National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI)

Second Year Audit Report
Overcoming the challenges of NCASRI

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The National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI)

The National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and led by London North West Healthcare NHS Trust, which hosts the **UK Rehabilitation Outcomes Collaborative (UKROC)**, together with its subcontracted partners:

- The **Trauma Audit and Research Network (TARN**), based at University of Manchester,
- The **Cicely Saunders Institute for Palliative Care Policy and Rehabilitation, King's College London** (KCL).

Engagement of rehabilitation specialists across England is achieved through the **British Society of Rehabilitation Medicine (BSRM)** Trauma Rehabilitation Working Group, and the **NHSE Clinical Reference Groups for Major Trauma and for Specialist Rehabilitation**. It is supported by active patient and public involvement.

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The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the NCAPOP, comprising more than 30 clinical audits and clinical outcome review programmes that cover care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish government, the Northern Ireland Department of Health, the States of Jersey, Guernsey, and the Isle of Man. www.hqip.org.uk

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Second Year Report: Overcoming the Challenges of NCASRI

Contents

1 Executive Summary

The National Clinical Audit for Specialist Rehabilitation following major Injury (NCASRI) was commissioned in 2015 by the Healthcare Quality Improvement Partnership (HQIP), as part of its National Clinical Audit and Patient Outcomes Programme (NCAPOP).

NCASRI will determine the scope, provision, quality and efficiency of specialist rehabilitation services across England and improve the quality of care for adults with complex rehabilitation needs following major trauma.

A key component of NCASRI is to link data from the Trauma Audit Research Network (TARN) and the UK Rehabilitation Outcomes Collaborative (UKROC) datasets through the NHS number, in order to track patients along their journey from the Major Trauma Centres to the specialist (Level 1 and 2) rehabilitation services and to examine the outcomes and cost efficiency of rehabilitation for patients with major trauma.

1.1 The three NCASRI elements.

NCASRI has 3 main elements in the first three years of funding:

1. An organisational audit to identify the current provision of specialist rehabilitation for trauma patients and to map the pathways of care into and out of these services.
2. A prospective clinical audit of new patients presenting within NHS Major Trauma Centres (MTCs) who have complex needs and receive specialist rehabilitation.
3. A feasibility study for identifying the pathway and outcomes for patients who require specialist rehabilitation on discharge from MTCs, but do not subsequently attend.

The FIrst NCASRI Report in October 2016 presented the findings from the organisational survey.

NCASRI is unusual for an NCAPOP audit in that it encompasses a very small number of patients with highly diverse needs, managed across an equally diverse range of services. A number of challenges were recognised from the outset that would require the NCASRI team and HQIP to work closely together to address. In this Second NCASRI Report, we describe some of these challenges, the steps that we have taken to overcome them and the lessons learned. We present some preliminary data from the MTCs for the cohort of patients enrolled in the prospective audit to date.

Throughout the first two years of NCASRI, we have listened to the teams on the ground, and to other stakeholders including patients and members of the public, about what is working and what is not, in order to try to incorporate their feedback in our plans for future rounds of the audit.

Concerns have been expressed about the highly specialised nature of NCASRI, confined as it is to the few patients with highly complex needs. The original topic proposal was more widely based, but the scope was restricted to specialist rehabilitation by NHSE, partly to avoid duplication of the development work on the standard Rehabilitation Prescription, which was on-going through the CRG for Major Trauma. It was always intended, however, that these parallel streams of work should come together more closely for year 4-5.

We therefore set out the case for extension of the NCASRI audit into year 4-5, and make recommendations for how this could be achieved, if extension funding is granted.

1.2 Key challenges addressed

1.2.1 The very low starting base of knowledge, data recording and service provision

At the outset we did not know where the services were, how the MTCs and specialist rehabilitation services operated together, nor how many patients required specialist rehabilitation following major trauma. Because some specialist rehabilitation services are commissioned locally by CCGs (Clinical Commissioning Groups) and others centrally by NHS England, little information was shared between them. There was no clear coordinated pathway to identify patients with complex rehabilitation needs or to direct them to the most appropriate rehabilitation service.

- A 'Rehabilitation Prescription' (RP) was a requirement for the enhanced 'best practice' tariff in the MTCs, but the mandated data collection comprised just 4 data fields in the TARN database. In the absence of central guidance on what form the RP should take, individual MTCs had each developed their own systems with little commonality between them.
- Fewer than half the MTNs complied with the national recommendation for consultants in Rehabilitation Medicine (RM) to be appointed to provide clinical and strategic leadership of acute trauma rehabilitation services, and many MTCs had little or no input from RM consultants at any level.

1.2.2 The absence of an agreed audit dataset, or established data collection tools for rehabilitation following major trauma

The British Society of Rehabilitation Medicine (BSRM) had recommended a Specialist Rehabilitation Prescription (SpRP) for patients with complex needs requiring further in-patient specialist rehabilitation when they were ready to leave the MTC. However, there was little information about how MTCs were using these – if at all. The SpRP does not stand alone, but adds a set of validated tools to the standard RP, which are designed to categorise and describe the needs for different types of rehabilitation service. A Complex Needs Checklist (CNC) serves as a screening tool to help identify patients with complex (category A or B) needs and the remaining SpRP tools measure impairment, dependency and the rehabilitation resource requirements.

It was acknowledged that some of the SpRP tools were detailed instruments that could potentially create a considerable burden of data collection, especially for teams who were not yet familiar with them. However, data from the organisational audit suggested that the number of patients eligible for enrolment would be small (total circa 500 per year). It was thus considered reasonable to include all the SpRP tools in the first round of prospective audit and to determine after that, which would be useful/feasible to collect for future rounds. This first round of the NCASRI audit is therefore particularly critical, because it is likely to be the only one that will include data on all the SpRP tools. It is important to capture as many patients as we can towards the target of 500 with the full NCASRI dataset.

1.2.3 Data collection methods and engagement of MTC teams

During the planning phase, many MTC teams reported that they were clinically overwhelmed and struggled to collect and enter data at any level. To support engagement in the prospective audit, the NCASRI team worked with the individual MTCs to try to find solutions that would fit in with their local practice and existing data collection systems to avoid duplication of effort. In contrast to other national clinical audits, which only utilise one data collection platform, we accepted data from four different computer platforms. These included TARN, UKROC, the Integrated Rehabilitation Management System (IRMA) on the ORION cloud-based platform, and one local clinical database. As a last resort, we also accepted paper copies of assessments, which were anonymised and sent to the NCASRI team to enter

onto the central database. In this way we hoped to improve engagement and reduce burden on clinicians.

Allowing the use of multiple platforms for data entry, however, has posed significant challenges for software development to create data linkage between the various systems. Given the relatively small patient numbers involved, this has been just about manageable for this first round of audit, but is not sustainable going forward. For future rounds, we recommend that all MTC data for NCASRI should be entered onto the TARN database.

The original model for data collection proposed by the BSRM was that an RM consultant would be responsible for drawing up the SpRP and completing the tools. This did not prove workable, especially in those MTCs that lacked RM consultant input, so alternative solutions have been explored (Section 4.7).

Despite these various efforts to facilitate engagement, only 9/22 MTCs started data collection on schedule in July 2016. Seven more joined later, leaving six MTCs yet to engage – four of which currently have no RM consultant. Enrolment for the first round of prospective audit was extended until 31st August 2017 to accommodate the late starters and to try to ensure a full data set for at least 500 patients.

1.2.4 Complex data linkage and software development

As noted above, a key component of NCASRI is to link data from the TARN and UKROC datasets through the NHS number, in order to track patients and identify the services that they access during their recovery following major trauma. At the outset, TARN already collected the NHS number, but UKROC did not.

In addition to permission for NCASRI, UKROC also required permission to collect and hold NHS numbers for clinical and commissioning purposes. Each of these uses had a different legal basis, requiring a separate permissions process.

- The creation of a central clinical registry supports longitudinal data collection to monitor progress and track patients through their longer term care and rehabilitation. This requires permission from the Caldicott Guardians from each of the services that contribute clinical data.
- The reporting of identifiable data to NHS Digital for commissioning purposes supports accurate recording of activity and costing information. This requires a mandate from NHS England.
- Linkage of identifiable data between two or more datasets without the specific informed consent of the patients requires permission from the Health Research Authority under Section 251 of the NHS Act 2006. This 's251' permission is specific to any given audit or research project.

The simplest and quickest solution to obtaining permission to collect and link the NHS numbers for NCASRI would have been to apply for s251 permission for this purpose alone, but it would have lapsed at the end of the audit. By first gaining permissions to hold NHS numbers for clinical and commissioning purposes, and then obtaining s251 permission for data linkage, we have achieved a more sustainable solution going forward. Although these three separate processes took longer than originally anticipated, they did not delay the first planned data linkage and UKROC can now continue to hold NHS numbers to improve the long term clinical care of trauma patients, even after the audit finishes. We consider this an important lesson in sustainability, not only for NCASRI, but also potentially for other NCAPOP audits.

Data from the retrospective analysis of UKROC data in Element 1 suggested that patients may take up to 12 months post injury to appear in the UKROC database, which is longer than originally projected (Section 4.4). Future rounds of this audit will therefore need to be planned on the basis of a 2-year (rather than an 18 month) timescale, to support robust data linkage and maximum case ascertainment.

1.2.5 Working towards a more manageable and consistent dataset - Preliminary data analysis

At the time of preparing this second year report in July 2017, recruitment for the first prospective audit round is still on-going in the MTCs. Data had been recorded for a total of 1312 episodes, of which 606 had complex (category A or B) rehabilitation needs. Although not all of these had complete data on all the SpRP tools, NCASRI is generally on track to enrol its target of 500 patients with the full MTC dataset for this first round audit by the end of August 2017.

As yet no definitive data are available, but a preliminary analysis of the processes and data collected in MTCs up to March 2017 proved highly informative. The findings are presented in Section 6 of this report, but some key points have emerged:

- Due to a lack of staff capacity and burden of data collection, 4/16 (25%) MTCs had already opted to collect a reduced dataset comprising just the Complex Needs Checklist (CNC), and the Rehabilitation Complexity Scale for Trauma (RCS-ET) – a measure of rehabilitation resource use.
- One MTC (Bristol) collected the CNC and RCS-ET for all patients requiring rehabilitation at 72 hours, rather than just those with complex needs. They reported a substantially higher proportion of patients with category A or B needs (approximately 20% of admissions) compared with 5-10% in other MTCs. This could suggest that eligible patients are being under-identified and that the use of a simpler dataset in all patients who still require in-patient rehabilitation when ready to leave the MTCs could help to ensure full case ascertainment. In addition, this would also provide important information about the larger population of patients with less complex (category C and D) needs requiring treatment in their local non-specialist rehabilitation services.
- Evidence from parallel data in 84 patients from other MTCs who had the full SpRP dataset collected, suggested that the CNC could identify patients with category A and B rehabilitation needs with acceptable accuracy (98% sensitivity and 91% specificity). Even though the more detailed Patient Categorisation Tool (PCAT) provides extra useful clinical information, the CNC offers a simple and timely means to capture complex needs for rehabilitation.
- In accordance with the BSRM Core Standards, teams had been asked to complete the SpRP at the 'R point' (when the patient is ready to leave the MTC and be transferred to rehabilitation). However, there were several interpretations of the 'R point', including the time when patients were 'ready to engage' in rehabilitation; 'ready for referral' to rehabilitation and 'ready for transfer' to rehabilitation. Going forward it is important for all MTCs to collect data at an equivalent point to ensure consistency and to enable national comparison of data and outcomes.
- Comparison of the SpRP measurements across the MTCs showed wide variation, but with some consistency between tools. This suggests that the variation is not simply the result of inaccurate scoring, but possibly different thresholds for the identification of category A/B needs, or the different timing of assessments between centres. This will require further investigation in the final dataset and will need to be addressed in future rounds, should NCASRI be extended.

At a national workshop of all participating MTCs in June 2017, it was agreed that the primary time point for data capture should be at the 'Transfer Ready' (TR) point - when the patient is ready to be transferred or discharged to rehabilitation. Experience from this first round suggests that the TR point is often different from the actual transfer or discharge date, due to a shortage of specialist rehabilitation beds.

Although the design of standard RP is not within the remit of NCASRI, feedback from the MTC teams suggested that it would be helpful if the core dataset for NCASRI could be mandated as part of the standard RP for all patients requiring further inpatient rehabilitation on discharge from the MTCs. This would help to embed data collection into on-going routine practice.

1.2.6 Proposals for a second round of prospective audit supported by the NCASRI Board

The following proposals for a second round of prospective audit were supported by the NCASRI Programme Board

1. Prospective data collection starting on 1st September 2017 should include a reduced core dataset consisting of the CNC, and the Rehabilitation Complexity Scale for Trauma (RCS-ET), alongside the clinical category of rehabilitation needs, collected at the TR point for all patients requiring further in-patient rehabilitation at that point
2. All MTC data should be collated within the TARN database. Locally-used databases and electronic patient records should provide data in a form that can be accessed by TARN data coordinators and entered onto the TARN platform for future linkage with the UKROC database.
3. The other SpRP tools will remain to be available within the TARN data platform for MTCs to complete on an optional basis if they find the tools useful for clinical decision-making. For example, if MTCs teams prefer to use the PCAT rather than the CNC to record rehabilitation needs, the CNC can be extracted from PCAT data to avoid duplication of effort.

1.2.7 Strength and weaknesses

The report examines openly the strengths and weaknesses of our approach.

- One of the founding principles of the NCAPOP programme is to develop sustainable audit that may be embedded into clinical practice after the end of the funded audit programme. Although it has taken longer than originally projected to reach some milestones within NCASRI, a major strength is the extensive work that we have undertaken with a wide range of stakeholders to find out what works best for them and so develop sustainable data collection going forward.
- The simpler core dataset proposed for future rounds of NCASRI, has the support of the majority of participating MTCs. Whilst more timely to complete, it will still provide critical information about the number of patients needing further in-patient rehabilitation, the types of need and the resources required to deliver the services, in order to develop service capacity to match demand.
- If data collection can be incorporated into the standard RP, it will expand the impact of NCASRI beyond the original target group of patients with complex needs for rehabilitation, and benefit also the wider population of patients with category C and D needs requiring Level 3 (non-specialist) rehabilitation after trauma. The approach also has potential for wider application across other areas of care, such as neurosciences, critical care and acute stroke services.
- A major weakness is that, as currently contracted, the NCASRI audit will end in June 2018. To meet reporting deadlines, the final data linkage between TARN and UKROC would need to be made in December 2017. At this time up to 50% of patients may still be undergoing treatment in the Level 1 and 2 services, and so will not yet have appeared in the UKROC database.
    - This premature linkage to complete the report within the 3-year timescale may under-estimate the proportion of patients receiving specialist rehabilitation, and so give misleading results.
    - Furthermore, failure to test out the reduced dataset and embed sustainable data collection into clinical practice will mean that the whole programme 'falls at the first hurdle'. The extensive development work conducted in the first 2 years of the programme will come to nothing and the anticipated benefits of directing severely injured patients to appropriate and timely rehabilitation will not be realised.

1.3 Summary and recommendations

The majority of other national clinical audits have started out with well-established quality standards and service structures. Our First Year Report, highlighted the very low base from which the NCASRI programme started in comparison with some other national clinical audits, due to a lack of published data on the rehabilitation needs of severely-injured patients or their access to rehabilitation services. Moreover, the variance in adoption of standards, commissioning of services, service structure and service delivery in both rehabilitation and MTC settings made benchmarking extremely challenging. Development has therefore formed key part of the NCASRI programme during its first 2 years.

This second year has been an important formative time for NCASRI. Starting from this low base, we were aware that there would be significant challenges. An enormous amount of work has been done with stakeholders and teams on the ground to find a process and methodology for this national clinical audit that will not only answer the important questions that we set out to answer, but will continue to improve the access to and quality of specialist rehabilitation offered to patients following major trauma after the end of the audit.

We anticipated and found some major challenges, most of which have now been overcome to some extent, but it was never expected that all could be achieved within a single round of prospective data collection. The Stroke Sentinel Audit, for example, has made major improvements to the care of stroke patients, but has taken over 15 years to embed into clinical practice.

For this reason, we recommend progression of NCASRI to a second round of audit, which will require extension of the current contract into years 4-5. This further round of audit will enable us to test the revised data collection algorithm, timeline and dataset; to support the establishment of a single MTC data collection platform through TARN; and hopefully also to engage the six non-participating MTCs in this revised scheme. Importantly it will enable us to work with the RP Development Group to integrate the NCASRI core dataset as part of the mandated RP and so embed data collection into routine clinical practice for future sustainability.

1.4 Recommendations

The NCASRI Programme Board makes the following recommendations for the next round of audit, which will be included in the proposals for the extension of NCASRI to year 4-5.

