Process of UK ROC data access request

There are currently four methods for obtaining data/analysis from the UK ROC dataset

1. **Local database**
   All participating sites have local access to their UK ROC database with the facility to filter data for analysis and the option to export admission and discharge data into an Excel format.

   Monthly data submissions of local database to UK ROC is mandatory – the data is processed by UK ROC and a psuedonymised Excel site report containing cumulative monthly data for occupied/weighted bed days by CCG and by episode is produced in addition to information on nightly occupancy and identification of missing/invalid data. The report can be re-identified by the individual unit using the export facility within the UK ROC software to assist in local interpretation of results.

   Quarterly summary reports (Appendix 1) are produced by UK ROC and sent to local units – these reports provide a 3 page summary of the core standard listed in the service specification for specialist rehabilitation units "D02/S/a NHS Standard Contract for Specialised Rehabilitation for Patients with Highly Complex Needs (all ages)" http://www.england.nhs.uk/wp-content/uploads/2014/04/d02-rehab-pat-high-needs-0414.pdf
   Page one of the report provides a table with descriptive statistics for the current reporting period and the previous 2 years for both the local unit and benchmarked with other units providing a similar service. Page 2 and 3 of the report provide graphical representation of the data.

   Compliance reports detailing the percentage of reporting for the mandatory minimum reporting requirements at admission and discharge are tabulated. Compliance reporting covers a 3 year period.

2. **UK ROC process specific request for bespoke analysis**
   Limited capacity is available within the UK ROC team to provide bespoke analysis upon request from a service. The service would need to apply in writing to the UK ROC team expressing analysis required; this may be to demonstrate a change in service complexity and would normally be reported back to the unit in table format rather than a full report.

   A request form for bespoke analysis is given in Appendix 2. If the analysis is a substantial piece of work, the UKROC Oversight Group will need to consider if this can be accommodate within the NHSE funded programme, or whether additional funding would need to be sought.

3. **Researcher analyses data with supervision of UK ROC team**
   Normally a service/commissioner has specifically identified a researcher to conduct analysis requiring data from the UKROC dataset. A summary of the project, aims and objectives, data required (time frame/fields) would need to be provided by completion of UK ROC data access form/data sharing (Appendix 3) and potentially a privacy impact assessment form will need to be completed. The researcher would be based in the UK ROC office to analyse data exported from the UK ROC dataset based on identified fields. Access to psuedonymised patient level data will be available but strict restrictions on use. The data cannot be transferred on to USB sticks or researcher's laptop/computer; all analysis is conducted in the UK ROC office. Tables and reports produced can be saved in a secure format once aggregated data is processed.

4. **Request for dataset**
   Full purpose of project aims and objectives would need to be provided/completion of UK ROC data access form and privacy impact assessment. Specific data fields required along with usage to achieve the project aims is mandatory in addition to completed data sharing agreement. No potentially identifiable data will be shared and where possible aggregated data only will be provided. The data sharing form in Appendix 3 is also used for such requests

