National Joint Registry
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NATIONAL JOINT REGISTRY STEERING COMMITTEE

MINUTES

Meeting: Steering Committee meeting 2003/ No. 7 Date: Monday 29 September 2003

Location: BOA, The Royal College of Surgeons, 34 – 43 Lincoln's Inn Fields, London WC2A 3PN

Present:	Bill Darling	BD	Chair
	Paul Gregg	PG	Vice chair
	Jan van der Meulen	JM	Royal College of Surgeons (representing the surgical profession)
	Andy Smallwood	AS	NHS Purchasing and Supply Agency
	Alex MacGregor	AM	St Thomas' Hospital (representing public health and epidemiology)
	Martyn Porter	MPo	British Hip Society
	Tim Wilton	TW	British Association for Surgery of the Knee
	Colin Thomson	CT	All Wales Community Health Councils (patient group representative)
	Andy Crosbie	AC	Medicines and Healthcare products Regulatory Agency (MHRA)
	Chris Dark	CD	Director of Clinical Services, BUPA Hospitals (representing the IHA)
	Sally Couzens	SCo	National Association of Theatre Nurses
	Paul Woods	PW	Department of Health
	Stephen Chamberlain	StC	National Assembly for Wales
	Elizabeth Noakes	EN	Arthritis Care (deputising for Neil Betteridge)
	Ken Bateman	KB	Smith & Nephew Healthcare Ltd, ABHI (representing the orthopaedic device industry)
	Colin Howie	CH	Scottish Executive (observer status)
	Fiona Davies	FD	AEA Technology (contractor)

The following AEA Technology staff were also present:

David Carter	DC	NJR Project manager
David Pegg	DP	NJR IT Project manager
Sandra Hasler	SH	NJR Communications manager

Apologies Mick Borroff (DePuy International Ltd)
Christine Miles (representing NHS Trust management)
Hugh Phillips, British Orthopaedic Association (representing the surgical profession)

Item	Welcome and Introductions	Action by
1	The meeting opened at 10.30. BD welcomed all SC members present.	
2a	**Progress on actions** See Appendix 1.	
2b	**Approval of minutes – NJRSC (03) 31** Minutes were approved. **[Action 2003 /114]** AEAT to make minutes available on the NJR website.	 **AEAT**
3	**Potential Participation in the European Arthroplasty Register (EAR) – NJRSC (03) 37** PG asked the SC for their feedback to the paper circulated for information. The following issues were raised. • the NJR and current EAR minimum datasets are notably different. • the NJR has not yet achieved a compliance level of 90 - 95% so a dataset submitted at this point would not be considered complete. • participation would be of considerable value if surgeons and patients were transferred across national boundaries. • involvement in EAR could be a conduit to European Research. • the National Pacemaker Database (NPD) has undergone a parallel process and the NJR could learn from their experiences. • issues relating to the current status of the EAR MDS (e.g. can the NJR influence it?), definitions of the terms used, and implications for NJR patient consent need to be explored. **[Action 2003 /115]** AEAT to contact the NPD. It was agreed that before a decision to whether the NJR would participate could be taken more discussion with the EAR was required. **[Action 2003 /116]** AEAT to contact the EAR.	 **AEAT** **AEAT**
4	**IT update** DP outlined the following: • No major IT updates were made to the NJR data entry system during the reporting period. • The NJR data entry system did not experience any unscheduled down time, particularly noteworthy due to the recent spate of viruses. • A new system is being developed to improve the management of missing components, or those components poorly labelled or which the user perceives to be missing. • AEAT has received the National Strategic Tracing Service (NSTS) contract for signature. • NJR data entry training took place at the Queen Elizabeth Hospital in	