	Issue	Recommendation
1	We now know that patients discharged from the MTCs may take 12 months or more to appear in the UKROC database. Data linkage prior to this time is likely to underestimate the number of patients requiring specialist rehabilitation.	Future audit rounds should therefore be conducted over a 2-year cycle – ie data capture is over 2 years reporting every 2 years
2	This first round of the NCASRI audit is critical as it is the only one that is expected to have the benefit of the detailed information provided by the full SpRP dataset.	Final data linkage for this first round should be deferred until September 2018 in order to maximise the chance of capturing all the patients who received specialist rehabilitation.
3	Deferring linkage would also mean deferring Third Year Report encompassing the fill results for this first round of NCASRI. However the reliability and impact of the report will be substantially greater.	The draft report should be submitted to HQIP in December 2018, with a view to publication in March 2019.
4	There is evidence that the burden of completing all SpRP tools in this first round may have inhibited enrolment. It is anticipated that the reduced core dataset will capture a greater proportion of the eligible patients in future rounds.	Data collection should continue in the MTCs into a second round of prospective data audit using the revised NCASRI core dataset on all patients requiring further in-patient rehabilitation, collected at the TR point.
5	The recommendations above will require extension of the NCASRI funding to years 4-5.	Funding of the extension should be granted to deliver a second 2-year round of audit and accommodate the adjusted times lines recommended in 2 and 3 above.
6	The extension request will be submitted in October 2017 and reviewed by the NHSE Panel in November 2017.	In the meantime, MTCs should commence the second round audit data collection on 1st September 2017, with all centres uploading data onto TARN.
7	If the extension is granted final NCASRI report will be due at the end of year 5 in June 2020 in an informal progress report in pdf form on our website in year 4	In order to meet the final reporting deadline, the following deliverables are recommended: • Final linkage between TARN and UKROC conducted in Sept 2019, and with HES/ONS in Oct 2019 • The Draft final report submitted to HQIP in March 2020 • Final publication end June 2020.
8.	Mandated data collection is likely to be required for future sustainability	Work should continue with the RP Development Group towards integration of the NCASRI core dataset into the standard rehabilitation as part of the requirement criteria for the best practice tariff within MTCs

1.5 List of Abbreviations and glossary of terms

1.5.1 List of abbreviations

Abbreviation	Full Term
BSRM	British Society of Rehabilitation Medicine
CAG - Trauma	Clinical Advisory Group (for Major Trauma)
CAG - HRA	Confidentiality Advisory Group (to the Health Research Authority)
CNC	Complex Needs Checklist
CRG	Clinical Reference Group
CRM	Consultant in Rehabilitation Medicine
DARS	Data Access Request Service
DH	Department of Health
HES	Hospital Episode Statistics
HQIP	Health Quality Improvement Partnership
IQR	Inter-quartile Range
ISS	Injury Severity Score
KCL	King's College London
MDT	Multi-disciplinary Team
MTC	Major Trauma Centre
MTN	Major Trauma Network
NCASRI	National Clinical Audit for Specialist Rehabilitation following major Injury
NHSE	NHS England
NICE	National Institute for Health and Care Excellence
NIS-Trauma	Neurological Impairment Set for Trauma
NPCNA	Northwick Park Care Needs Assessment
NPDS	Northwick Park nursing Dependency Score
ONS	Office of National Statistics
PCAT	Patient Categorisation Tool
RCP	Royal College of Physicians
RCS-ET	Rehabilitation Complexity Score - Trauma
RCS-M	Rehabilitation Complexity Score – Medical subscale
RM	Rehabilitation Medicine
RP	Rehabilitation Prescription
RR&R	Recovery, Rehabilitation and Re-enablement
SpRP	Specialist Rehabilitation Prescription
SSNAP	Sentinel Stroke National Audit Programme (SSNAP)
TARN	Trauma Audit and Research Network
TU	Trauma Unit
UKROC	UK Rehabilitation Outcomes Collaborative

1.5.2 Glossary of terms

Term	Description
Clinical Advisory Group (Trauma CAG)	The NHS Clinical Advisory Group that reported to the Department of Health in 2010 making recommendations for Regional Networks for Major Trauma
Confidentiality Advisory Group (HRA)	The Confidentiality Advisory Group to the Health Research Authority that reviews applications for access to confidential patient information without consent under Section 251 of the Care Act 2014
Complex Needs Checklist (CNC)	A screening tool to assist MTC staff to identify patients with complex needs requiring further inpatient specialist rehabilitation
Clinical Reference Group (CRG)	Groups appointed by NHS England to provide clinical advice for the strategic planning and commissioning of Specialised Services
Consultant in Rehabilitation Medicine (RM)	A consultant physician with higher specialist training and accreditation in the field of rehabilitation medicine
Data Access Request Service	A service offered by NHS Digital to provide NHS data for analysis and linkage with other datasets
Major Trauma Centre (MTC)	A specialist hospital responsible for the care of the most severely injured patients involved in major trauma. It provides 24/7 emergency access to consultant-delivered care for a wide range of specialist clinical services and expertise
Major Trauma Network (MTN)	The collaboration between the providers commissioned to deliver co-ordinated trauma care services in a geographical area
Neurological Impairment Set for Trauma (NIS-Trauma)	A clinical for tool for recording the severity and types impairments. The NIS-Trauma is adapted specifically for use with trauma patients
NHS England (NHSE)	An executive non-departmental public body of the Department of Health that oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England
Northwick Park nursing Dependency Score /Northwick Park Care Needs Assessment	A clinical for tool for measuring a patient's level of dependency on care and nursing, which translates by a computerised algorithm to estimate the needs for, and costs of providing, care in the community
Patient Categorisation Tool (PCAT)	A clinical tool for identifying and describing a patient's complex needs for rehabilitation, and categorising these into four levels (A-D) in line with the NHSE criteria for requiring specialist rehabilitation services
Rehabilitation	A process of assessment, treatment and management with on-going evaluation by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living
Rehabilitation Complexity Score – Trauma (RCS-E)	A clinical for tool for measuring a patient's resource requirements for rehabilitation in terms of nursing, therapy and medical care. The Trauma version (RCS-ET) is adapted specifically for use in acute trauma care settings
Rehabilitation Prescription (RP) (standard)	*A* document detailing a patient's rehabilitation needs and making recommendations for how these should be met after they are discharged from the acute trauma services
Specialist rehabilitation	The total active care of patients with complex disabilities by a multi-professional team who have undergone recognised specialist training in rehabilitation, led/ supported by a consultant trained and accredited in rehabilitation medicine
Specialist rehabilitation prescription (SpRP)	The rehabilitation prescription for a patient who is identified as having highly complex needs requiring further specialist in-patient rehabilitation. It include the RP together with four standardised tools to record rehabilitation needs
Trauma Audit and Research Network (TARN)	An organisation that provides the national clinical database for acute trauma care in England
Trauma Unit (TU)	A hospital that is part of the major trauma network providing care for all except the most severe major trauma patients
UK Rehabilitation Outcomes Collaborative (UKROC)	An organisation commissioned by NHSE that provides the national clinical database for specialist rehabilitation services in England

2 Introduction and overview

The National Clinical Audit for Specialist Rehabilitation following major Injury (NCASRI) was commissioned in 2015 by the Healthcare Quality Improvement Partnership (HQIP), as part of its National Clinical Audit and Patient Outcomes Programme (NCAPOP).

The NCAPOP programme[1] is a set of centrally-funded national clinical audit projects that collect data on compliance with evidence based standards, and provide benchmarked reports on the compliance and performance. They also measure and report patient outcomes. Contracts to deliver these audits are awarded by tender with funding usually for 3 years in the first instance, with potential to extend for a further 2 years, subject to agreement. There is an expectation that, following the initial investment, audits will become embedded in clinical practice going forward. Key examples of NCAPOP audits that have been embedded into clinical practice leading to demonstrable improvements in the quality of care and patient outcomes include the Stroke: Sentinel stroke national audit programme[2] the Myocardial Ischaemia National Audit Project (MINAP)[3] and the National Emergency Laparotomy Audit (NELA)[4]. However, it should be noted that this embedding has generally taken more than 15 years.

The Trauma Network has been operating since 1989 and became self-funding in 1997. The TARN database is the largest trauma database in Europe with more than 200,000 cases including over 22,000 paediatric patients. However, data entry was only mandated in 2012 and, even then, comparison and linkage of longer term outcomes was limited to emergency and acute clinical care. Until now, little meaningful data has been collected on rehabilitation, so the NCASRI audit is an exciting and essential process to get the collection of trauma rehabilitation data embedded into TARN for the longer term.

NCASRI will determine the scope, provision, quality and efficiency of specialist rehabilitation services across England and improve the quality of care for adults with complex rehabilitation needs following major trauma[5].

- A key component of NCASRI is to link data from the Trauma Audit Research Network (TARN)[6] and the UK Rehabilitation Outcomes Collaborative (UKROC)[7] datasets, using the NHS number, in order to track patients from the MTCs to the specialist rehabilitation services and to examine the outcomes and cost efficiency of rehabilitation following major trauma
- Outcomes and quality of care will be evaluated in accordance with standards and recommendations laid out in national documents from the Department of Health (DH), NHS England (NHSE), the British Society of Rehabilitation Medicine (BSRM) and the National Institute for Health and Care Excellence (NICE). It will also make recommendations on data collected within tools that highlight any specific shortcoming in the clinical care and rehabilitation of major trauma patients.

NCASRI has 3 main elements in the first three years of funding:

- An organisational audit to identify the current provision of specialist rehabilitation for trauma patients and to map the pathways of care into and out of these services (1st year).
- A prospective clinical audit of new patients presenting within NHS Major Trauma Centres (MTCs) who have complex needs and receive specialist rehabilitation (2nd and 3rd year).
- A feasibility study for using existing datasets such as the UKROC, ONS and HES data to identify the pathway and outcomes for patients who require specialist rehabilitation on discharge from MTCs, but do not subsequently attend(3rd year).

The First NCASRI Report in October 2016 presented the findings from the organisational survey[8].

For this Second Report we aim to:

- Describe some of the challenges that NCASRI has faced in its developmental stages, the steps that we have taken to overcome them and the lessons learned for the future.
- Present some preliminary data from the prospective cohort of patients enrolled so far in the Major Trauma Centres for Element 2.
- Make recommendations for how the NCASRI audit could be taken on into year 4-5, if extension funding is granted.

3 History and background

3.1 History of NCASRI

In 2011, HQIP put out a call for new topic proposals for its NCAPOP programme, and a proposal for "*Specialist Rehabilitation for Patients with Complex Rehabilitation Needs"* was one of 11 chosen topics for procurement. The original proposal was widely based, encompassing neurological rehabilitation following all major illness and injury, and including rehabilitation services in the local Level 3 pathway, as well as Level 1 and 2 specialist services.

3.1.1 Scoping of NCASRI

The NCASRI audit was one of the last in the series of 11 audits to be procured. A scoping workshop was held in October 2013 and following this a decision was made to restrict the scope of the audit to Major Trauma patients only, focusing on rehabilitation in the Major Trauma Centres and Level 1 and 2 services only, at least in the first instance. There were several reasons for this:

1. Scale – the original scale of the topic proposal was too broad to be executed within the time frame and funding available
2. Priority – Major trauma was one of NHS England's key priorities for development
3. Parallel developments – work was already underway within the Clinical Reference Group (CRG) for Major Trauma to develop a more standardised Rehabilitation Prescription (RP) and there was a wish to avoid duplication.

3.1.2 Procurement and contracting

Following the Scoping Workshop in 2013, HQIP put out a call for tenders to deliver the NCASRI audit. The contract for the provision of the NCASRI was awarded to the London North West Healthcare NHS Trust (NWLHT) in 2015. Led by Prof Lynne Turner-Stokes, it is undertaken in a tripartite collaboration between:

- The UK Rehabilitation Outcomes Collaborative (UKROC) at Northwick Park Hospital
- The Trauma Audit and Research Network (TARN) at Manchester University
- The Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation at King's College London.

Key stakeholder groups were identified as follows:

- The BSRM Trauma Rehabilitation Working Group(chaired by Dr Judith Allanson) providing oversight and direction, while supporting the engagement of the Consultants in Rehabilitation Medicine (RM) in the audit.
- The Clinical Reference Groups (CRGs) for 'Major Trauma' and for 'Specialist Rehabilitation' providing oversight and direction for the audit process and supporting engagement of NHSE commissioners for implementation of recommendations. Both CRGs include active Patient and Public Involvement (PPI) membership.

3.1.3 Adjustments to the tender at contracting

The original tender for the NCASRI programme included two feasibility studies:

- Element 3: to explore the feasibility of capturing data on patient- and carer- reported outcomes and experience (PROMs/PREMS), including vocational outcomes. This was to be conducted by TARN in partnership with Quality Health through interviews and questionnaires using appropriate validated and piloted tools.
- Element 4: to explore the feasibility of identifying the pathway and outcomes for patients who required specialist rehabilitation on discharge from MTCs, but did not subsequently attend. This element originally included information collected at follow-up interview in Element 3 on the patient's reported experience of rehabilitation and outcomes outwith the Level 1 and 2 services.

In the event, Element 3 was not contracted as NHSE policy no longer supported the collection of PROMS and PREMS and the funding for this element was withdrawn. Element 4, therefore, no longer includes follow-up interviews, but has been reduced to the exploration of what information can be gleaned through linkage with existing datasets such as HES and ONS-mortality data.

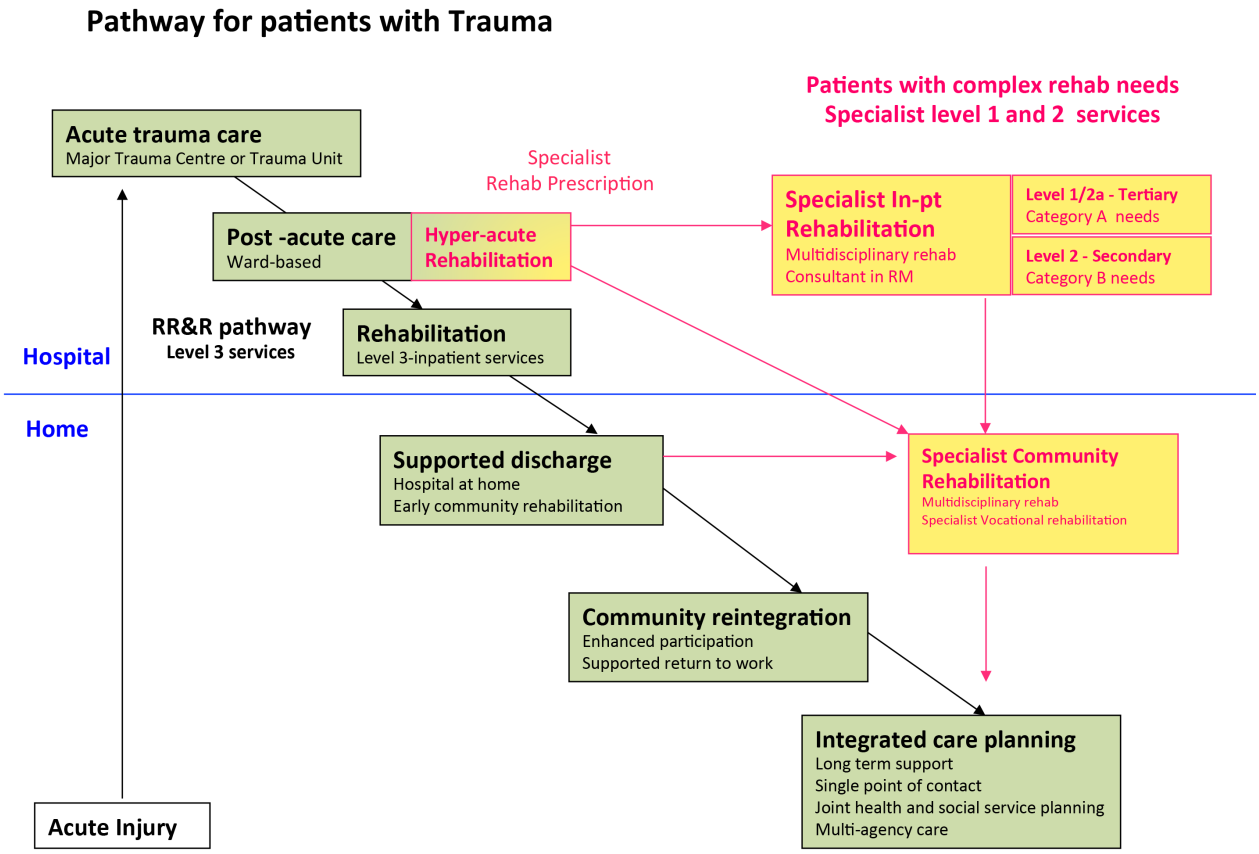
3.2 Setting and standards

The NCASRI audit is undertaken against a background of continuing development of the Major Trauma Networks (MTNs). Regional trauma networks are now well-established in England, and 22 Major Trauma Centres (MTCs) treat adults with major traumatic injuries, with a series of Trauma Units (TUs) providing more locally-based trauma care.

