35 years	13%	81%
36 – 45 years	12%	72%
46 – 55 years	16%	78%
56 – 65 years	15%	64%
≥ 66 years	29%	49%
<b>Median Age (IQR)</b>	<b>52 (34 - 69)</b>	<b>67%</b>

## Age and gender (responses at 6 months)

	Age	Male
	%	%
16 – 25 years	<b>7%</b>	69%
26 – 35 years	<b>6%</b>	91%
36 – 45 years	<b>8%</b>	74%
46 – 55 years	15%	75%
56 – 65 years	23%	60%
≥ 66 years	40%	47%
<b>Median (IQR)</b>	<b>61 (49 – 74)</b>	<b>61%</b>

# PROMS - Progress & Initial Findings

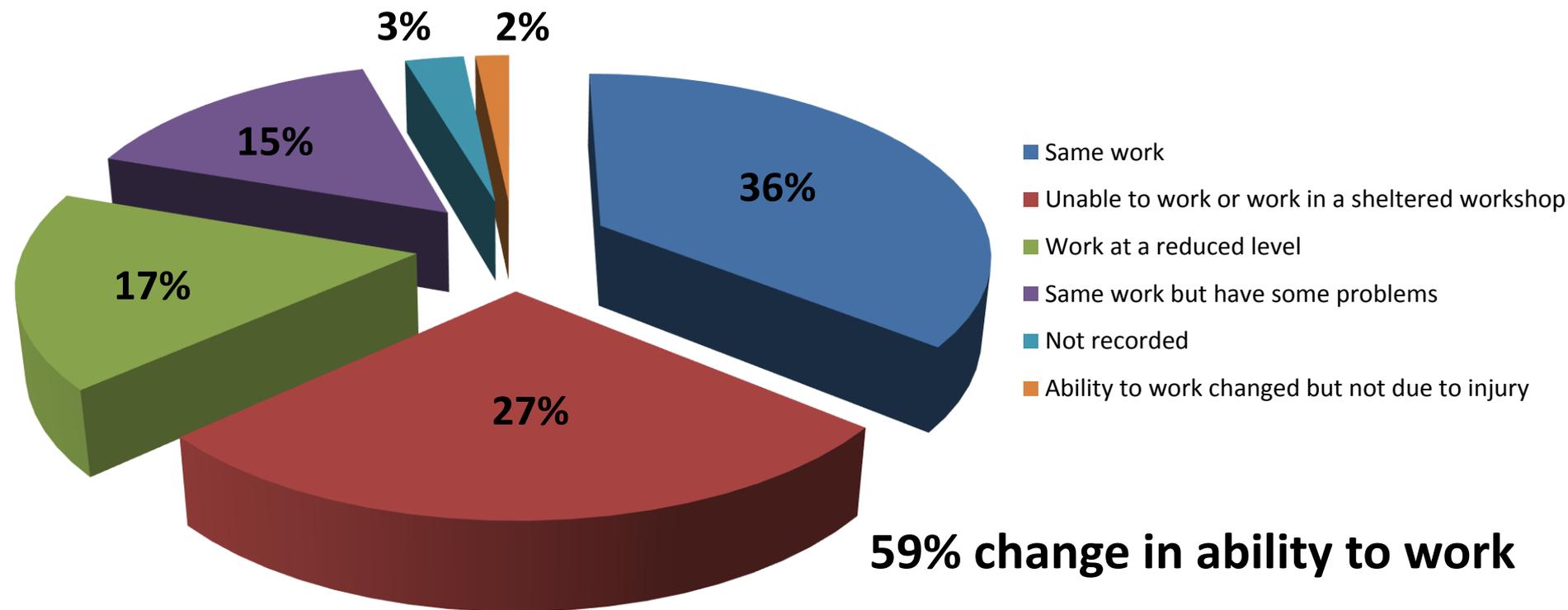
## Patients reporting moderate to extreme problems



# PROMS - Initial Findings

## Change in ability to work

(patients that were working, looking after family or studying before incident)



**59% change in ability to work**

*n=245 cases*

# PROMS - Initial Findings

**Patients that were working, looking after family or studying before incident**

Most severely injured body area

Area	N	%
Head	72	29%
Chest	46	19%
Abdo	4	2%
Spine	17	7%
Limbs	60	24%
Multiple	46	19%
<b>Total</b>	<b>245</b>	

# PROMS - Initial Findings

## Patient Experience – Q1

Based on CQC Survey & National Cancer Patient Experience Survey

- Were you involved as much as you wanted to be in decisions about your care and treatment?  
**56% = Yes definitely**
- Do you think the hospital staff did everything they could to help control your pain?  
**85% = Yes definitely**
- When you had important questions to ask a doctor, how often did you get answers that you could understand?  
**71% = All or most of the time**

# PROMS - Progress & Initial Findings

## At 6 months

- After leaving hospital, were you given enough care and help from health or social services?

**36% = Yes definitely    28% = Yes, to some extent**

- As far as you know, was your GP give enough information about your condition and the treatment you had at the hospital?

**69% = Yes**

- Did the different people treating and caring for you work well together to give you the best possible care?