	Woolwich and at the BOA Congress. Training is arranged in response to direct requests from users. This process is managed by and through the NJR Centre with RCCs and other local hospitals involved as appropriate. • The current NJR MDS is now in the NHS data dictionary as a formal data collection process. **NJR statistics** DP outlined the following: • More than 20,000 operations (completed records) have been recorded on the database to date. • An average of about 800 operations are being recorded per week. • There is an expectation that the number of operations recorded on the database will increase as a result of the letters sent to NHS Trusts CEx where the data entries are zero. • For some hospitals, the numbers of hip and knee operations entered into the NJR are at a much lower rate than would be expected from comparison with 2000/01 HES data. The following issues were discussed: • Some hospitals are still collecting data on paper proformas alone and have not allocated local resources to enter data electronically. • A significant number of electronic records have not been entered due to specific hospitals awaiting the availability of the bulk data upload facility, this does not, however, account for all the current shortfall in total numbers expected. • CHAI who are developing audits on a national basis have stated that hospitals need to provide local facilities to input data. Prof Sir Ian Kennedy, chair of CHAI, has been contacted to discuss how the NJR can feed into the functions of CHAI. • Compliance is the responsibility of the NHS Trust CEx and is also a measure of their delivery of Clinical Governance. • PW forwarded details of NHS Diagnostic & Treatment Centres (DTCs) to AEAT. DTCs require unique ID codes (as each hospital currently has). The same applies to the recently announced independent sector treatment centres (ISTCs) and the preferred bidders. Compliance with the NJR is written into the ISTCs. • There is a need to look at the definitions of 'Consultant in charge' and 'Lead surgeon' in the current MDS since their current intended use could be misinterpreted within DTCs / ISTCs (this is addressed in section 10 - Reviewing the MDS). **[Action 2003 /117]** BD to raise the issue of resourcing Trusts with Lord Warner. **[Action 2003 /118]** PW requested that models of good practice, i.e. demonstrations of how hospitals have implemented the NJR within their local systems, be made available on the NJR website. **[Action 2003 /119]** PW requested that future statistics reports also include separate totals for the NHS and Independent hospitals.	**BD** **AEAT** **AEAT**

	[Action 2003 /120] PG to contact Southport and Ormskirk Hospital to ensure overseas orthopaedic surgical teams are capturing NJR data.	**PG**
	[Action 2003 /121] AEAT to check that DTCs have OCS codes assigned. If not, unique IDs should be allocated.	**AEAT**
	[Action 2003 /122] AEAT to contact each DTC and obtain key contact details and enquire as to their state of readiness for compliance with the NJR.	**AEAT**
	[Action 2003 /123] AEAT to obtain estimates of numbers of paper proformas awaiting electronic data entry, including identification of locations with sizeable backlogs and how the trusts / independent healthcare providers are intending to address them.	**AEAT**
5	**Reporting the NJR statistics and Annual Report – NJRSC (03) 34** JM summarised the key requirements to ensure delivery of quality data reports, including the desire for a dedicated team and appropriate resources.	
	[Action 2003 /124] JM, AM & AEAT to work together with PW to outline the content of the first years Annual Report and identify the resources required.	**JM, AM & AEAT**
	AC raised the need for annual data reports to be reported on a calendar year (as opposed to reporting on an annual basis from 1 April 2003). This would bring the NJR in line with other databases / registries that MHRA are involved with.	
	[Action 2003 /125] AEAT to confirm annual reporting cycle dates with PW.	**AEAT**
6	**Draft Report on Barcoding Scoping Study – NJRSC (03) 39** The NJR currently requires the user to enter component details manually. The use of barcode readers could increase the accuracy of data entry and simplify the data entry process for components. DP summarised the issues that have arisen from the study: • Barcode readers would simplify the data entry process for components but could not totally automate the process. • There would be a cost implication for hospitals, since each PC used to enter NJR data would need a barcode reader and software (and there would be associated training costs in most cases). • Not all suppliers provide component ID barcodes on the component packaging and many do not provide them as detachable sticky labels (the NJR proformas require the sticky labels to be affixed). • There is variability in the barcode formats used by suppliers. • The NJR system could need modification if suppliers changed their barcode systems. • There could be cost implications for suppliers if there was a national or European barcoding system. PASA have expressed an interest in working with the results from the survey.	