The MTCs were established to carry out lifesaving treatments. Once patients are stabilised they should be transferred promptly to the next stage of care to avoid blockages in the pathway. At this stage:

- Some patients will still require acute hospital treatment and are repatriated to their local Trauma Unit (TU) for further trauma care
- Others may be discharged directly to the community
- However, a proportion will require a period of in-patient rehabilitation before they are ready for transfer to the community. The rehabilitation pathways are summarised in Figure 1.

Figure 1: Rehabilitation pathways following major trauma



Specialist rehabilitation is also provided across regionally-based networks, although these are not necessarily co-terminus with the MTNs.

The NHS England service specification for Specialised Rehabilitation for patient with highly complex needs[9] identifies 3 levels of service and four categories of rehabilitation needs (A-D). Following major trauma, the majority of patients have category C or D needs, and will make a good recovery with the support of their local (Level 3) rehabilitation services. However a small number will have more complex (category A or B) rehabilitation needs requiring the skills and facilities of a specialist (Level 1 or 2) in-patient rehabilitation unit to make the transition from hospital to the community and to maximise their recovery of physical, psychological and social function.

In addition to optimising outcomes for patients and their families, specialist rehabilitation services (Level 1 and 2) therefore form a critical component of the trauma pathway by moving patients to the most appropriate care setting, thus relieving pressure on acute care beds and enabling the MTNs to function efficiently.

3.2.1 Reference standards and performance indicators.

Reference standards and indicators are drawn from the following national clinical guidelines and standards documents shown in Table 1.

Table 1: Key standards and Guidelines

Year	Standards document	Source
2005	The National Service Framework (NSF) for Long term neurological conditions (LTNC)	DH*
2009	NICE guidelines for Rehabilitation after Critical Illness	NICE**
2009	Standards for Rehabilitation Services mapped on the NSF for LTNC	BSRM***
2015	Specialisation in Neurorehabilitation Services	BSRM
2013	Core Standards for Rehabilitation following Major Trauma	BSRM
2010	The NHS Clinical Advisory Group Report on Regional Networks for Major Trauma	NHS England
2014	Service specification for Major Trauma	NHS England
2014	Service specification for Specialist Rehabilitation for patents with Highly Complex Needs	NHS England

*Department of Health; **National Institute for Health and Care Excellence; *** British Society of Rehabilitation Medicine

Performance indicators are intended to provide a valid measure of a provider's quality of care. The NCASRI audit examines the quality of specialist rehabilitation received by patients with complex needs following major injury, including:

- At service level: structure, organisation and pathways
- At patient level: needs, inputs, processes and outcome.

The performance indicators will include:

- Process of care, including the identification of rehabilitation needs while in the MTCs
- Assessment and transfer to Level 1 and 2 specialist rehabilitation units
- Quality of care, including outcomes and cost-efficiency within the specialist rehabilitation services.

Further detail about how expected performance will be evaluated and compared is provided in the Analysis plan (Appendix 1)

3.2.2 Major Trauma Networks (MTNs)

The National Confidential Enquiry in Patient Outcome and Death entitled 'Trauma Who cares?"[10] drove the need for the establishment of Major Trauma Networks (MTNs). The first four MTNs were established in London in 2010. The rest of England followed in 2012, following a report to the Department of Health by the NHS Trauma Clinical Advisory Group (Trauma CAG) entitled "Regional Trauma Networks for Major Trauma" in 2010[·]. Although this Trauma CAG report recognised the importance of early and specialist rehabilitation in managing flow and removing bottlenecks in the acute patient pathway, most of the emphasis in planning and implementation was on the development of the acute and frontline services. As with the establishment of the stroke networks, rehabilitation was added as something of an afterthought – and in some cases not at all. This may have adverse consequences both for individual patients and for the efficient operation of the MTNs.

However, the Trauma CAG report 2010 was the source publication for recommendation of the "Rehabilitation Prescription" (RP) for severely injured patients, setting out the patients needs for further rehabilitation after they leave the MTC. The term attracted some controversy at the time, but was coined not to suggest that a doctor should 'prescribe' the type and amount of rehabilitation, but to indicate that recommendations for rehabilitation should be regarded with the same importance and priority as any other treatment or intervention prescribed on discharge from the MTC.

[·] The Trauma CAG Report 2010 is not included in the reference list as it is no longer accessible on line, but a pdf copy is available upon request to the NCASRI team.

3.2.3 British Society for Rehabilitation Medicine (BSRM) Core Standards for Trauma

The BSRM published its Core Standards for Specialist Rehabilitation following Major Trauma in 2012[11].The standards recommend that patients who are likely to have complex needs requiring further specialist in-patient rehabilitation should be assessed by a Consultant in Rehabilitation Medicine (RM). If confirmed as having category A or B needs, they should receive a "Specialist Rehabilitation Prescription" (SpRP). This should document their requirements for treatment in a Level 1 or 2 rehabilitation service, and ensure a timely referral to an appropriate rehabilitation centre according to their individual needs.

The SpRP recommended by the BSRM does not replace the RP, but builds on it through the addition of four validated standardised tools to identify patients with complex needs and to describe and justify their requirements for specialist rehabilitation. These tools are:

- The Neurological Impairment Set for Trauma (NIS-Trauma)
- The Patient Categorisation Tool (PCAT)
- The Rehabilitation Complexity Scale (RCS-ET)
- The Northwick Park Dependency Score and Care Needs Assessment (NPDS/NPCNA)

The purpose of each of these different tools within the audit is described in section 4.2.

3.3 The problem addressed by NCASRI

The BSRM standards for specialist rehabilitation within the major trauma pathway were aspirational. Moreover, there is a recognised disparity in equity and access to specialist rehabilitation services across the country which was specifically demonstrated in our First Year NCASRI report.

The NCASRI audit addresses this problem, which is illustrated in Figure 2.

- In an ideal world, patients with category A or B needs requiring further specialist inpatient rehabilitation would be identified in the MTCs and transferred promptly into a Level 1 or 2 specialist rehabilitation service as soon as they are ready to leave the MTCs (the so-called 'Transfer Ready' (TR) point).
- The reality is that, due to insufficient capacity in the Level 1 and 2 rehabilitation services, patients are often repatriated to their local trauma unit (TU) or district general hospital to wait for a specialist rehabilitation bed to become available.
- We know that many patients do not actually get to the Level 1 or 2 services, but we do not know why. It may be that their needs have changed and they no longer need these services, or that they simply get lost in the system.
- A key component of NCASRI will be to link the Trauma Audit Research Network (TARN) and the UK Rehabilitation Outcomes Collaborative (UKROC) datasets. This will enable us, not only to track patients in their journey from the MTCs to the specialist rehabilitation services, but also to determine the extent to which the pathways are explained by patient needs or by service capacity and provision.

In other words, NCASRI will perform the usual roles of a national clinical audit, by examining performance of current service against the expected standards and performance indicators. In addition, it will provide important information to improve our understanding of the clinical pathways and trajectory of recovery for a group of patients about whom little is known at present.

3.4 Key aims of the prospective audit in NCASRI

NCASRI aims to enrol all adult patients in England who require specialist inpatient rehabilitation to maximise their recovery from severe injury following acute treatment in an MTC.

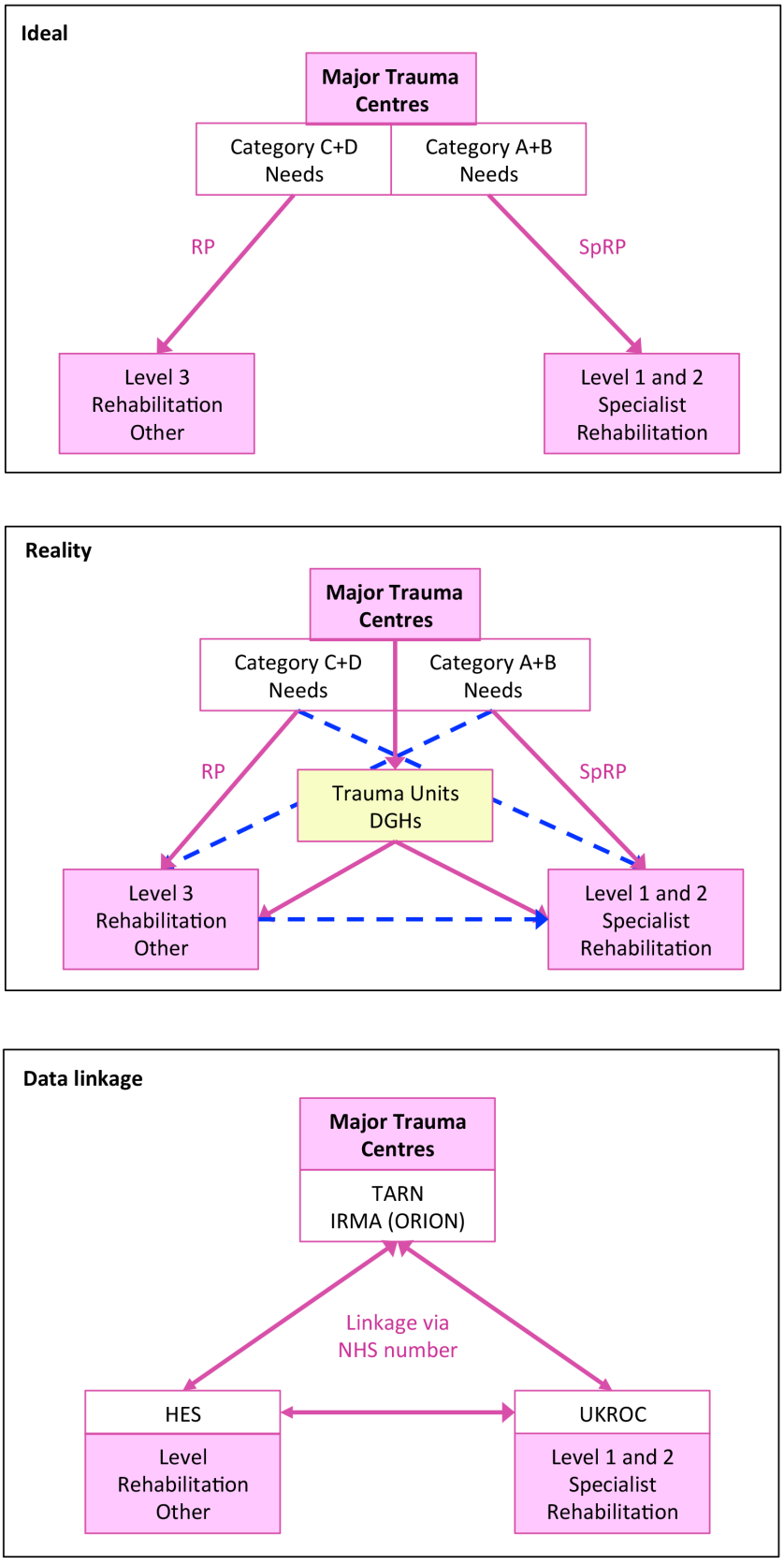
Eligible patents are severely injured adults (16+ years with ISS ≥9) who require specialist in-patient rehabilitation (category A or B needs) at the "transfer-ready" point or on discharge from an MTC.

Key objectives are:

- To determine the proportion of eligible patients who are subsequently admitted to a Level 1 or 2 specialist rehabilitation service.
- To examine how well their needs are met and the outcomes from rehabilitation in terms of functional gain and cost-efficiency.

Unfortunately it is beyond the scope of the audit, as currently commissioned, to determine in detail what happens to those patients who require specialist rehabilitation but do not subsequently receive it. However, we will explore the feasibility of obtaining information about alternative pathways of care (ie the other forms of inpatient rehabilitation that patients access) from existing NHS datasets (eg Hospital Episode Statistics (HES) data).

Figure 2: The problem illustrated and data linkage to capture it

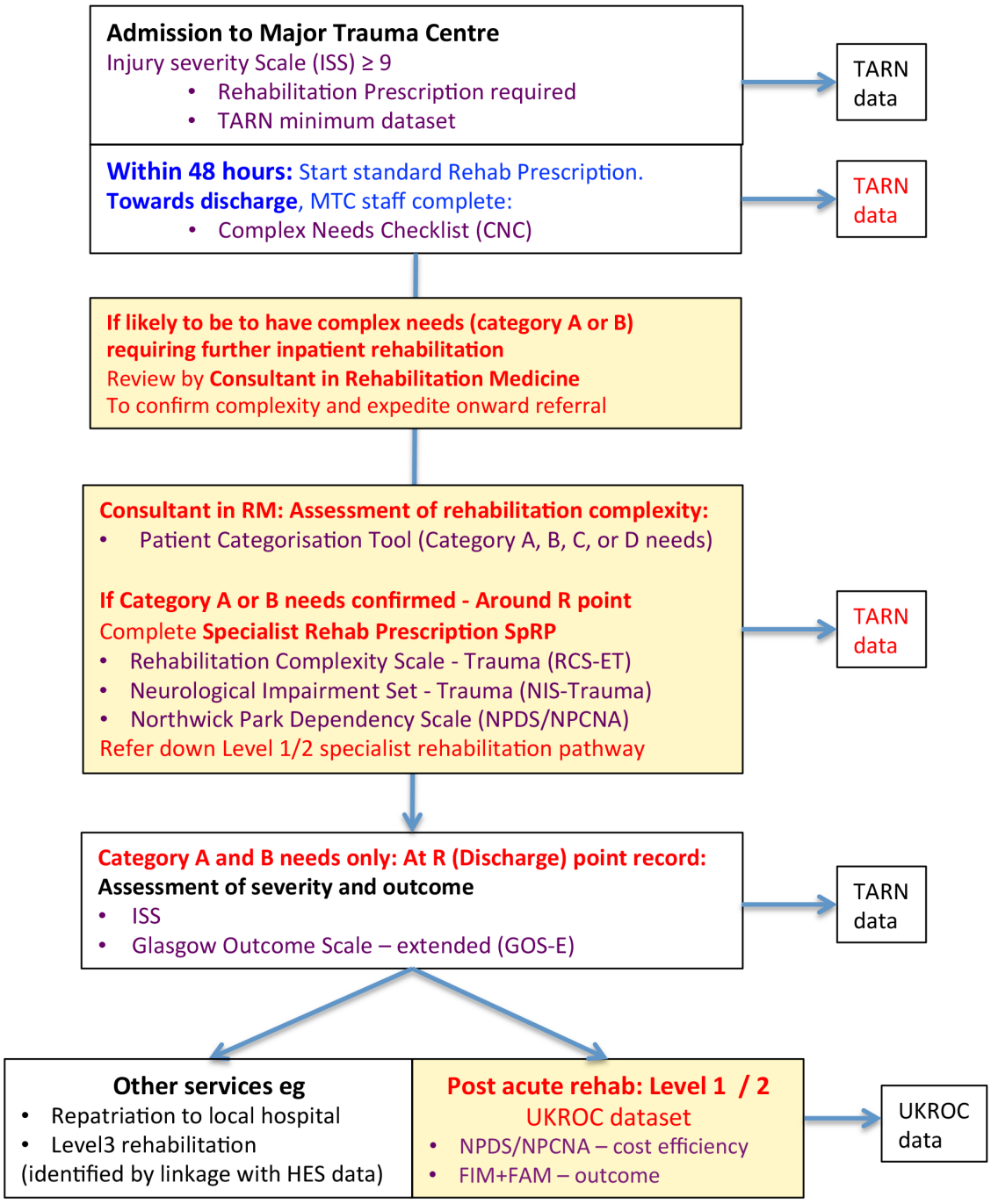


(DGH = district General Hospital, TARN = Trauma Audit and Research Network; IRMA =Integrated Rehabilitation Management Application on the ORION cloud-based platform); HES= Hospital Episode Statistics; UKROC = UK Rehabilitation Outcomes collaborative)

3.5 Proposed overview of patient pathways and data collection for NCASRI

Figure 3 summarises the patient pathway and data collection for NCASRI adapted from the standards proposed in the BSRM Core Standards for Rehabilitation following Major Trauma[11] for the first year prospective audit.

Figure 3: Patient pathway and data collection according to the BSRM standards



The NCASRI audit builds on the existing mandated data collection within the TARN and UKROC datasets, but adds a limited set of tools to identify and describe patients with complex rehabilitation needs in the MTCs.

3.5.1 Operationalisation

This data collection was operationalised within the actual patient pathway as follows:

- Patients admitted to the MTCs with severe injury (Injury Severity Score ISS ≥9) require a Rehabilitation Prescription (RP) which is recorded on TARN as part of the minimum dataset to receive Best Practice Tariff as an MTC.
- The RP should be commenced within the first 48 hours, but it is often completed once the rehabilitation needs of the patient have been assessed and defined, to enable referrals to appropriate rehabilitation units- or at discharge from the MTC.
- The TARN minimum data set for the RP requires four questions to be answered:
    - Does the patient have a) Physical, b) Cognitive/Mood or c) Psychosocial problems?
    - And do they have rehabilitation needs requiring an RP?