Appendix 1

UK ROC Summary - 2018/19 month 12

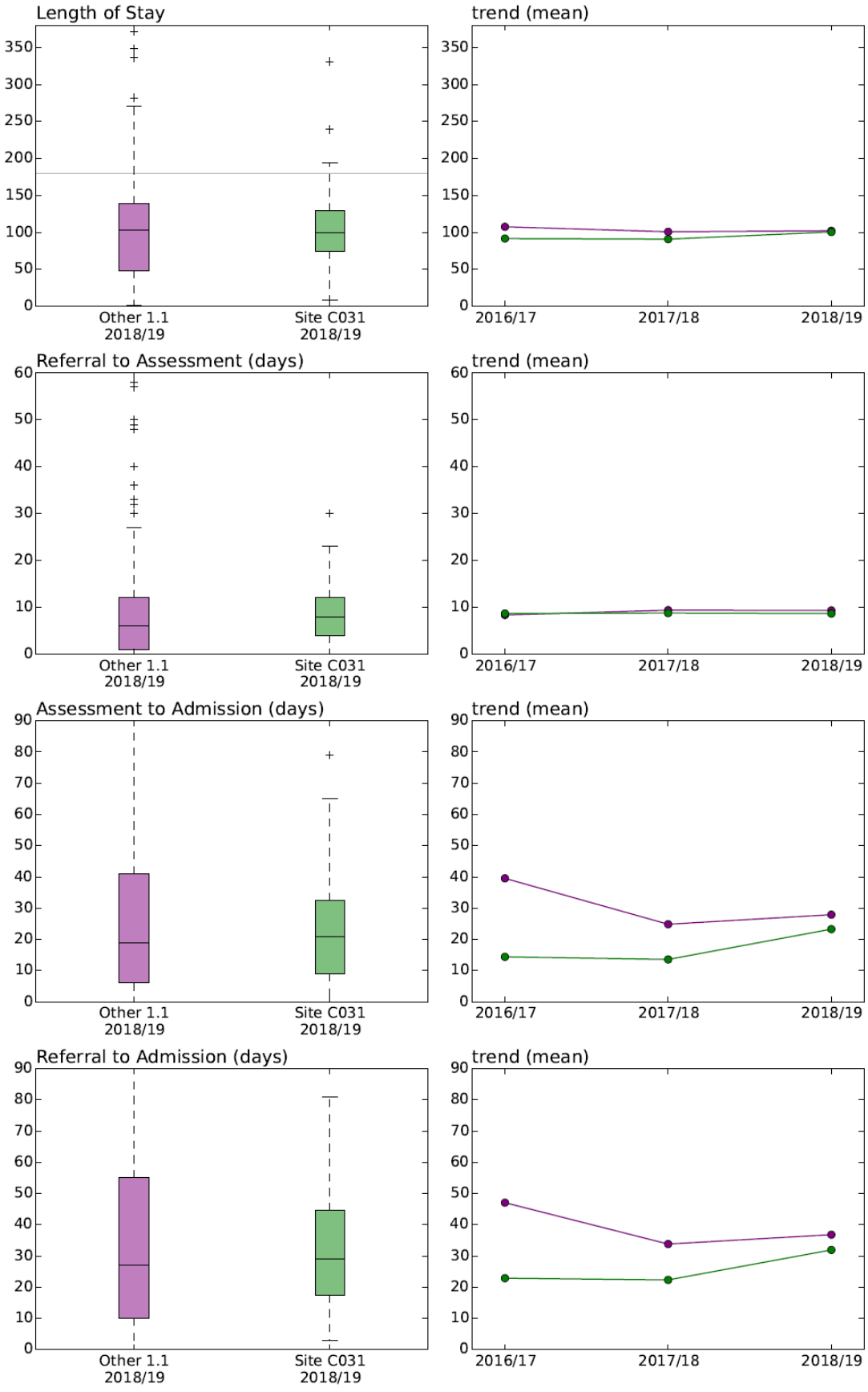
C031: Regional/Hyperacute Rehabilitation Unit, Northwick Park Hospital

Service Class	1.1
Reference Group	other 1.1 services
Latest data submission	09/05/2019