**46% = Yes, always      31% = Yes, most of the time**

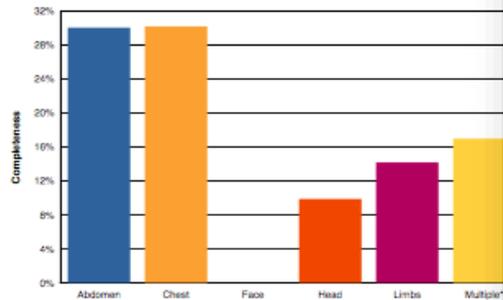
**13% = Yes, some of the time**

### Completeness by transfer type

Transfer type	TARN submissions	PROMs Q1 responses	PROMs Q1 completeness
Admission from scene	272		
Referral in	129		
Transferred out	122		

### Completeness by body area injured

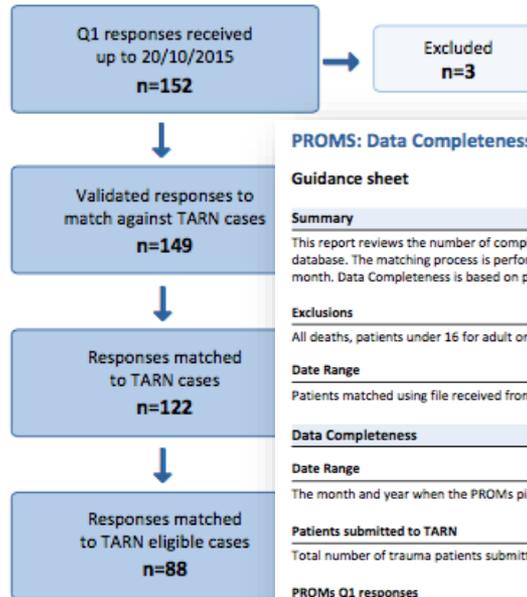
Most severely injured body area	TARN submissions	PROMs Q1 responses
Abdomen	10	
Chest	136	
Face	23	
Head	132	
Limbs	99	
Multiple*	59	
Spine	64	



### Submissions with head as the most severely injured body area

Severity of head injury	TARN submissions	PROMs Q1 responses
AIS under 3	1	
AIS 3	16	
AIS 4	57	
AIS 5 and over	58	

## 1. In-hospital survey responses (Q1): Summary



### Excluded

Deceased patients and duplicate PROMs responses are excluded.

### Unmatched cases

Cases that have a PROMs response but no matching TARN submission. This is that the case hasn't been submitted to TARN yet or the response (e.g. date of completion, NHS number, date of completion).

### Non-eligible cases

Cases that have been matched to a TARN submission but are not eligible (cases that have been rejected, returned for review or not completed).

## PROMs: Data Completeness Report

### Guidance sheet

#### Summary

This report reviews the number of completed questionnaires that can be matched to corresponding patients on the TARN database. The matching process is performed by TARN with a data file received from Quality Health Limited once per month. Data Completeness is based on patients admitted each month.

#### Exclusions

All deaths, patients under 16 for adult only MTCs or adult & children MTCs where PEDsQL is not administered.

#### Date Range

Patients matched using file received from Quality Health Limited (20/10/2015).

#### Data Completeness

#### Date Range

The month and year when the PROMs pilot was launched at your hospital.

#### Patients submitted to TARN

Total number of trauma patients submitted to TARN by your hospital.

#### PROMs Q1 responses

Total number of patients who were approached and completed Q1 (in-hospital questionnaire prior to discharge).

#### PROMs Q1 completeness

Percentage of trauma patients at your hospital that have a completed PROMs questionnaire.

#### No match

Patients that have completed a questionnaire but case not available on the TARN system. This may be due to the following reasons:

1. Patients at Major Trauma Centres are submitted to TARN within 25 days of discharge. There may be patients that were stable enough to complete a questionnaire but still in-hospital at the time of the matching process.
2. Admitted patients that had eligible injuries but whose length of stay was less than 3 days.
3. Admitted patients whose injuries did not meet the TARN inclusion criteria.

#### ISS 1 - 8

Patients on the TARN database with an Injury Severity Score (ISS) of 1-8. This defined as a minor injury.

#### ISS 9 - 15

Patients on the TARN database with an Injury Severity Score (ISS) of 9-15. This defined as a moderate to major injury.

#### ISS > 15

Patients on the TARN database with an Injury Severity Score (ISS) greater than 15. This defined as a major injury.

# PROMS - Summary

- 18 months to implement a PROMs Feasibility
- PROMs process and patient involvement encouraging
- **TARN Board agreed to TARN funding further 12 months**  
All MTC's from April 2016-March 2017
- Complete PROMs Analysis Report
- 2016 Away Day
- Develop future plans to maintain a PROMs programme

**Thank you**  
*Pilot sites*  
*Patients*

**web:** [www.tarn.ac.uk](http://www.tarn.ac.uk)



**@TARNAudit**



'AAAIIGGGHHH'.... So would that be a 'yes' to the question 'I believe my needs are understood'?