  These are the only four data fields currently required to receive best practice tariff.
- For the NCASRI audit, MTC staff were requested to complete the Complex Needs Checklist (CNC) for patients whom they consider to have complex rehabilitation needs requiring further in-patient rehabilitation. The CNC is a checklist outlining the nature of the needs for rehabilitation.
- If the CNC indicates that the patient is likely to have category A or B needs, then they request assessment by a Consultant in Rehabilitation Medicine (RM).
- The Consultant in RM (or designated deputy) uses the Patient Categorisation Tool (PCAT) to confirm whether or not the patient has complex needs requiring further in-patient rehabilitation in a Level 1 (category A needs) or Level 2 (category B needs) specialist rehabilitation unit.
- Subsequently, the rest of the specialist rehabilitation prescription (SpRP) is completed for patients with category A or B needs at the 'R point' (when the patient is ready to leave the MTC and be transferred to rehabilitation).
- The SpRP describes and quantifies their impairments, level of dependency and their types of need for rehabilitation; and their requirements for medical, nursing and therapy input. These are collected using validated standardised tools:
    - The Rehabilitation Complexity Scale for Trauma (RCS-ET) details resource requirements for medical, nursing and therapy input, and also equipment/facilities
    - The Neurological Impairment Set for Trauma (NIS-Trauma) details the severity of impairment
    - The Northwick Park Dependency Score and Care Needs Assessment (NPDS/NPCNA) details nursing and care needs and ongoing costs of care in the community.
- At the R point, patients with category A or B needs requiring further inpatient rehabilitation should ideally be transferred directly to the specialist rehabilitation unit. In practice, they are frequently repatriated to their local hospital or Trauma Unit to relieve pressure on MTC beds whilst they wait to be admitted for inpatient specialist rehabilitation.
- At the time of discharge from the MTC, TARN offers the option to record a crude assessment of outcome using the Glasgow Outcome scale (GOSE), although it is not clear how often this is completed by the MTCs. TARN is also piloting patient reported outcomes (PROMS and PREMS) six months after discharge. These data are not formally part of the audit but will be included in the analysis if available. However, many eligible patients are still undergoing rehabilitation at 6 months.

- Patients who are subsequently admitted to a specialist Level 1 or 2 rehabilitation service have the UKROC dataset completed on admission and discharge, as a commissioning requirement for these services. This includes evaluation of their outcome from rehabilitation in terms of:
    - Change in their levels of functional independence (measured using the UK Functional Assessment Measure (UK FIM+FAM) and
    - Reduction in the on-going costs of caring for them in the community (measured by the NPDS/NPCNA).
    - Cost efficiency - measured in terms of the time taken for savings in on-going care to offset the cost of the rehabilitation episode.

3.5.2 Data linkage

Data linkage between the TARN and UKROC databases will collate the data for patients who have category A or B needs on leaving the MTCs, and who are subsequently admitted to specialist rehabilitation units. It will evaluate the quality of care and outcomes. Through data linkage with HES, NCASRI will also explore the feasibility of ascertaining which other rehabilitation services were accessed by patients who do not receive the Level 1 and 2 rehabilitation.

3.6 Patient and Public Involvement (PPI)

Patients and public have been involved in all aspects of design and planning of this audit:

- UKROC, TARN and KCL all have their own established PPI groups, and there is PPI representation on the NCASRI Programme Board
- PPI members were actively involved within the CRGs for both Major Trauma and Specialist Rehabilitation that oversaw the development of NCASRI from preparation of the initial topic proposal to development of NCASRI project plan as this matured.
- A group of PPI members provides a sounding board providing direct feedback to the NCASRI project team, as well as being involved in the various stakeholder workshops.

Particular concerns raised by PPI members that will be addressed by this audit are:

- Lack of continuity of care between acute care services and rehabilitation.
- Insufficient capacity within the existing rehabilitation services to meet the needs of patients requiring on-going rehabilitation after major trauma – particularly for patients with non-neurological injuries.
- Repatriation to local general services that are ill equipped to manage patients with complex needs, as opposed to timely transfer to specialist rehabilitation.

3.7 Term

The initial contract for the NCASRI audit is for three years with the potential to extend for an additional two years subject to approval by NHSE. The scope of NCASRI was restricted to Level 1 and 2 specialist rehabilitation, partly because further development work on the standard Rehabilitation Prescription (RP) was already underway and there was no desire to duplicate this. However, it was anticipated that these two strands of work would come together if the programme continued into Year 4-5.

A key purpose of the NCAPOP is to embed data collection into routine clinical practice after the end of the funded audit. Years 1-3 therefore include preparatory work (analysis of data and exploration of feasibility with teams on the ground) towards a reduced dataset in years 4-5. The ultimate aim is to hone data collection down to a core dataset that is feasible for use and informs clinical decision-making so that teams on the ground actually want to continue to implement it as part of their everyday practice going forward. It is likely, however that it will, require more than one round of audit to achieve this goal.

4 Challenges for NCASRI

NCASRI is unusual for an NCAPOP audit in that it encompasses a very small number of patients with highly diverse needs, managed across an equally diverse range of services. A number of challenges were recognised from the outset that would require the NCASRI team and HQIP to work closely together in problem-solving mode. These are discussed below.

4.1 Low base of knowledge and service provision

NCASRI started from a very low base of both data recording and service provision. At the outset:

- We did not know where the services were, how the MTCs and specialist rehabilitation services connected with each other, or how they were staffed.
- Neither did we know how many patients in the MTCs required specialist rehabilitation. In the absence of linkable data, we had no idea how many patients who were admitted to Level 1 and 2 rehabilitation services had come via the trauma networks.
- The need for a 'Rehabilitation Prescription' (RP) was widely acknowledged, as it was a mandated requirement for the enhanced 'best practice tariff' in the MTCs. However, as noted above, qualification for the tariff required the completion of just 4 data fields in TARN.
- There was no consistent assessment or data collection on the type of rehabilitation needs within the MTCs.
- Although the BSRM had recommended the SpRP tools, there was little information about how MTCs were using them – if at all.

The organisational audit conducted in the first year of NCASRI provided some information about the issues above, but the answers were not encouraging:

- The Trauma CAG 2010, and the NHS England (NHSE) Service Specification for Major Trauma[12] had both recommended the appointment of an RM consultant as Director of Rehabilitation in every MTN, to support strategic development and provide clinical leadership of acute trauma rehabilitation services. In fact, just 12/22 MTNs had an RM consultant in this role and 5 did not have a Director of Rehabilitation at all, leaving a major gap in clinical leadership for trauma rehabilitation.
- RM Consultant input into the MTCs also varied widely, with half the MTCs receiving visits just once a week or less often, and 4/22 MTCs having no RM consultant input at all.
    - London was particularly poorly served - none of its four MTNs had a Director of Rehabilitation with a background in RM, and (perhaps as a result of this) there was just one funded RM consultant session between all the four networks.
- In the absence of central guidance on what form the RP should take, individual MTCs had each developed their own systems with little commonality between them.
    - Some used an electronic RP (50%), some used a paper form (36%); and others used a combination of the two (14%)
    - Some gave the RP to the patients (36%), others used it for inter-professional communication only – and some seemingly just filed it in the notes.
    - Most of the information in RPs was collected in text form only.
    - Locally produced RPs were in very different formats with little or no comparable information other than the 4 mandated fields of the TARN Minimum Dataset.

- With respect to the SpRP:
    - Half of the MTCs did not use any of the SpRP tools at all, and only 1 used all of them.
    - There was no central repository for collecting the SpRP data and, where tools were being used, they were often applied using local house rules and integrated into local computer systems in a form that differed substantially from the original tools so that data recorded were no longer comparable.

4.2 Choice of audit tools

The SpRP tools each have a different purpose:

- The Complex Needs Checklist (CNC) is designed as a screening tool to assist clinical teams to identify patients with complex needs who may require referral for further specialist in-patient rehabilitation.
- The Patient Categorisation Tool (PCAT)[13] details the types and complexity of rehabilitation need in accordance with the NHSE service specification criteria. Completion of the PCAT is a requirement for admission to Level 1 and 2 services and is often used by those services as part of their pre-admission assessment. It provides the definitive classification of category A and B needs.
- The Rehabilitation Complexity Scale for Trauma (RCS-ET)[14] is a measure of resource requirements (medical, nursing and therapy inputs) to meet the complex needs for rehabilitation. While it correlates with the PCAT and CNC, it describes the service elements, rather than individual patient characteristics. It cannot be used alone to describe category of need. However serial collection of the RCS-ET Medical score can be used to identify the 'Transfer Ready' (TR) point – the point at which the patient's medical needs could be met in a rehabilitation setting as opposed to an MTC or trauma unit.
- The Neurological Impairment Set for Trauma (NIS-Trauma) [11, 15] details the type and severity of impairment. It is generally acknowledged that the Injury Severity Score (ISS) recorded by TARN does not capture the range of impairments that are typically the target for rehabilitation. The NIS-Trauma records neurological and musculoskeletal impairments and their impact on function. It also records co-morbidities.
- The Northwick Park Dependency Score and Care Needs Assessment (NPDS/NPCNA)[16] details nursing and care needs and estimates the on-going costs of care in the community. It is used to demonstrate the cost benefits of rehabilitation – and in this context to help us estimate the cost of the NHS of not providing timely specialist rehabilitation.

The SpRP tools are available for download on the NCASRI website[5].

It was acknowledged from the outset that some of the tools (especially the PCAT, NPDS and NIS) were detailed instruments that could create a considerable burden of data collection, especially for teams who were not familiar with them. There were detailed discussions with stakeholders about whether to include all, or just some, of them - with arguments both for and against their inclusion.

After considerable debate, we decided to include all of them in this first round for the following reasons:

1. Each of the tools has an identified purpose and had their own strong proponents who argued for their inclusion.
2. The enrolment rate in each MTC was expected to be quite low with an average of perhaps 1-2 patients per week, so that the overall data burden would not be so great, especially once the teams became familiar with the tools.
3. Given the small numbers expected, the NHSE would expect a reasonably rich and informative dataset to justify their investment in the audit.

It was agreed that the tools would be reviewed at the end of the first round. Their inclusion going forward would depend on the rates of completion and their contribution to the data analysis, which are summarised in our draft Analysis Plan (see Appendix 1).

4.3 Engagement of teams on the ground

When approached by the NCASRI team to engage in the audit, many MTC teams reported that they already felt overwhelmed by the clinical load and the lack of local resources to enter even the TARN data. So the fact that participation in the NCAPOP programme is a requirement under the terms of the National Standard Contract meant little to the teams on the ground, who were struggling to cope as it was. A substantial role for the NCASRI team was therefore to work with the individual MTCs to try to engage staff and to find solutions that would fit in with their local practice and systems, avoiding duplication so far as possible, but still ensuring data collection in a form that would be comparable.

In order to support engagement, the NCASRI team worked individually with each MTC to determine to most effective method of data collection locally. A variety of different data collection platforms and methods were made available which included using:

a) The TARN database

b) The Integrated Rehabilitation Management Application (IRMA) in the ORION platform

c) Their own local computer system

d) A paper proforma for collection/data entry by the NCASRI team, directly into the UKROC database.

The start date for the prospective audit was at the beginning of the second year in July 2016. Again it was acknowledged that this was a difficult time to start new data collection, but the tight time frame for the first 3 years did not permit delay. In the event just 9 MTCs were able to start data collection in July; a further 3 started by September and 4 more joined later in the year. In June 2017, there were currently 16/22 MTCs participating (see Section 6). Because fewer than half the MTCs started prior to September 2016, the NCASRI Programme Board has agreed to extend enrolment for the first audit round until the end of August 2017, to increase the likelihood of achieving representative data.

Despite this slightly slow start, the majority of MTC teams have responded magnificently and have increasingly gained momentum. We are extremely grateful for their hard work and enthusiasm despite being clinically over-stretched.

Of the six MTCs currently not participating, four had no RM consultant input, but two were well supplied with consultant sessions (see section 6). Their lack of participation is less easy to explain, other than on the basis of a lack of strong local leadership for the monitoring and development of trauma rehabilitation services – or perhaps a lack of appreciation of the potential impact of the NCAPOP audit programme.

4.4 Timescale for completion of rehabilitation

As originally planned, the prospective NCASRI audit was based on an 18-month cycle. We estimated that the large majority of trauma patients would filter through to UKROC within 6 months of discharge from the MTC, so that 6 months post injury would be an appropriate timescale for data linkage.

In fact, as demonstrated in the analysis of UKROC data in our first year report, this would have captured only 50-75% of patients. Given the small total numbers anticipated, even a 25% attrition rate is highly significant.

- The upper quartile for the delay between referral and admission was 3 months, following which patients stay up to 6 months in rehabilitation on the standard contract, although 10% stay longer.
- The UKROC database records episodes after discharge from specialist rehabilitation and, allowing for a 1 month 'flex and freeze' period for data corrections, reliable episode discharge data do not appear in UKROC until 2 months after discharge for the rehabilitation service.
- In total, therefore, it is necessary to allow 12 months before non-appearance in the UKROC database provides a reasonable level of certainty that a given patient has not been admitted for specialist rehabilitation.

Going forward this mean that each audit cycle should be over 2 years, allowing for 12 months of enrolment through the MTCs and up to 12 months for the cohort to appear within the UKROC database.

4.5 Data linkage and permissions

A key component of NCASRI is to link data from the TARN and UKROC datasets, using the NHS number, in order to track patients along their journey from the MTCs to the specialist rehabilitation services and to examine the outcomes and cost efficiency of rehabilitation for patients with major trauma. The linkage methodology is outlined in the NCASRI Analysis plan (see Appendix 1)

At the start of this audit, TARN already collected the NHS number but UKROC did not. However, since July 2015 (coinciding with the start date of NCASRI), UKROC has been commissioned directly by NHSE to provide the national commissioning dataset for all Level 1 and 2 rehabilitation services in England. Under the terms of NHSE contract, UKROC was mandated to provide identifiable patient level activity data to flow through to the Data Service for Commissioners Regional Offices (DSCROs) for contract and performance monitoring of the various service providers.

In addition, patients with complex disability following severe illness or injury form a vulnerable group of people for whom services are scarce. Clinical care can easily become fragmented as patients move between services (often over a wide geographical area) – and some patients literally get lost in the system. In line with the principles of the Long Term Neurological Conditions Dataset (from which it was originally developed) UKROC was also seeking registry status, to enable use of the NHS number to support tracking and longitudinal monitoring for clinical purposes as patients move from one service to another.

UKROC therefore required permission to collect and hold the NHS number for three different purposes - clinical, commissioning and audit. Each of these had a different legal basis requiring a separate permissions process. In short:

- Audit: Since 2013, the Health Research Authority (HRA) Confidentiality Advisory Group (CAG) is responsible for authorising the collection of identifiable patient data for the purpose of audit and research under Section 251 (s251) of the NHS Act 2006, where it is not possible to use anonymised information and where seeking consent is not practical (having regard to the cost and technology available).
- Clinical: s251 does not cover collection for clinical purposes. This requires permission from the Caldicott Guardians for each of the service providers who contribute to the dataset.
- Commissioning: In 2015-16 it was far from clear what the process was and whether s251 was required for commissioning purposes.

In addition to seeking guidance from the Information Governance Lead at LWNHT, we consulted extensively with the HRA CAG helpline, with NHS England and with a number of key Caldicott Guardians, who were kind enough to offer advice (two of whom had also served on the HRA CAG). We also engaged in lengthy dialogue with NHSE between March 2016 and Jan 2017.

At first sight the simplest solution would have been to apply for s251 permission for NCASRI alone. However, there were two significant problems with this approach:

1 CAG permissions have a short time span (usually 18 months at most) and are specific to the given project. If retension of the NHS number relied on the NCASRI audit alone, permissions would cease at the end of the project. The NHS numbers would then have to be deleted and lost to future use. So whilst the permission could be renewed for the duration of the NCASRI, it would not underpin the embedding of data collection into routine practice thereafter, despite this being a long term aim of the NCAPOP programme.

2 CAG permissions are based on the minimum dataset possible to fulfill the aim. As reliable identification of major trauma patients was not possible within the UKROC dataset, we would have had to request the NHS number for all patients in order to pick up the number (possibly 5% or less) who had come through the MTCs. This broad-based data capture was thought likely to pose a barrier to successful application.

On the other hand, if UKROC already had permission to collect and retain the NHS number for clinical and commissioning purposes, then we only had to ask for s251 permission to use the NHS number to link the NCASRI data. Not only was the application more likely to be successful, but there would be no loss of data if the s251 permission lapsed.