	Other 1.1				Site C031			
	2016/17	2017/18	2018/19	Total	2016/17	2017/18	2018/19	Total
Number of Admissions	429	411	408	1248	95	94	83	272
Number of Discharges	431	412	413	1256	97	93	83	273
Activity Figures								
Number of months	12	12	12		12	12	12	
% OBDs banded	99%	100%	98%		100%	100%	100%	
Unweighted OBDs					8675	8748	8732	
Weighted OBDs					13485	13756	13928	
Episode Length								
Mean length of stay (nights)	107	101	102	104	92	91	100	94
% episodes > 180 days	16.9%	10.7%	10.4%	12.7%	4.1%	1.1%	3.6%	2.9%
Response times (days)								
% referral date reported	100%	100%	99%	99%	100%	100%	100%	100%
Mean referral to assessment	8	9	9	9	9	9	9	9
Mean assessment to admission	40	25	28	31	14	14	23	17
Mean referral to admission	47	34	37	39	23	22	32	25
Patient Categorisation								
% reported	100%	100%	99%	100%	99%	100%	100%	100%
% admissions for cat. A (clinical impression)	78.4%	90.7%	87.6%	85.5%	94.6%	100.0%	100.0%	98.1%
% WOBDs for patients in category A	87.5%	91.7%	93.6%		98.4%	97.5%	100.0%	
% total ≥ 30	78.0%	87.6%	88.6%	84.6%	97.9%	96.8%	100.0%	98.2%
% WOBDs for patients with PCAT total ≥ 30	89.6%	92.7%	92.6%		98.4%	99.3%	100.0%	
Complexity (serial RCS-E scores)								
RCS-E v12 score (mean)	14.0	14.3	14.2	14.2	15.5	15.7	15.9	15.7
% High/Very High assessments	93.6%	94.4%	91.4%	93.2%	97.8%	99.7%	99.6%	99.0%
Functional gain (FIM+FAM scores)								
% reported	98%	100%	99%	99%	96%	97%	96%	96%
Motor score on admission (mean)	38.7	37.0	37.5	37.7	27.9	26.6	23.9	26.2
Motor score on discharge (mean)	54.1	53.6	54.2	54.0	46.8	43.5	38.1	43.0
Motor gain during episode (mean)	15.4	16.7	16.7	16.2	18.9	16.9	14.3	16.8
Cognitive score on admission (mean)	42.9	40.9	40.0	41.3	38.3	36.2	32.8	35.9
Cognitive score on discharge (mean)	56.0	52.8	53.1	54.0	48.8	46.2	42.6	46.0
Cognitive gain during episode (mean)	13.1	11.9	13.0	12.7	10.5	10.0	9.8	10.1
FIM+FAM efficiency (median)	**0.2**	**0.2**	**0.2**	**0.2**	**0.2**	**0.2**	**0.1**	**0.2**
FIM+FAM efficiency (pop. mean)	**0.3**	**0.3**	**0.3**	**0.3**	**0.3**	**0.3**	**0.2**	**0.3**
Reduction in cost of ongoing care								
% reported (optional)	96%	98%	94%	96%	99%	99%	100%	99%
Mean NPCNA cost/week on admission	£2235	£2262	£2154	£2218	£2095	£2153	£2383	£2203
Mean NPCNA cost/week on discharge	£1868	£1835	£1721	£1810	£1577	£1683	£1918	£1718
Mean saving in cost/week	£367	£427	£433	£408	£518	£469	£465	£485
NPCNA cost efficiency index (median)	**0.0**	**0.6**	**1.2**	**0.4**	**4.5**	**4.4**	**3.3**	**4.0**
NPCNA cost efficiency index (pop. mean)	**3.4**	**4.2**	**4.2**	**3.9**	**5.7**	**5.2**	**4.6**	**5.2**

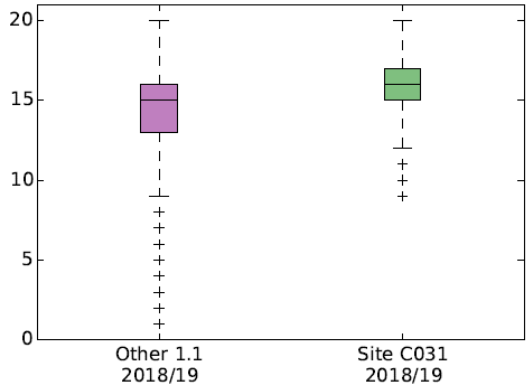
Please note... the raw data used to generate these reports is still in the process of being cleaned.