	AC informed the SC that the European standard for implants is due to be revised. It was agreed that the AC should contact the relevant Commission to include the NJRs requirements in the revised standard. **[Action 2003 /126]** AC to write to the Commission to include the NJRs requirements in the revised standard. It was agreed that the SC needed to know the cost of implementing a barcode reader system within the NJR. **[Action 2003 /127]** AEAT to provide an estimate of the cost (including the costs to hospitals and the cost of NJR development) to implement a barcode reader system.	**AC** **AEAT**
7	**Cost of the Levy for FY 2004/05 – NJRSC (03) 40** PW summarised the key issues that needed to be considered in setting the levy for the next financial year (i.e. FY 2004/05): • The DoH must not make a profit from the NJR levy. • The levy must be set at a rate that covers the costs of running the Registry. • Whilst the levy has not yet been collected for a full 12 months, the present levies collected and the expenditure to date indicate that the current levy rate is appropriate. The SC agreed that the levy should remain at £25.00 for the FY 2004/05.	
8	**Report from the BOA Congress** The BOA Congress had more than 1000 delegates attending. The NJR had a stand in a prominent position. PG provided the following feedback he received from delegates: • Individuals felt that their visit to the NJR stand had been worthwhile. • There were still some concerns about the possibility of league tables emerging but there were no great criticisms. FD provided the following feedback the NJR Centre had received: • Delegates who visited the NJR stand had high awareness of the NJR and had specific individual queries. • Some delegates had suggestions on what should be included and excluded from the minimum datasets (MDS). All suggestions were provided to the relevant MDS working group for consideration. • The format of the CSV files that surgeons can download to look at their own data is generally found to be too comprehensive. AEAT are investigating ways in which to improve the format to allow easy reference. PG requested (on the behalf of the BOA Council) for the SC to provide a statement on what resources hospitals need to comply with the NJR. The SC agreed that a response should be made but it should be appropriate to both the NHS and the independent sector. It was agreed that the statement should be made available on the NJR website, be provided to the RCCs and placed on the BOA Clinical Director / Lead Clinician Network website.	

	[Action 2003 /128] BD, PG & PW to provide a statement to the BOA Council on what resources hospitals need to comply with the NJR. **[Action 2003 /129]** AEAT to place the statement on the NJR website and to make it available to the RCCs and BOA Clinical Director / Lead Clinician Network website.	**BD, PG & PW** **AEAT**
	AOB **Dates for future meetings** The following dates for future SC meetings were proposed and agreed. **2003** Wednesday 17 December **2004** Thursday 15 January Monday 19 April Thursday 15 July Thursday 21 October	
(ii)	**Agenda items for next meeting** The next meeting (Wednesday 17 December) will primarily look at the NJR's future activities and will include the following: • Level of patient consent (suitably detailed to account for first few months of NJR release) • Annual reporting (content outline and responsibilities) • Proposed Patient Feedback Questionnaire process – for review.	
10	**Reviewing the minimum dataset (MDS)** BD thanked PG for managing the review of the MDS with the MDS working groups. The Hip MDS working group met on 24 September and the Knee MDS working group met on 25 September. PG reported that the two review meetings had been productive and a consensus for each MDS had been reached. DC prepared the MDS documents over the weekend 26-28 September in time to table them for this Steering Committee meeting. This tight timescale meant that both the members of the Steering Committee and the Programme team were seeing the revised MDS for the first time. This did not allow the AEAT IT manager to review implications for the amount of effort and the timescale required for necessary IT development. **[Action 2003 /130]** AEAT to update the programme plan to reflect all the activities related to putting MDS v2 in place. TW requested that the proposed Knee MDS be forwarded to BASK for	**AEAT**

	consideration (at their committee meeting due to take place at the end of October). BD explained that there could be no further delay in the preparation of the MDS for the associated IT development to progress in readiness for pilot phase to commence in early January 2004. The next SC meeting is not due until 17 December 2003. PG noted that BASK and BHS representatives had been involved in the review of the relevant MDS via the MDS working groups. DC circulated the documents that reflected the proposed revised Hip MDS and the Knee MDS. PG & DC explained the reasons behind the proposed changes. Some inconsistencies were identified and discussion took place concerning some of the proposed changes. PG requested that the members of the MDS working groups be provided with the relevant updated MDS document for reference, and to confirm that interpretation of their original comments was correct. **[Action 2003 /131]** AEAT to amend the MDS documents to reflect SC discussion / decision and provide a copy to BD, PG & the members of the MDS working groups for review. PG reported that the MDS working groups also considered the Patient Feedback Questionnaire process. The working groups proposed that the hip and knee questionnaires should be sent at one, five and ten year intervals and should reflect the Oxford Hip and Knee Scores but should also include five generic questions (to include for example, a 'satisfaction' question with a yes/no answer, and perceived complications). Further advice was required from statistician and epidemiological sources to define a cohort size and stratification required. **[Action 2003 /132]** JM & AM to advise AEAT on the sample size required. The MDS working group discussions will be considered in the preparation of AEAT's paper.	**AEAT** **JM & AM**