In reality, we did not need to use the NHS number for data linkage until patients discharged from the MTCs were reasonably likely to have completed their rehabilitation programme and appeared in the UKROC database. As noted above, this will take 12 months in some cases. Therefore, the earliest possible linkage date between TARN and UKROC would be June 2017. Consequently, although the NCASRI 'contract deliverables' set a notional date for achievement of s251 permission as December 2015, we took the advice of the HRA CAG, Caldicott Guardians and NHSE to seek permissions to hold the data for clinical and commissioning purposes first; and then to apply for s251 for NCASRI primarily for linkage on the basis that those other permissions were (or would be) already in place. The HQIP team was kept appraised of these developments throughout this process.

We wrote to the Caldicott Guardians for all the contributing service providers, requesting permission to collect and store the NHS number for clinical purposes. This in itself was a labour-intensive process. Repeated emails and phone calls were often required to get a response, and subsequently we completed many individual data-sharing request forms for different providers. By the time we submitted the s@251 request to the HRA CAG in July 2016, this process had been underway for over 6 months, and 80% of those permissions were in place. At the time of writing this report, we now have permissions confirmed (or in principle pending data sharing agreements) for 94/95 (99%) of service providers.

We also corresponded at length and over several months with NHSE and HSCIC (subsequently NHS Digital), who were themselves working to establish and define the legal basis for collection of identifiable data for the purpose of commissioning.

Based on these permissions, we prepared our s251 request for NCASRI primarily for linkage between the TARN and UKROC datasets, and also with HES and ONS data. It was submitted to the HRA CAG on 18th July 2016, and approved in January 2017.

In January 2017 we also received the following confirmation from NHSE

> *"s251 is not required for commissioning… The NHS Directions set out the legal basis upon which data are provided to NHS England as outlined in schedule 6 of the NHS Contract. They direct the collection of data required for commissioning purposes and specifically refer to the collection of data from clinical registries… The Directions also refer to the Prescribed Specialised Services Manual which clarify that NHS England are the responsible commissioner for this service and requires the relevant information in order to be able to meet our statutory duties.*
> *The route for the provision of this data is via the Arden and Gem Data Services for Commissioners Regional Officer (DSCRO) who process identifiable data on behalf of NHSE in line with the requirements of the Health and Social Care Act 2012… The data is processed by the DSCRO and anonymised in line with the ICO Anonymisation Code of Practice before flowing to the appropriate NHS England team for analysis.*

4.5.1 Linkage with HES and ONS

The purpose of linkage with HES and ONS Mortality data was to explore the feasibility of identifying alternative pathways of care accessed by patients who survived following severe injury and were identified as having complex rehabilitation needs in the MTCs, but who never reached a Level 1 or 2 specialist rehabilitation service.

Permission for linkage with HES and ONS data is obtained through application to the Data Access Request Service (DARS) in NHS Digital (previously the Health and Social Care Information Centre (HSCIC).. Following discussion with NHS Digital, we were advised that:

a) There is a short window for data access following the request being granted and a limited number of times that it can be extended
b) The more targeted the request and the smaller the volumes of data, the more likely the request is to be granted.

The DARS request would therefore need to be timed accordingly because otherwise permission will 'time out' before we are able to execute it.

In this audit, we only need to know which alternative inpatient rehabilitation services were accessed by patients who were not admitted to Level 1 and 2 services. The NHS numbers of these patients will only be available after 12 months, once the TARN and UKROC data are linked. Therefore, we will only be able to submit a DARS query 12 months after the end of the enrolment period. Given that the 3 year audit period ends in June 2018, the earliest date for which we could set the enquiry would be March/April 2018. The DARS application is now in process with this timescale in mind.

4.5.2 Lessons learned

Section 251 approval was set as a deliverable for this audit to be achieved within the first 6 months of this audit. With hindsight this was not only unrealistic but short-sighted as, even if obtained, the permission that we could have sought at that stage would have lasted only as long as the audit.

By taking a more holistic approach, we now have sustainable permissions in place to continue to embed the collection of patient identifiable data into clinical practice. This will support the continuation after the NCASRI programme finishes. We have described the process in detail here because we believe that this is an important lesson in sustainability not only for NCASRI, but also for HQIP and potentially for other NCAPOP audits.

4.6 Software development

Allowing the use of multiple platforms for data entry within the MTCs has posed significant challenges for software development to support data linkage. The UKROC data manager has worked with each of the IT managers in TARN, ORION and the local hospital using its own system, to try to ensure that data are collected in a consistent form that can be uploaded and linked with UKROC. Even so, as the data come through, we have found glitches that have required correction by hand. For this first round of the audit, it has been simpler in some cases for the NCASRI team just to re-enter the data directly from the paper forms into the UKROC software.

Given the relatively small numbers involved at this stage in the audit, this has proven manageable, but is not sustainable going forward. For future rounds, we recommend that all MTC data should be uploaded onto TARN, and then all future linkages will just be between UKROC and TARN.

4.6.1 Reporting of NHS numbers

Quality reviews of the MTC data collated to date confirm reasonably good compliance with recording of the NHS numbers. Level 1 and 2 service providers have been made aware of the requirement to record NHS numbers from April 2016, but compliance within the UKROC dataset is currently undergoing checks.

The UKROC software is based on Microsoft Excel, held locally by providers. Data are exported at monthly intervals and transmitted securely to UKROC via NHS Netmail for upload into the central database. Annual updates to the software are released in March/April for the beginning of each new financial year. One of the challenges for this data collection system is that Microsoft releases updates for Excel at regular intervals, and these frequently require updates to the UKROC software to ensure that the extensive 'macros' and complex formulae programmed within the software still work. In the long term UKROC is likely to transfer to an alternative platform, but in the meantime these features are essential to create the calculated fields and user-friendly outputs that have been so important in engaging clinicians to use the software.

The UKROC software held locally by each rehabilitation provider service includes identifiable data fields (name, date of birth NHS number). Until 2017, these fields were automatically excluded from the exported pseudonymised dataset, when these were submitted to UKROC, leaving just the UKROC ID available in the central UKROC database. The 2017 UKROC software update now exports the NHS number and date of birth. The downloads include retrospective data and all Level 1 and 2 services are being asked to make certain that the NHS number is included for patients admitted back to April 2016.

Unfortunately in March 2017, Microsoft issued an update that caused Excel documents with complex formulae to crash. Although Microsoft corrected this with a further update the following month, this bug in software updates came at a critical time causing the roll out of the UKROC 2017 software update to be put temporarily on hold while the bug was fixed.

The various rehabilitation services have different response rates for installing software updates. As yet we do not know how many service providers have successfully migrated to the new UKROC software. We are currently in the process of checking the monthly data uploads and providing support to those providers who are not yet submitting their NHS numbers, ahead of the first data linkage.

4.7 Feedback from MTC teams – lessons learned

Throughout this first year of prospective data collection for NCASRI, we have listened to the teams on the ground about what is working and what is not in order to try to incorporate their feedback in our plans for future rounds of the audit. Some key lessons learned in this first round are discussed below.

4.7.1 Who completes the SpRP?

The scheme for implementation of the SpRP, as set out in the BSRM Core Standards for Specialist Rehabilitation following Major Trauma and Section 3.5 of this report, was that patients who were likely to have on-going needs for in-patient rehabilitation on discharge from the MTC should be screened by the MTC clinical therapy team using the Complex Needs Checklist (CNC). If the patient was deemed to have complex needs requiring admission to an in-patient specialist rehabilitation service, they should be assessed by a consultant in RM (or their designated deputy) who would confirm their category of need using the Patient Categorisation Tool (PCAT). If category A or B needs were confirmed, the consultant in RM would then complete the rest of the SpRP tools (the NIS, NPDS and RCS-ET).

A preliminary analysis of the data collected in TARN up to March 2017 (see Appendix 2) showed that a third of the units did not have any such consultant input, and on average 65% of the tools were collected by the MDT teams rather than the RM consultant. This was also confirmed by our most recent analysis (see Section 6).

This first round of the NCASRI audit has therefore demonstrated that the scheme originally proposed by the BSRM is not practicable for several reasons.

- Firstly, because many of the MTCs do not have regular input from an RM consultant.
- Secondly, even when they do, it is the MTC teams on the ground who typically have the detailed knowledge of the patient to be able to complete the SpRP tools.

In addition, some of the teams reported that they felt under-valued by the requirement for this to be done by an RM consultant. This is not acceptable.

Going forward, it is absolutely critical to make sure that everyone is working together, that every team member feels included and empowered to contribute to the NCASRI audit. The data may now be completed by any member(s) of the team including doctors, nurses and AHPs – we simply ask that they indicate their discipline and band to enable us to analyse data more effectively. This was communicated back to the MTCs following the workshop in June 2017.

4.7.2 Capturing patients with complex non-neurological needs

Concerns have been expressed that the current NHSE criteria for category A and B needs may not allow inclusion of patients with complex needs for musculoskeletal rehabilitation following severe multiple trauma, as the PCAT was designed primarily for patients with requiring neuro-rehabilitation.

The NCASRI team shares this concern, but this is one of the key purposes of the audit.

- If the tools fail to cater for certain groups of patients, then they must be adapted for future iterations of the audit. That said, however, the evidence to date is that the Level 1 and 2 services do accept patients with non-neurological injuries and that the PCAT does identify complex needs in this group as well, so it may be that this first round audit will serve towards allaying these concerns - or at least defining the way forward.
- The imminent review of the NHSE service specification for specialised rehabilitation services will also provide an opportunity to review and add to the criteria to make sure that patients with complex non-neurological injuries are included where appropriate.

- In light of the recent increase in major atrocity incidents, such as those in London and Manchester, it is important that tools capture the rehabilitation needs of patients with different mechanisms and patterns of injuries such as blast injury, high velocity bullets and dirty bombs. We are also working with the teams who responded to those atrocities to learn the salient lessons that derive from them.

4.7.3 Limitation of the audit to a very small group of patients

Concerns have also been expressed by a number of stakeholders, including our PPI members, about the highly specialised nature of NCASRI, confined as it is to just the small group of patients with highly complex needs, rather than encompassing the wider group with category C and D needs for whom Level 3 rehabilitation services are also sparse.

As noted in Section 3.1 on the history of NCASRI, this is largely out of our hands. The original topic proposal for NCASRI was more widely based, encompassing all three levels of rehabilitation service, but the scope was restricted to Level 1 and 2 specialist rehabilitation by NHSE at the scoping workshop, partly to avoid duplication of the development work on the standard Rehabilitation Prescription (RP) which was on-going through the CRG for Major Trauma.

However, it was always intended that these parallel streams of work should come together more closely for year 4-5. Hence, we have worked alongside the RP Development Group to incorporate the lessons learned from this first round of NCASRI to inform a more integrated process of data collection for the future. Specific recommendations are discussed below.

4.8 Working towards a more manageable and consistent dataset

4.8.1 Preliminary analysis of TARN data to March 2017.

The preliminary analysis of the data collected in TARN up to March 2017 (see Appendix 2) proved highly informative.

- Of the 9 MTCs regularly enrolling patients in the NCASRI audit through TARN:
  - 6 collected the SpRP tools for at least a proportion of their patients.
  - 3 were recording only the CNC and RCS-ET.
- One MTC (Bristol) has helpfully collected the CNC and RCS-ET for all patients requiring rehabilitation at 72 hours post injury, including those with category C or D needs.
  - Although Bristol was not collecting the other SpRP tools, and the timing of their data collection was somewhat anomalous (being at 72 hours rather than at the TR point), this expanded dataset has provided some very useful information about patients with lower categories of need.
  - Notably, through systematic recording of rehabilitation needs, this MTC was reporting many more patients with category A or B needs than any of the other MTCs - suggesting that these patients may be under-identified in other centres – possible due to the excessive data burden of recording the full set of SpRP tools
- In the 84 episodes for which both a CNC and PCAT were recorded, there was 96% agreement in the categorisation of needs. Table 2 shows the agreement between the CNC and the PCAT in the identification of category A and B needs. The CNC assessment identified category A needs (as confirmed by the PCAT) with a sensitivity of 98% and specificity of 91%.

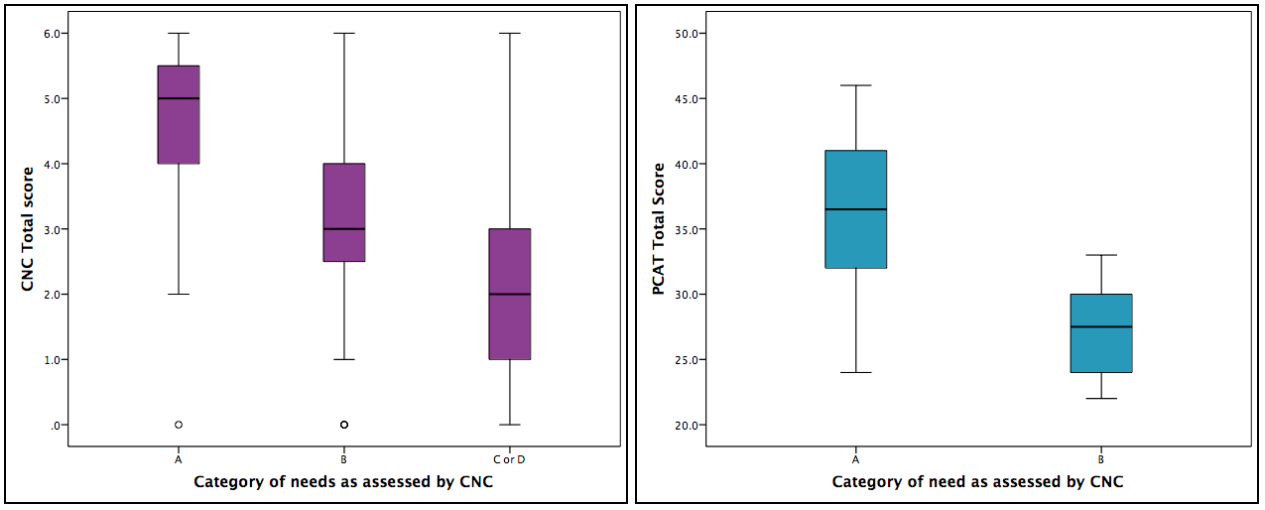
Table 2: Agreement between the CNC and PCAT in the identification of category A and B needs

	PCAT Category A	PCAT Category B	Total	Predictive value
CNC Category A	60	2	62	Positive 97%
CNC Category B	1	21	22	Negative 95%
Total	61	33	84	
	Sensitivity 98%	**Specificity** 91%		

This suggests that the CNC applied by MTC Teams can identify patients with complex category A and B needs with very acceptable accuracy.

There was also some evidence that the CNC could work as a simple 6-point ordinal scale. Figure 4 summarises the distribution of total ordinal CNC and PCAT scores within the different categories of rehabilitation need. The data should be interpreted with some caution, as the majority the CNC data come from one MTC where the CNC was recorded at 72 hours and the Categorisation of need at discharge or transfer from the MTC. Nevertheless, they suggest that the CNC total score may provide a basic ordinal level scale. Whilst scale development is not included within the scope of this audit, this is an interesting observation with potential relevance for future analysis and further research.

Figure 4: Boxplots of the total 6-item CNC and PCAT Total scores in relation to the category of needs



The RCS-ET complements the CNC by providing a measure of the resource requirements in terms of medical, therapy and nursing input. It can also be used to calculate staffing requirements, but in addition, the serial recording of the RCS-ET Medical score may help to identify the 'TR-point' (M scores of 3-4 reflecting the point when patients are medically fit for transfer to rehabilitation as shown in Table 3.)