C031: Regional/Hyperacute Rehabilitation Unit, Northwick Park Hospital

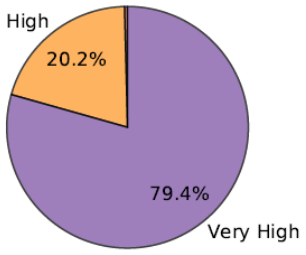


C031: Regional/Hyperacute Rehabilitation Unit, Northwick Park Hospital

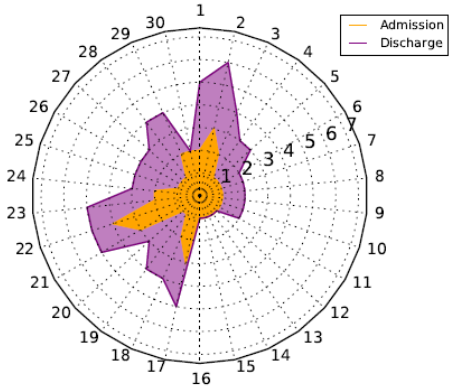
RCS-E v12 total



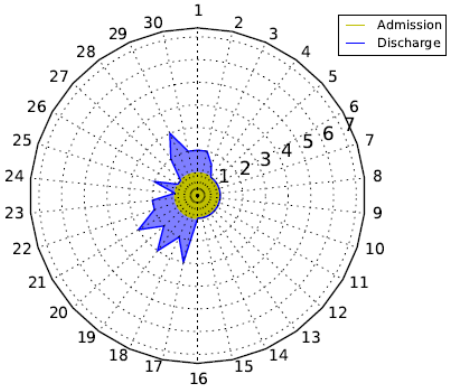
RCS-E complexity (Site C031) - 2018/19



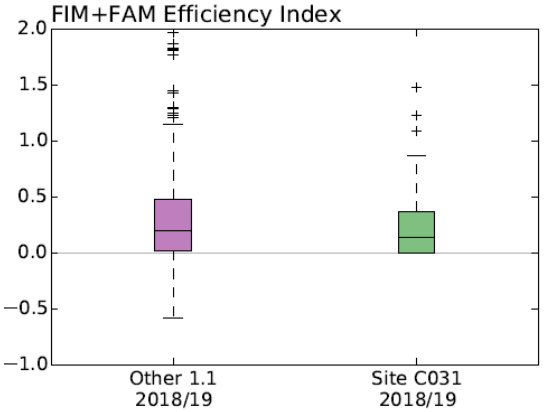
FIM+FAM splat (Other 1.1) - 2018/19



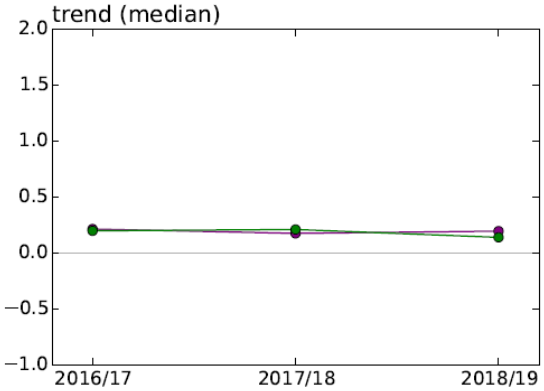
FIM+FAM splat (Site C031) - 2018/19



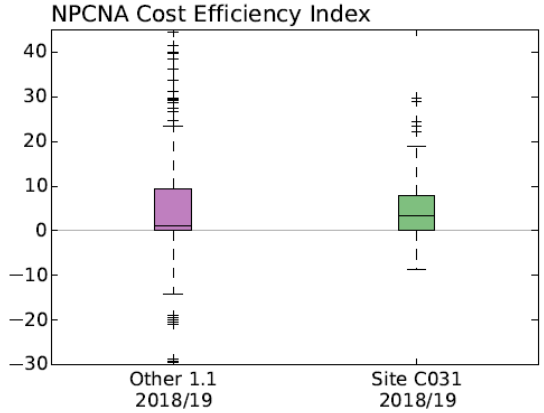
FIM+FAM Efficiency Index



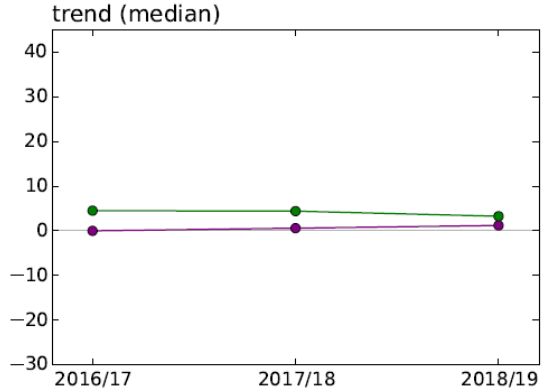
trend (median)



NPCNA Cost Efficiency Index



trend (median)



Appendix 2: UK ROC process specific request for bespoke analysis

Title of project:	

Background and overview	Why do you want to do this analysis? What is it that you want to know? – state broadly what you are hoping to get from it and how the information will be used

Methods	If this is part of a broader project describe how the UKROC analysis will fit into that
Provider permissions	If individual providers are to be named / or identifiable (for example because there are only a few within the scope of the analysis, you are responsible for obtaining their permission to release the data – please confirm that this has been obtained and how.

Project Team	Who is involved in this project: Who is leading it? Please state any other organisations / data sources involved
UKROC recognition	How will UKROC's input be recognised
Funding	How will UKROC's input be funded: Are you requesting this as part of the NHSE funded workplan or are you proposing to seek additional funding – if so from where

UKROC data request for bespoke analysis

Questions	State specifically the questions you are asking

Design:	e.g. Retrospective observational analysis
Data source:	**UKROC database**
Data extraction	Time frame: e.g. 1 April 2012-31 March 20119 (7 years) Scope: Is there geographical limitation? If so how? • Specified providers? • Specified CCGs?