Table 3: RCS-ET Medical Scores and their descriptors

M Score	Descriptor
6	Requires complex coordinated trauma care only available in an MTC
5	Primary needs are still medical / surgical, requiring acute coordinated trauma care in a TU
4	Still unstable – but can be managed in DGH or in a Hyper-acute rehabilitation unit
3 and below	Could be managed in a Rehabilitation unit with the appropriate out of hours medical cover

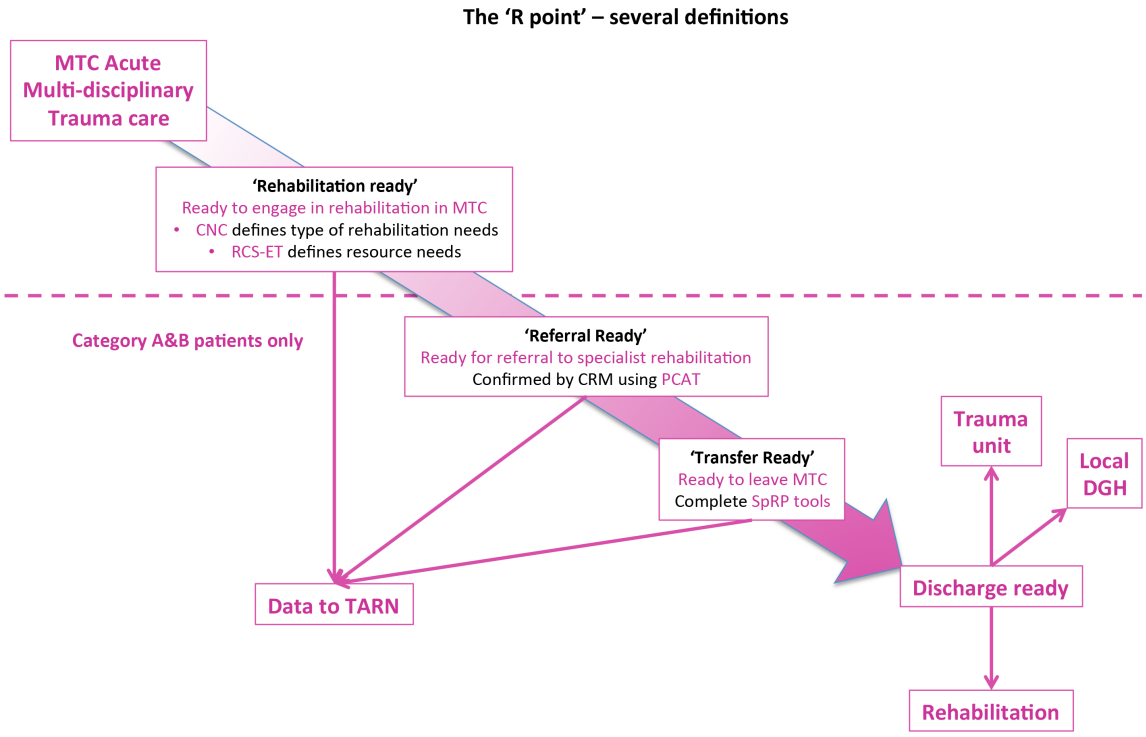
4.8.2 Timing of data collection in MTCs – the 'R point'

Through data analysis and feedback from the MTC teams, we found that there were several interpretations of the 'R point' originally described in our operationalisation plan (see Section 3.6.1). These are illustrated in Figure 5

- Some defined the R point as the time when the patient was ready to start to engage in rehabilitation in the MTC (eg around 72 hours after admission to the MTC)
- Others defined it as the point when the patient was ready to be referred to rehabilitation, and was assessed by the consultant in RM
- Still others defined it as the point when the patient was ready to transfer out of the MTC and move either to rehabilitation, or back to their local TU / DGH to wait for a specialist rehabilitation bed to become available.

The fact that MTCs were interpreting the 'R point' differently may account for some of the variation seen in scores in this first round audit (See Section 6), and needs to be addressed in future audit rounds.

Figure 5: Definitions of the 'R point'



4.8.3 Feedback and consensus from survey and stakeholder workshop 8th June 2017

4.8.3.1 Survey

An on-line questionnaire was sent to all MTCs prior to a stakeholder workshop held on the 8th June. The purpose of the questionnaire was to obtain preliminary feedback on what was working well and not so well in relation to data collection, the burden of data collection, familiarity with the tools and preferred methods of receiving audit data feedback. It was completed by 22 participants from 17 MTCs.

Key results were as follows:

- Familiarity: Only nine (40%) participants were familiar with the tools prior to starting the audit.
- Clinical usefulness: Eleven (58%) participants felt that some of the tools were clinically useful to determine what type of rehabilitation patients required, but 4(20%) felt that none of the tools helped with their clinical decision making.
    - The RCS-ET was regarded as the most useful (n=10; 56%) followed by the PCAT (n=8; 44%).
    - Only 25 % (n=5) of participants regarded the CNC as useful and yet this was widely used.
- Relationship between audit data and RP: Disappointingly, despite the overlap in RP and TARN data sets, only one MTC used the audit data to populate the RP in TARN. Fifteeen (71%) responders collected TARN data and the RP completely separately and did not use any of the tools to describe patient's dependency or rehabilitation needs in the rehabilitation prescription. Only 4 (20%) of participants had used some of the data to argue for local improvements (eg increase in therapy resources) in rehabilitation for Trauma patients.
- Burden: 52% (n=11) people thought that it took longer to collect the data than anticipated and just 23% (n=5) regarded it as an acceptable amount of time.
- Useful outputs: asked what sort of output participants would like to receive to enable data use locally for quality control
    - 11 (55%) participants wanted to be able to compare their progress to other MTCs and wanted a report that will explain the clinical meaning and significance of the data
    - 8 (40%) requested information on how the audit data can be used for therapy reports and the RP.

Patient representatives who attended the meeting or responded to the audit via email emphasised the importance and the need to extend data collection to as many as possible patients and not just category A and B patients. They also were surprised that clinicians were not using the audit data to populate the RP and suggested greater cohesion between clinical practice and audit participation as this will allow them more time to deliver rehabilitation interventions. This emphasises the need to create closer links between the RP and NCASRI audit data in future rounds.

4.8.3.2 Stakeholder workshop

The stakeholder workshop was attended by 15 of the participating MTCs (see Appendix 3 for summary). The discussions throughout were both helpful and positive.

The consensus from this one-day workshop was as follows:

- Although it has been challenging to get data collection off the ground, this first round of the NCASRI audit has been useful. Now that they have got going, the MTC teams are, for the most part, committed to see data collection continue.
- The complete NCASRI toolset collected in this year will be informative, but is too burdensome to continue and may not be capturing all people with complex needs. For future rounds it would be better to collect a reduced dataset and potentially capture more people.
- The variation in time point for data collection has limited the potential for comparability in this first round. In future round it was agreed that primary point for data capture for NCASRI should be the 'Transfer Ready' (TR) point, if different from discharge.

- Teams agreed it would be feasible to collect CNC and RCS-ET for all patients who require further in-patient rehabilitation, alongside clinical categorisation of needs (A, B C or D) at the TR point. The RCSE-ET should be recorded on the basis of rehabilitation 'needs' at that point.
- On this basis, they were keen to engage in the next round of audit, and willing to continue data collection when the current audit round ends on 31st August – ie starting 1st September 2017, in the hope that an extension will be granted to enable NCASRI to continue for a second round.
- Data should be collated on a single database (TARN) as after the end of the audit there will be no additional resource to support collation from multiple data sources. Locally-used databases and electronic patient records should provide data in a form that can be either be uploaded or accessed by TARN data collectors and entered directly into TARN..
- Completion of the other SpRP tools (PCAT, NPDS, and NIS-T) at the TR point should be optional going forward, but would undoubtedly help to make the case for specialist rehabilitation services, and plan their delivery. Therefore, their use is still encouraged in order to provide comparable information, especially patients with very complex (Category A) needs. (The small numbers should not create an excessive data collection burden).
- For MTC teams that prefer to use the PCAT, CNC data can be derived electronically from the itemised PCAT scores to avoid the need to record both instruments.

4.8.4 Integration to the standard RP

Although the design of standard RP is not within the remit of NCASRI, feedback from the teams suggested that it would be helpful if the core dataset for NCASRI (RCS-ET, CNC and category of need) could be built in as a mandated requirement for the standard RP for all patients requiring further inpatient rehabilitation on discharge from the MTCs, as this would embed data collection into routine practice going forward. This request was put to the Rehabilitation Prescription Development Group which met on 13th June 2017.

It was also noted that many locally developed RPs currently record information in areas of assessment that relate to impairment and dependency for daily activities. There would be significant advantage if the NIS and NPDS could replace these non-standardised elements within the data elements for future iterations of the standard RP in order to provide comparable data for future analyses.

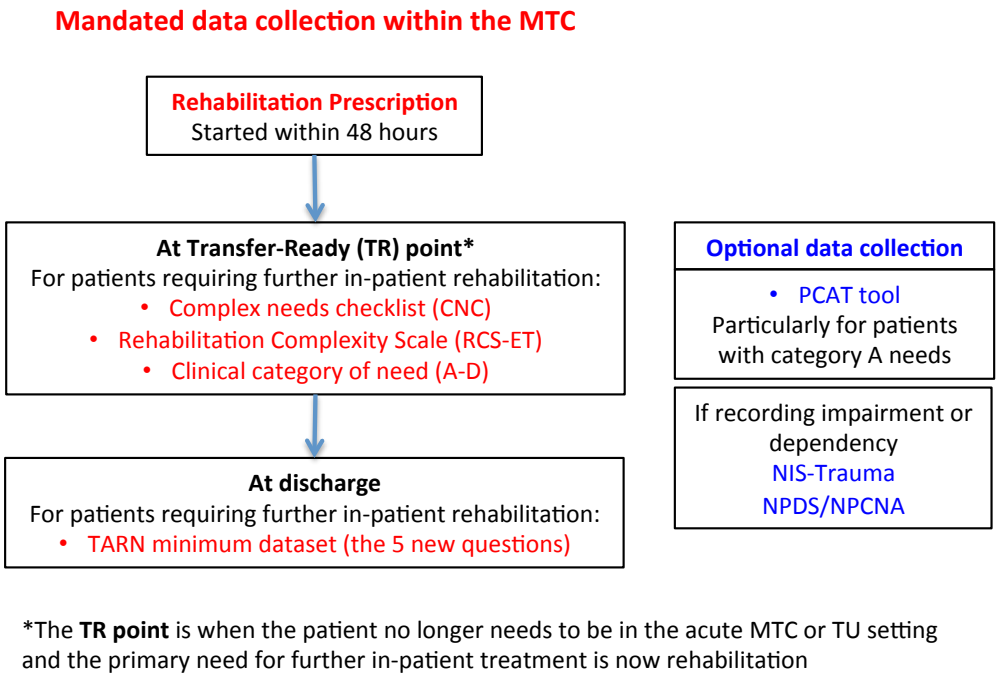
4.9 Summary of recommendations for a more manageable dataset for future rounds of NCASRI

From the various data and extensive discussions held with stakeholders, the following consensus emerged with respect to data collection for the next round of NCASRI.

1. The CNC, RCS-ET and Category of rehabilitation needs should form the core dataset for NCASRI and should be collected in all patients who still require inpatient rehabilitation at the TR point when they are ready to leave the MTC (see data collection form in Figure 7).
2. In future cycles of NCASRI:
    a. The CNC should form the basis for identifying patients with category A and B needs,
    b. The other SpRP tools should continue to be available within TARN for completion on an optional basis
        i. The PCAT remains the gold standard and its continued use is encouraged for detailing complex needs – and also to improve our understanding of complex non-neurological needs
        ii. Use of the NIS-T and NPDS is promoted in patients with category A or B needs for standardised assessment of impairment, dependency and care costs
3. All data should be collated on TARN. Locally-used databases and electronic patient records should provide data in a form that can be uploaded into TARN for future linkage with UKROC.

These proposals are supported by the NCASRI Programme Board for the second round audit, with prospective data collection starting on 1st September 2017. These are summarised in Figure 6.

Figure 6: Proposed new scheme for MTC data collection going forward



*The **TR point** is when the patient no longer needs to be in the acute MTC or TU setting and the primary need for further in-patient treatment is now rehabilitation

Figure 7: The Complex Needs Checklist (CNC) and Rehabilitation Complexity Scale (RCS-ET)

Complexity Needs Checklist and RCS-ET

NHS Number:		DOB:	
TARN Minimum dataset	Date of assessment:		

Rehabilitation Prescription completed
☐ Yes ☐ No

Presence factors affecting activities/participation
☐ Physical
☐ Cognitive/mood
☐ Psycho-social

Discharge Destination only if known:
☐ Level 1 or 2a Other.....
☐ Level 2b
☐ Level 3
☐ Trauma Unit
☐ Home

Does the patient have COMPLEX clinical needs?	Date of assessment:	
Complex Physical eg	**Complex Cognitive / Mood** eg	**Complex Psychosocial** eg
❒ Complex musculoskeletal management ❒ Complex neuro-rehabilitation ❒ Complex amputee rehabilitation needs ❒ Re-conditioning / cardiopulmonary rehab ❒ Complex pain rehabilitation ❒ Profound disability / neuropalliative rehabilitation	❒ Complex communication support ❒ Cognitive assessment/management ❒ Complex mood evaluation/support ❒ Challenging Behaviour management ❒ Evaluation of Low Awareness state	❒ Complex discharge planning eg ○ Housing/placement issues ○ Major financial issues ○ Uncertain immigration status ❒ Major family distress/support ❒ Emotional load on staff

Checklist of needs that are likely to require specialist rehabilitation (tick any that apply) (Examples)		Specialist needs?
Specialist rehab medical (RM) or neuropsychiatric needs	☐ On-going specialist investigation/ intervention ☐ Complex / unstable medical/surgical condition ☐ Complex psychiatric needs ☐ Risk management or Treatment under section of the MHA	❒ Yes ❒ No
Specialist rehabilitation environment	☐ Co-ordinated inter-disciplinary input ☐ Structured 24 hour rehabilitation environment ☐ Highly specialist therapy /rehab nursing skills	❒ Yes ❒ No
High intensity	☐ 1:1 supervision ☐ ≥4 therapy disciplines required ☐ High intensive programme (>20 hours per week) ☐ Length of rehabilitation ≥ 3 months	❒ Yes ❒ No
Specialist Vocational Rehab	☐ Specialist vocational assessment ☐ Multi-agency vocational support (for return to work /re-training /work withdrawal) ☐ Complex support for other roles (eg single parenting)	❒ Yes ❒ No
Medico-legal issues	☐ Complex mental capacity / consent issues ☐ Complex Best interests decisions ☐ DoLs / PoVA applications ☐ Litigation issues	❒ Yes ❒ No
Specialist facilities / equipment needs	☐ Customised / bespoke personal equipment needs (eg Electronic assistance technology, communication aid, customised seating, bespoke prosthetics/orthotics) ☐ Specialist rehabilitation facilities (eg treadmill training, computers, FES, Hydrotherapy etc)	❒ Yes ❒ No

Provisional Categorisation of Rehabilitation Needs

☐ **Category A** (requiring Level 1 or 2a Rehabilitation)
☐ **Category B** (requiring Level 2 Rehabilitation)
☐ **Category C or D** (requiring RR&R pathway)

If probable category A or B needs, refer for specialist rehabilitation review
Referred Yes / No Date...../...../.....
Reviewed Yes / No Date...../...../.....

Rehabilitation Complexity Score (RCS-ET - adapted) *(Only count highest score for Care **OR** Risk, not both)*

Medical	Care/Risk	Nursing	Therapy-Disciplines	Therapy-Intensity	Equipment	Total Score
0 1 2 3 4 5 6	0 1 2 3 4 / 0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3	...../25

Completed by (please circle): Band 8 / Band 7/ Band 6/ Other:_____

This core dataset will reduce the burden on MTC teams, but still provides substantially more rehabilitation-related information than was available prior to NCASRI when the only mandatory data fields collected in TARN were the four boxes circled as the TARN Minimum Dataset.

4.10 Further rounds of audit

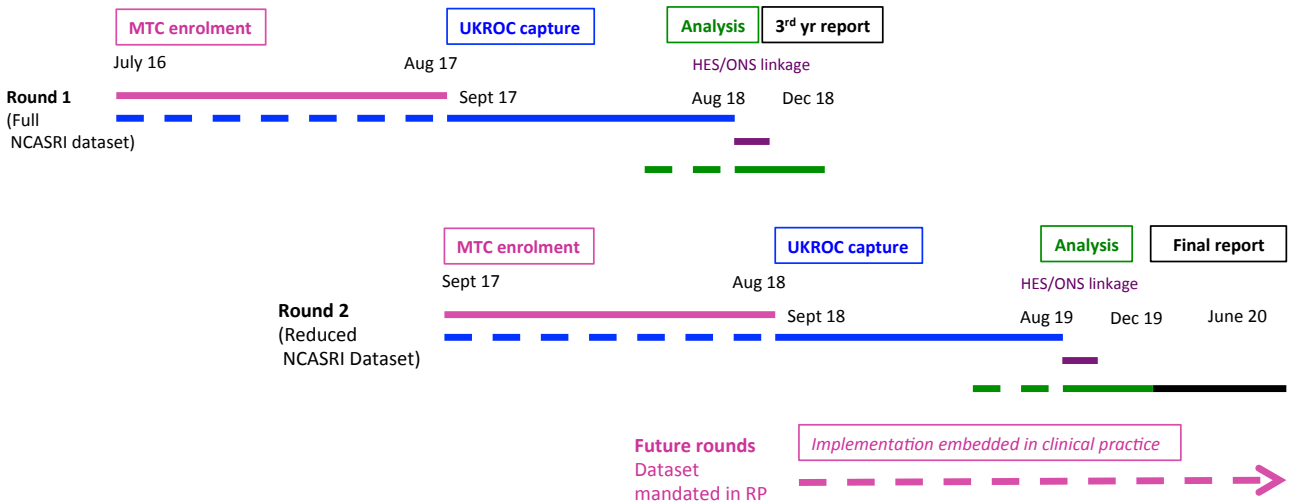
For reasons described in section 4.4 above, data for patients who received rehabilitation may not come through to the UKROC data until up to 12 months after discharge from the MTCs. As the enrolment period within MTCs has been extended to end August 2017, this means that if the final data linkage between TARN and UKROC is complete in December 2017, as per the original audit plan, the results are likely to under-estimate very significantly the number of patients coming through to the specialist rehabilitation services. Ideally, linkage should be delayed until after the UKROC data submission in September 2018 for this first round, in order to maximise the benefits of the audit. Otherwise a report prepared in June 2018 based on premature linkage may under-estimate the proportion of patients receiving specialist rehabilitation, and so give misleading results.

The NCASRI Programme Board has therefore recommended extension of the current 3 year programme until 31st Dec 2018 at minimum, to ensure that outcome data for the recruited cohort can be included in the final analysis. Going forward, for full capture of linked data, the audit should have a two-year cycle, although successive audit rounds can overlap to sustain continuous data collection.

The Board has also recommended extension of the NCASRI audit into year 4-5 with a second audit cycle starting from September 2017 using the reduced dataset as set out in Figure 7 above. Figure 8 below sets out the proposed scheme for data collection. This second round would involve further work to refine the data set and embed collection into the standard RP, so that future rounds may be implemented as part of routine clinical practice. Failure to achieve this would mean that the extensive development work conducted in the first 2 years of the programme will come to nothing and the anticipated benefits of directing severely injured patients to appropriate and timely rehabilitation will not be realised.

The full proposals are outlined in an application for extension to contract which is currently in preparation and due submission by October 2018.

Figure 8: Overlapping 2 year audit cycles



5 Strengths and weaknesses of our approach

We recognise some weaknesses but also some strengths to our approach

Relative weaknesses are that some of the original timelines have slipped, and we have submitted a contract variation form to change the dates of some of our deliverables. For example

- The delivery date for obtaining s251 approval was delayed from Dec 2015 to Jan 2017.
- The delivery date for sign off of our analysis plan has been delayed from Dec 2016 to Sept 2017
- Completion of our pilot analysis had changed from Dec 2016 to August 2017
- The delivery date for Element 4 has been delayed from December 2017-June 2018.

On the other hand, knowing what we do now at the end of Year 2 of the programme, in hindsight many of these delivery dates were unrealistic.

The relative strengths of the approach we have taken are that, although it has taken longer than expected to achieve some of the steps, the processes we have put in place will enable data collection to be embedded into clinical practice at the end of the audit.

- We now have a better understanding of the time that severely injured patients may realistically take to complete their in-patient rehabilitation programmes and appear in the UKROC database.
- Although the rich dataset collected in the first round of the audit will provide important information about this patient group, we have now agreed a more manageable dataset that will tell us much of what we need to know with respect to performance indicators in the future.
- Importantly, if this reduced dataset can be built into the standard RP it will potentially support data collection for patients with category C and D needs, as well as those with Category A/B needs that are included in NCASRI, and so spread the benefits and impact of the audit across a much broader spectrum of patients than are covered in the scope of NCASRI alone.
- Our PPI members are particularly supportive of this approach because of their concerns regarding the limited scope of the NCASRI project. Failure to achieve this critical nest step would mean that the extensive development work conducted in the first 2 years of the programme will come to nothing and the anticipated benefits of directing severely injured patients to appropriate and timely rehabilitation will not be realised.

6 Summary of data collected from the MTCs to date

A full analysis of the MTC data will be conducted in October / November 2017, after the end of the enrolment period for the first cohort. However, in this section we present a brief outline of the data collection to date in the participating MTCs.

Table 4 shows the mode of data collection and who collects the data in the 16 participating centres, which represent 73% of the MTCs. Nine MTCs are submitting data through TARN; 2 through IRMA (ORION), 5 on paper. At this stage in June 2017 we are collating the data from these various sources by hand, which is labour-intensive. The dataset is by no means complete. One MTC that had hoped to download data from its own computer system has recently switched to submitting on paper.

6.1 Enrolment and data completion rates

Table 5 shows the number of patients enrolled by each centre and the completion rates for the various tools. A total of 1312 patients have been collated so far in the 16/22 centres. The NHS number is available in 97%, and one centre with missing NHS numbers has been asked to provide these.

As noted in the preliminary analysis (Appendix 2) and in Section 4.8.1 above, a substantial proportion of the enrolled patients (55%) are from the MTC in Bristol, which is atypical in a number of respects.

- They collect the CNC and RCS-ET within 72 hours of admission (rather than at the TR point).
- They identify the category of needs with clinical reference to the PCAT at discharge, although they do not actually record the PCAT.
- Through this systematic (but simpler) approach to data reporting, they identify many more patients with category A/B needs than the other MTCs, which may skew the data

We have therefore given the total and % of SpRP tool data collection both including and excluding the Bristol patients.

6.1.1 Apparently missing data

Although some centres had a high proportion of missing data in the clinical categorisation of rehabilitation needs, the PCAT (if present) may be used to categorise needs for rehabilitation. Thus, overall there was some classification of rehabilitation needs in 1182 (>90%) patients.

In six MTCs, the CNC is not necessary because the team uses the PCAT in preference. In this situation the CNC can be compiled retrospectively from the PCAT for the purposes of comparison. In total, CNC data are available in 80% patients and RCS-ET data in 94%; whereas data for the other SpR tools are available in only about a third of patients.

At first sight this completion rate may seem disappointing, but there are several factors to consider:

a) On average MTCs collected data for 5-15 patients per month
b) The data are dominated by Bristol which has only collected CNC and RCS-ET data. Amongst the other 15 units, collection rates are significantly higher - PCAT data are available in 75%, NPDS in 66%, and NIS-T data in 61%.
c) Moreover, the audit only requires completion of the SpRP tools in patients who are identified as having category A or B needs, of which there are 606 in Table 5, (although this figure may change as further data come through and are re-checked)
d) Across the 13 units that recorded the PCAT, NPDS, and/or NIS-T, 451/502 (90%) of patients had category A/B needs, and completion rates in this group were PCAT n=458(98%), NPDS n=394 (87%) and NIS-T n=362 (80%), suggesting that NCASRI is largely on track towards the target of 500 eligible patients with complete SpRP data for this first round of prospective audit.

Table 4: Major Trauma Centres participating, the mode of data entry and who collects the data.

	Major Trauma Network (MTN)	Major Trauma Centre (MTC)	MTC Short name	CRM sessions (no. of PAs)	Data collected by	Start date	Platform
1	Northern (Newcastle, North East & Cumbria)	Royal Victoria Infirmary, Newcastle	Newcastle	Yes (6)	CRM	Jul-16	TARN
2	Northern (Middlesbrough and South)	James Cook University Hospital, Middlesbrough	Middlesborough	Vacant (6)	RC	Jul-16	TARN
3	North Yorkshire and Humberside	Hull Royal Infirmary	Hull	Yes (2)	RC	Jul-16	TARN
4	Greater Manchester	Manchester Collaborative MTC	Manchester	Yes (12)	MDT	Jul-16	UKROC
5	Cheshire and Merseyside	Liverpool Collaborative MTC	Liverpool	Yes (1)	RC and Therapists	Feb-17	Walton: TARN Aintree: Paper
6	South Yorkshire	Northern General Hospital Sheffield and Royal Hallamshire Hospital	Sheffield	Yes (10)	RC	Oct-16	Paper
7	Birmingham, Black Country, Hereford and Worcester	Queen Elizabeth Hospital Birmingham	Birmingham	Yes (10)	CRM and Therapists	Sep-16	TARN
8	Central England	University Hospital Coventry	Coventry	Yes (4)	RC	Sep-16	TARN
9	East Midlands	Queen's Medical Centre, Nottingham	Nottingham	Yes (8)	RC and CRM	Jul-16	TARN
10	East of England	Addenbrookes, Cambridge	Cambridge	Yes (10)	CRM	Jul-16	ORION
11	Severn	Southmead Hospital, Bristol	Bristol	Yes (10)	CRM and RC	Jul-16	TARN
12	North West London	St Mary's Hospital, London	NW London	Yes (1)	CRM and Therapists	Jul-16	Paper
13	South West London and Surrey	St George's Hospital, London	SW London	None (0)	Therapists	Nov-16	Paper
14	Wessex	Southampton General Hospital	Southampton	Yes (1)	CRM	Dec-16	TARN
15	Peninsula	Plymouth Derriford	Plymouth	Yes (6)	CRM	Jul-16	ORION
16	North West Midlands and North Wales	University Hospital of North Staffordshire, Stoke-on-Trent	Stoke-on-Trent	Yes (11)	MDT	Sep-16	Paper
MTCs NOT PARTICIPATING							
17	West Yorkshire	Leeds General Infirmary	Leeds	Yes (5)	N/A		N/A
18	Lancashire and South Cumbria	Royal Preston Hospital	Preston	Yes (10)	N/A		N/A
19	Thames Valley	John Radcliffe Hospital, Oxford	Oxford	Vacant (10)	N/A		N/A
20	North East London and Essex	Royal London Hospital	NE London	None (0)	N/A		N/A
21	South East London, Kent and Medway	King's College Hospital, London	SE London	None (0)	N/A		N/A
22	Sussex	Royal Sussex County Hospital, Brighton	Brighton	Vacant (?)	N/A		N/A

Table 5: SpRP Tool completion rates for the 16 participating MTCs

				Clinical categorisation				SpRP tools collected					
	Major Trauma Centre (MTC)	**Episodes**	**NHS No available**	**A/B**	**C /D**	**Missing***	**% A/B**	**CNC***	**RCS-ET**	**PCAT**	**NPDS**	**NIS-T**	**Data collected by**
1	Newcastle	19	19	18	-	1 (5%)	95%	0 (18)	17	18	18	19	CRM
2	Middlesborough	10	10	8	-	2 (20%)	80%	8	8	8	8	10	RC
3	Hull	31	31	7	2	22 (71%)	23%	9	21	**N**	**N**	**N**	RC / Therapists
4	Manchester	51	51	28	11	12 (24%)	55%	0 (41)	45	41	47	33	MDT
5a	Liverpool Walton	10	10	9	-	1 (10%)	90%	9	10	**N**	**N**	**N**	RC
5b	Liverpool Aintree	50	**17**	3	14	33 (66%)	6%	50	50	**N**	**N**	**N**	RC / Therapists
6	Sheffield	22	21	18		4 (18%)*	82%	1 (20)	1	20	2	11	RC
7	Birmingham	48	48	42	1	5 (10%)	88%	0 (44)	46	44	41	33	CRM / Therapists
8	Coventry	33	33	33	0	0	100%	33	33	32	33	33	RC
9	Nottingham	27	27	27	0	0	100%	27	27	27	27	27	RC / CRM
10	Cambridge	92	92	90	-	2 (2%)		0 (90)	92	90	88	69	CRM
11	Bristol***	719	719	136	334	38 (5%)***	19%	508	696	**N**	**N**	**N**	RC / CRM
12	NW London	54	54	52	1	1 (2%)	96%	54	50	49	49	48	CRM / Therapists
13	SW London	31	31	29	2	0	94%	31	31	28	26	23	Therapists
14	Southampton	40	40	38	-	2 (5%)	95%	36	33	19	15	15	CRM
15	Plymouth	49	49	42	1	7 (14%)	86%	2 (42)	49	42	14	15	CRM
16	Stoke-on-Trent****	26	26	26	0	0	100%	26	26	26	26	26	MDT
	TOTAL	**1312**	**1278**	**606**	**366**	**130 *****	**35%**	**794 (1046)**	**1235**	**444**	**394**	**362**	
	% All Episodes		**97%**	**46%**	**28%**	**10%***		**61 (80)%**	**94%**	**34%**	**30%**	**28%**	
	(% Excl Bristol)*	**593**	**94%**	**79%**	**5%**	**16%**		**48 (91)%**	**91%**	**75%**	**66%**	**61%**	

* The PCAT (if present) may be used to categorise needs for rehabilitation and so supplement missing data for clinical categorisation data. (Total no. given in brackets)
**Where a PCAT is completed *de novo*, the CNC is not necessary, but can be compiled retrospectively from the PCAT for the purpose of comparison (Total no. given in brackets)
*** The Bristol data are current under review. Approximately a third had either ISS scores <9 or no further rehabilitation needs at discharge, and so were potentially ineligible for inclusion, but these figures are in the process of being re-checked at the time of writing.
****At the time of writing the total reported numbers have been received for Stoke on Trent but actual data are still awaited.

6.2 Understanding rehabilitation needs – the data captured in the NCASRI tools

6.2.1 Complex Needs Checklist (CNC)

As noted in Section 4.1, the TARN minimum data set for the rehabilitation prescription includes four questions:

- Does the patient have rehabilitation needs requiring an RP?
- Do they have a) Physical, b) Cognitive/Mood or c) Psychosocial problems?

At the top of the CNC (see Figure 7), these three categories are expanded to collect more detailed information on why these issues were identified. Until now TARN has been unable to separate out mood and cognition issues as they are categorised together. The CNC provides some further sub-types within each of the three TARN types of 'complex needs'.

Table 6 shows the number of patients with complex needs according to the mandatory tick boxes recorded on TARN, and the further characterisation of those needs. Data were available for this part of the CNC in 725 patients, of which many had needs in more than one type and sub-type.

- 70% had complex physical needs of which the commonest were a requirement for complex neurological or musculoskeletal rehabilitation
- 43% had complex cognitive or emotional needs, including cognitive assessment and mood evaluation
- 34% had complex psychosocial needs, including complex discharge planning or major family support.

Table 6: The breakdown of different types and subtypes of needs within the Complex Needs Checklist (CNC).

	Total patients with CNC data: 725	**n**	**%**
Type	**Complex physical needs**	**509**	70%*
Sub-types	Complex musculoskeletal management	193	38%
	Complex neuro-rehabilitation	207	41%
	Complex amputee rehabilitation needs	10	2%
	Profound disability / neuropalliative rehabilitation	6	1%
	Complex pain rehabilitation	47	9%
	Re-conditioning / cardiopulmonary rehab	68	13%
Type	**Complex cognitive / emotional needs**	**312**	43%*
Sub-types	Complex communication support	50	16%
	Cognitive assessment/management	131	42%
	Complex mood evaluation / support	126	40%
	Challenging behaviour management	31	10%
	Evaluation of low awareness state	25	8%
Type	**Complex psychosocial needs**	**249**	34%*
Sub-types	Complex discharge planning	137	55%
	Major family distress / support	111	45%
	Emotional load on staff	17	7%

(NB this stage the data need to be interpreted with some caution as the TARN dataset included only one option for the subtype of need selected under each of the three main types. In future we will collect all subtypes.)

The CNC itself is designed as a screening tool, or aid to clinical decision-making, to assist teams to identify patients with complex needs who may require referral for further specialist in-patient rehabilitation. It includes six items, each with a sub-item checklist detailing the types of needs that patients may have under each heading. Once again more than one sub-item may be selected.