Inclusion/exclusion criteria:	• Eg All patients admitted and discharged to [specify which] neuro-rehabilitation between [dates]
	• Exclusions eg:
	  ○ Admissions for Rehab only?
	  ○ Age range?

Variables	• Give broad description of variables of interests eg
	  ○ Pt socio-demographic characteristics:
	  ○ Clinical characteristics:
	  ○ Process data – eg waiting times, LOS
	  ○ Complexity data
	  ○ Outcomes – descriptors eg discharge destination
	  ○ Outcomes measures of….

Analysis	Give brief overview of the types of analysis you are looking for
	1. Descriptive statistics:
	• Comparative stats - specify comparator
	  ○ Within groups between groups etc
	• Regression / modelling
	• Psychometric analysis
	• Economic analysis
	2. Bench-marking / audit
	  • Compare with … UK average / peer group of services (specify)

Time scale	When are you hoping to have this analysis by?

Signed:

Person requesting data analysis:

Organisation

Contact details

Appendix 3

DATA SHARING AGREEMENT – UKROC DATASET

Title of project:	

Background	

Methods	

Research Team	

UK ROC data sharing application form

Aim:	

Method:	

Design:	e.g.Retrospective observational analysis
Data source:	UKROC database
Time frame:	E.g. 1 April 2009 -31 March 2014 (5 years)
Inclusion/exclusion criteria:	• Eg All patients admitted and discharged to [specify which] neuro-rehabilitation between [dates] • Exclusions:
Variables	• Give broad description of variables eg ○ Pt socio-demographic characteristics: ○ Clinical characteristics: ○ Process data – eg waiting times, LOS ○ Complexity data ○ Outcomes – descriptors eg discharge destination ○ Outcomes measures of….
Preparatory work	• Data will be cleaned • All individual patients will be allocated a unique but arbitrary number (that non-patient identifiable) • Format in excel spreadsheet
Analysis	Give brief overview of the types of analysis 3. Descriptive statistics: • Comparative stats - specify comparator ○ Within groups between groups etc • Regression / modelling • Psychometric analysis • Economic analysis 4. Bench-marking / audit • Compare with … UK average / peer group of services (specify)

Data fields required

In order to …… we propose to use the data collected in the UK specialist Rehabilitation Outcomes Collaborative (UKROC) database.

The data fields that we would like to use and the purpose for which the data will be extracted are listed in Table 1 below. EG

Data fields	**Potential use**
UKROC IDs	
Patient's age at admission	To group patients based on ages
Unit IDs	To build different models for different units
Date of referral	To estimate the probability of patient arrival at a given time
Date of assessment	To estimate the waiting time
Date of decision	To estimate the waiting time
Waiting times	Referral to assessment, assessment to admission, Referral to admission
Date of admission	To estimate the waiting times and LOS
Date of discharge	To estimate the length of stay
Length of stay	Excluding any interruptions to treatment
Source of referral	To model the demand transfer between units
Discharge destination	To model the demand transfer between units
Mode of discharge	To model the demand transfer between units
3-tier condition/aetiology classification	To group patients based on diseases
Admission complexity scores (RCSv13) - itemised	To understand the patient's complexity of rehabilitation needs on admission
Discharge complexity scores (RCSv13) - itemised	To understand patient needs for rehabilitation at discharge and change in need during programme
CCG name and NHSE local area team	To group patients based on CCG
Other data	

We would like to request data for

Data fields	**Potential use**
Participants	Which groups of patients?: • Diagnostic categories • Age range • Range of Length of stay
Dates	Period of interest
Geographic location	Limited area? • By provider • By CCG

Information Governance

While using the UKROC data for analysis, we will ensure the data privacy and confidentiality during and after the project.

- We confirm that the data and information collected and created in this project would be regarded as confidential, and would not be disclosed to any other party unless it's permitted.
- The analysis dataset will be kept at all times on the secure server at Northwick Park.
- Only aggregate data will be saved for external use
- No raw data will be stored on any external computer / drive
- The data management and analysis processes will comply with the Data Protection Act.

We confirm that the data will be used only for the purpose of this project. The data will return to UKROC for safe keeping when the project ends, i.e., all data analyses are finished and related manuscripts (if any) are submitted.

- The name of the person with overall responsibility for the security of the dataset is:

- The names of the individuals that will have access to the data are:

Applicant

Name	
Institution	
Date of application	

Application

Date received	
Approved	Yes / No / with qualification Date
Signed	Director of UKROC, on behalf of data custodians