Table 7 gives a breakdown of the frequency of the six principal items in the CNC checked to indicate a requirement for further inpatient rehabilitation. The commonest requirements were for:

- On-going specialist medical/psychiatric intervention (56%)
- Coordinated inter-disciplinary input (49%)
- Longer stay in rehabilitation - 3 months of more (41%)
- Specialist rehabilitation facilities (25%)

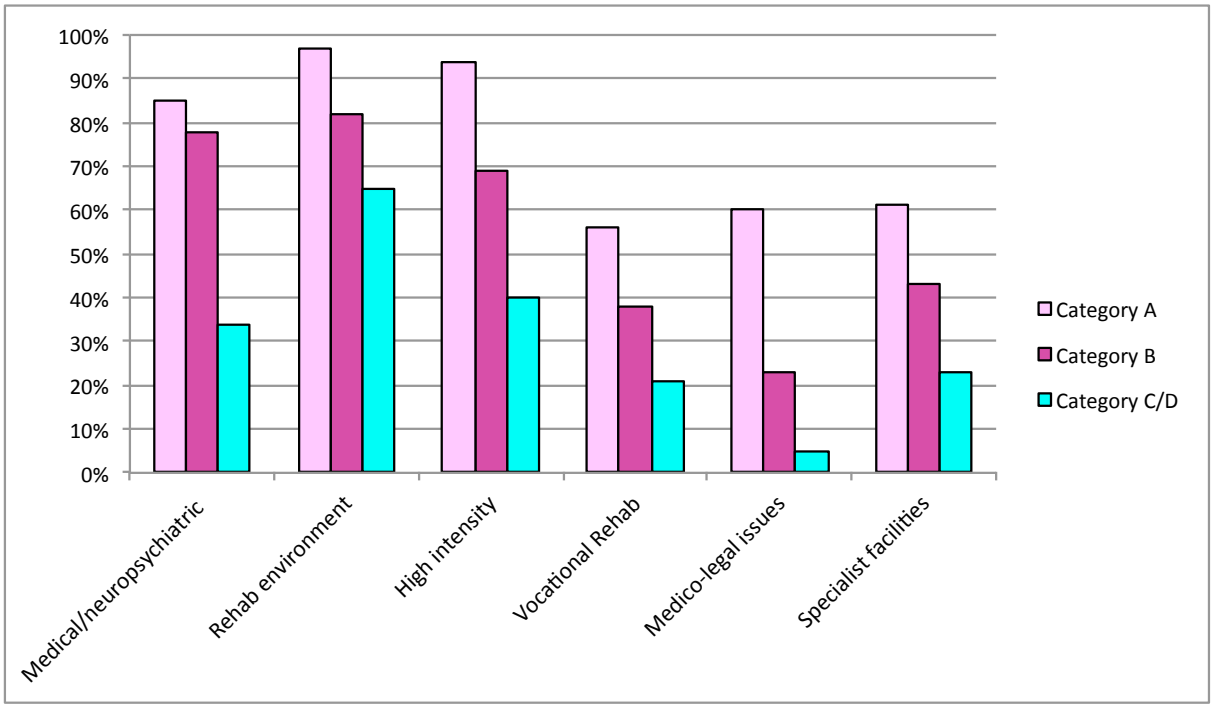
Table 7: A breakdown of the frequency of the six principal items in the CNC checked (N=725)

Item	Description	N	% within item	% of whole
1	**Specialist rehab medical (RM) or neuropsychiatric needs**	**483**		67%
Details	On-going specialist investigation/ intervention	408	84%	56%
	Complex / unstable medical/surgical condition	67	14%	9%
	Complex psychiatric needs	12	2%	2%
	Risk management or treatment under section of the MHA	16	3%	2%
2	**Specialist rehabilitation environment**	**567**		78%
Details	Co-ordinated inter-disciplinary input	355	63%	49%
	Structured 24 hour rehabilitation environment	168	30%	23%
	Highly specialist therapy /rehab nursing skills	107	19%	15%
3	**High intensity**	**437**		60%
Details	1:1 supervision	48	11%	7%
	4 or more therapy disciplines required	70	16%	10%
	High intensive programme (>20 hours per week)	46	11%	6%
	Length of rehabilitation 3 months or more	297	68%	41%
4	**Specialist Vocational Rehabilitation**	**251**		35%
Details	Specialist vocational assessment	125	50%	17%
	Multi-agency vocational support (for return to work/etc)	111	44%	15%
	Complex support for other roles (eg single parenting)	22	9%	3%
5	**Medico-legal issues**	**173**		24%
Details	Complex mental capacity / consent issues	59	34%	8%
	Complex Best interests decisions	36	21%	5%
	DoLs / PoVA applications	56	32%	8%
	Litigation issues	35	20%	5%
6	**Specialist facilities and equipment**	**266**		37%
Details	Customised / bespoke personal equipment needs	77	34%	11%
	Specialist rehabilitation facilities	179	79%	25%

Figure 9 shows the percentage of each of the six principal CNC items ticked in patients within each category of need from the TARN data. As expected the proportions are highest in patients with category A and B needs.

It is noteworthy that a significant number of patients with category C or D needs also have requirements under one or more principal item of the checklist – especially needs for medical / psychiatric input or a specialist rehabilitation environment. However the % figures may be skewed by the very small numbers (with the exception of Bristol), so further exploration is required into what exactly the teams mean when checking these subtypes.

Figure 9: The percentage of each principal CNC item ticked within each category of need



6.2.2 Resource requirements – data from the RCS-ET

The Rehabilitation Complexity Scale (RCS-ET) measures resource requirements in terms of medical, nursing and therapy inputs and, as noted in Table 3 (section 4.8.1), can also be used to identify the TR point. In addition it offers a description of the resource needs that can be used to plan rehabilitation inputs as shown in Table 8.

As expected category A patients had substantially higher needs for these clinical inputs across all disciplines.

Some teams reported that they record the RCS-ET to reflect the level of rehabilitation received, rather than the needs for rehabilitation. In this audit, it should be collected on the basis of rehabilitation needs. Once again this difference in approach may account for some of the observed variation in this first round.

Table 8: Breakdown of RCS-ET scores across the different categories of need

Score	Description	Category A	Category B	Category C/D	Unknown category	ALL
RCS-Medical scores – Medical environment		**N=224 %**	**N=226 %**	**N=365 %**	**N=173 %**	**N=988 %**
0	No medical needs	1	6	25	10	13
1	Low level monitoring only	1	12	14	24	13
2	Active investigation or treatment	16	20	5	31	15
3	Medically unstable – emergency out of hours are available	11	8	6	6	7
4	Medically / surgically unwell - emergency out of hours treatment	8	8	12	10	10
5	Requires on-going care in a trauma unit setting	12	15	21	6	15
6	Requires full medical facilities of an MTC	42	19	13	6	20
RCS-Care scores – Care needs						
0	No care needs	4	9	13	10	10
1	1 carer for most tasks	4	27	44	34	29
2	2 carers for most tasks	33	38	34	35	35
3	>= 3 carers or high risk	13	9	3	8	7
4	1: 1 care	41	12	4	8	15
RCS-Nursing scores – special nursing needs						
0	No special nursing needs	1	5	20	9	10
1	Care from a qualified nurse	5	21	28	18	20
2	Care from a rehabilitation nurse	22	25	12	45	23
3	Specialist nursing care (tracheostomy, behavioural)	28	20	23	13	22
4	High acuity nursing setting (eg HDU)	35	17	14	8	18
RCS-Therapy Disciplines						
0	No therapy required	0	1	10	3	5
1	1 therapy discipline only	1	7	22	2	10
2	2-3 therapy disciplines	28	44	50	8	36
3	4-5 therapy disciplines	39	31	14	5	22
4	>=6 therapy disciplines	22	5	1	0	7
RCS-Therapy Intensity						
0	No therapy required	0	1	10	3	5
1	Low level – less than daily – or group therapy only	2	9	23	4	12
2	Daily intervention with one therapist at a time	31	48	35	6	32
3	Daily plus assistant / additional group sessions	38	27	28	5	26
4	Highly intensive – 2 trained therapists to treat	19	4	1	1	6
RCS-E Equipment needs						
0	No equipment required	10	20	19	24	18
1	Basic off the shelf equipment only	39	56	68	58	57
2	Specialist equipment - customised	34	10	9	8	15
3	Highly specialist equipment only available in MTC	8	1	1	3	3

A further noteworthy finding in Table 8 is that 20% of RCS-M scores were rated at 6 ('Requires full medical facilities of an MTC'), reflecting the fact that these patients had not yet reached the TR point. This almost certainly reflects the large number of scores recorded by Bristol who elected to record the CNC and RCS-ET at 72 hours post admission, rather than at the TR point. This once again emphasises the need for agreement and consistency regarding the time point at which data are collected in future rounds of the audit.

6.2.3 Summary statistics

Table 9 Summary statistics for the SpRP tools – Category A and B patients only

Tool Min-Max		**CNC** 0-6	**RCS** 0-25	**PCAT** 0-50	**NIS-T** 0-113	**NPDS** 0-100	**Weekly Care Cost**
MTC	Episodes	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
Newcastle	18	-	19 (15,20)	32 (30, 33)	24 (10, 29)	26 (19,43)	£1100 (501, 2140)
Middlesbrough	8	5 (3,6)	15 (13,19)	36 (31, 40)	16 (10,22)	25 (14, 44)	£1100 (535, 1257)
Hull	7	4 (2, 5)	-	-	-	-	-
Manchester	28	-	12 (10,13)	29 (22,33)	11 (5,16)	16 (6, 32)	£1612 (216, 2190)
Liverpool Walton	9	4 (4,5)	18 (16, 21)	-	-	-	-
Liverpool Aintree	3	3 (2,4)	16 (15,16)	-	-	28	-
Sheffield	17	-	16	27 (24, 28)	8 (6,10)	46	£1211 (282,1211)
Birmingham	42	-	15 (11, 19)	29 (26, 33)	20 (10, 35)	39 (21, 48)	£1708 (1082, 2384)
Coventry	33	4 (3,5)	17 15, 18)	32 (26, 37)	31 (19, 46)	46 (32,51)	£2232 (1100, 2768)
Nottingham	27	6 (5, 6)	22 (19,24)	39 (33, 42)	39 (26, 50)	45 (24, 58)	£2036 (1146, 2727)
Cambridge	92	-	10 (9, 13)	31 (28, 37)	-	38 (26, 34)	-
Bristol	136	4 (3,4)	16 (10,19)	-	-	-	-
NW London	52	4 (3,5)	14 (13, 16)	33 (30, 36)	26 (19, 31)	40 (27, 43)	£1364 (1100, 1946)
SW London	29	4 (3,5)	14 (13,16)	29 (24, 35)	16 (11,26)	34 (12,47)	£1346 (300, 1960)
Southampton	38	4 (3, 4)	15 (14, 19)	30 (28, 37)	31 (20,46)	50 (40, 63)	£2676 (1100, 2768)
Plymouth	49	3 (2,3)	14 (11,18)	30 (25, 35)	-	34 (13, 55)	-
Stoke-on-Trent*	26	-	-	-	-	-	-
Totals							
N		**318**	**402**	**262**	**198**	**229**	**237**
Median IQR		4 (3, 5)	16 (13,19)	31 (27, 36)	24 (13, 35)	37 (21, 50)	£1636 (1100, 2267)
Range		0 - 6	0 - 25	18 - 46	1 - 63	0 - 80	£0 – 3544

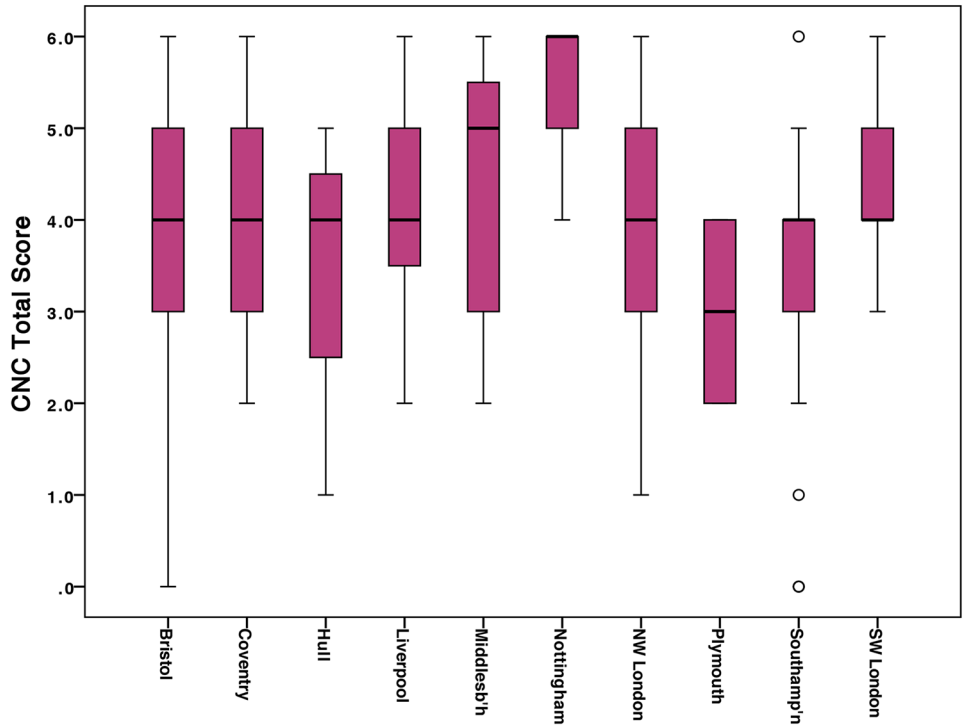
* Data awaiting data entry

Table 9 shows the summary statistics for the SpRP tools in the dataset collected to date for the patients with category A and B needs. Figure 10 illustrates box and whisker plots of the total CNC and RCS-ET scores.

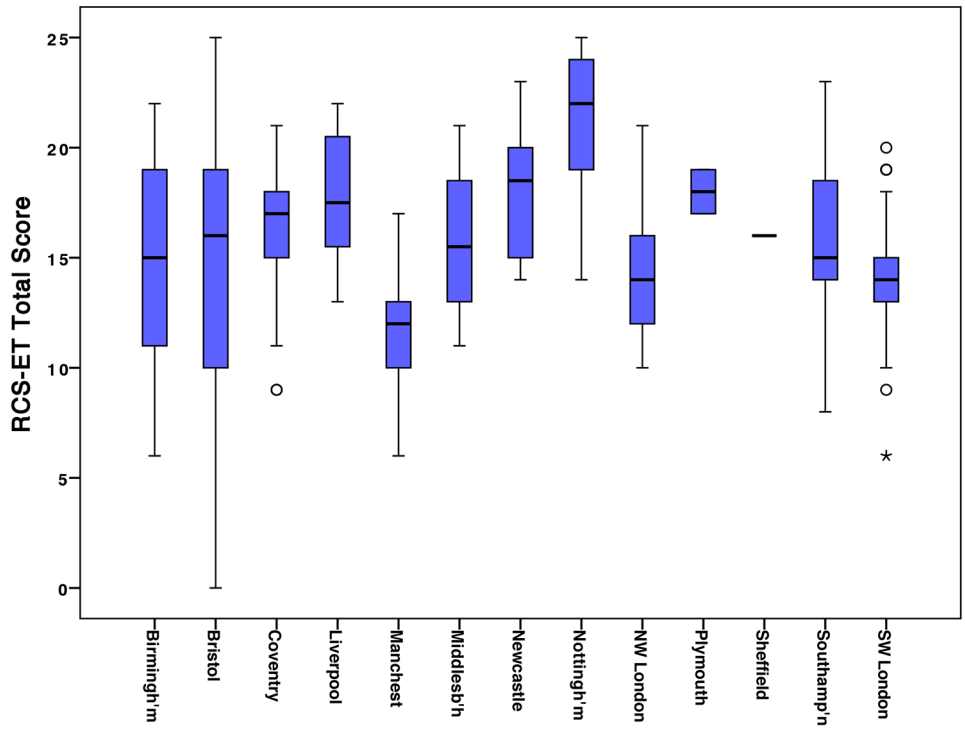
Considerable variation is seen across the centres, but with some consistency between the various tools. This suggests that the variation is not simply the result of inaccurate scoring, but possibly different thresholds for the identification of category A / B needs, or the different timing of assessments between centres. This will require further investigation in the final dataset nd in future rounds of NCASRI audit.

Figure 10 Box and Whisker plots of the total Complex Needs Checklist Scores

a) Complex need checklist scores



a) RCS-ET scores



Within the general neurorehabilitation population, a PCAT score of >=30 is generally indicative of category A needs, and scores of 24-29 indicative of category B needs[13]. Despite some variation between centres, the range of PCAT scores in this sample (median 31, IQR 27-36) suggest that the sample identified has a similar level of rehabilitation need to the other patients who are admitted to the Level 1 and 2 services.

A median NPDS score of 36/100 on discharge (IQR 21-50) confirms that this is a significantly dependent group of patients – the majority still needing 2 people for assist with their basic daily care needs. The median weekly care costs on discharge of £1612 per week confirm that, wherever they are cared for, this group will continue to place a substantial burden on the NHS in basic care costs alone, while they wait for rehabilitation, whereas there is evidence from other studies that these care costs reduce in the course of a specialist rehabilitation programme (Turner-Stokes et al 2015). Once linked to the UKROC dataset, our final data analysis for the prospective study will provide further exploration of the costs of delivering / failing to deliver timely transfer to rehabilitation.

6.3 Summary from data collected to date and lessons learned

At this stage the data are still being collated and assimilated. It would be premature to conduct a full analysis but the preliminary analyses from both the TARN dataset and the other platforms have provided some useful insights. Key conclusions are as follows.

- At the outset of the prospective data collection, we had no clear information about the likely number of patients, but we estimated approximately 500 might have category A/B needs. Even though only three-quarters of the centres are enrolling patients and data collection was slow to get started, we expect to reach, and hopefully exceed, this target by 31st August 2017.
- It is now recognised that the collection of the full set of SpRP tools will not be sustainable going forward. Nevertheless they have the potential to provide useful information about the needs of trauma patients for specialist rehabilitation, which has not been available to date.
- The information from this interim snapshot of data collection to date suggests that we should have a representative sample of data from the various SpRP tools on which to conduct our analysis as originally intended for this first round of the audit.

This first round of NCASRI audit has been important in many respects. We have worked with teams on the ground to engage them, and now that they are engaged, most report they are willing to continue.

Some important lessons have been learned, both about the volume of data that is feasible to collect and the timing of data collection to improve consistency and interpretability of the data.

- In future all MTCs will collect CNC and RCS-ET data as close to the TR point as possible, especially if this is different from the discharge date.
- Identified missing data fields (such as the completing discipline) will be added to data collection platforms (eg ORION), but for future rounds of the audit, all MTCs will be asked to ensure that the NCASRI data are entered into the TARN database to improve both the feasibility and efficiency of data linkage with UKROC.
- Inclusion of the CNC and RCS-ET as part of the mandated data reporting for the standard RP would help to improve case ascertainment and reduce missing data.
- Back translation of the PCAT to the CNC will still be available for teams that wish to use the full PCAT in preference to the shorter CNC.

7 List of appendices

1. Analysis plan
2. Preliminary analysis of TARN data to March 2017
3. Report from Workshop 8th June.

8 References

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