Sandra Hasler
Communications Manager, NJR Centre
6 October 2003

APPENDIX 1

Action no.	Progress	Action holder
Actions from January 2003 meeting		
2003 / 16	**Ongoing** The BHS and BASK to discuss how differences in epidemiological case mix for surgeons may be statistically addressed to ensure balanced reporting. It was agreed that both specialist societies (BHS and BASK) are well placed to consider whether there are any obvious omissions in the NJR MDS that would need to be addressed to take epidemiological case mix into full consideration for subsequent reporting. When reviewing the MDS, BHS & BASK should bear in mind that compliance with the NJR should not be hindered by a lengthy MDS. This was addressed by BHS and BASK representatives on the RCC MDS working groups, meeting on 24 and 25 September.	**MPo / KT & TW**
2003 / 20	**On hold to late 2003** Preparation of a paper on the benefits and financial implications that a PKI system would bring to the NJR.	**AEAT**
Actions from March 2003 meeting		
2003 / 44	**Completed** The NJR Centre now have contacts for all current 21 suppliers.	
2003 / 45	**Ongoing** The MOU content has been agreed by all parties involved. There is an outstanding issue with regards to VAT charges to charities. **PW to provide update**	**PW**
Actions from April 2003 meeting		
2003 / 63	**Ongoing** AEAT to provide a method of monitoring outstanding incomplete records' i.e. by hospital, and a plan of follow-up action. This action will form part of the participation and compliance procedures.	**AEAT**
2003 / 64	**Ongoing** PW and DC to look at the value of using peripatetic nurses (or similar) as part of the participation and compliance procedures. Action addressed in May and July SC meetings.	**PW / DC**
2003 / 67	**Superseded by Actions 2003 / 101 and 102** Once the amended MDS has been approved by ROCR, AEAT to update the NJR system to incorporate the amended MDS and to develop the bulk upload facility. Development of the bulk upload facility is on hold until version 2 of the MDS and related further development of the IT solution has been completed.	**AEAT**
2003 / 68	**Superseded by Action 2003 / 100** AEAT informed hospitals that the bulk update facility will be developed. Those hospitals that have indicated they are awaiting development of the bulk upload facility have been contacted individually to appraise them of the	**AEAT**

	latest situation (see Action 2003 / 67 above). Details also included in Issue 3 of the NJR newsletter.	
Actions from May 2003 meeting		
2003 / 82	**Completed** AEAT issued the "Possible options for reporting framework" paper to RCCs on 17 June 2003 and requested feedback by 31 August.	
2003 / 84	**Completed** Some SC members provided feedback on stakeholder group expectations and comments on the "Possible options for reporting framework" paper.	
2003 / 87	**Completed** FD received feedback from the SC and RCCs on options for reporting framework.	
2003 / 90	**Superseded by Action 2003 / 113** JM will approach the BOA and its specialist societies for orthopaedic representation on the research subcommittee.	
2003 / 91	**Ongoing** SC members are asked to identify suitable patient and industry representatives for the research subcommittee and forward suggestions to Jan van der Meulen.	**All SC members**
2003 / 92	**Completed** AEAT revised paper NJRSC (03) 30 (Development of a participation and compliance network) to include a job description for the staff role and the costs of implementing such a network. Job description amended to include data accuracy and completeness.	
2003 / 94	**Completed** Guernsey have indicated that they wish to join the NJR.	
2003 / 96	**Superseded by Actions 2003 / 101 and 102** ROCR approval of "Reoperation other than revision" is on hold until final changes to the MDS have been made. ROCR approval will be sought following final changes.	**AEAT / PW**
2003 / 97	**Completed** AEAT / PW and BD reviewed the NJR workplan to determine suitable future meeting dates. Dates were agreed by the SC at the September meeting.	
2003 / 99	**Completed** Minutes for May SC meeting have been made available on the NJR website.	
Actions from July 2003 meeting		
2003 / 100	**Completed** AEAT informed all hospitals of the NJR MDS, management and technical requirements necessary to comply. AEAT communicated with all hospitals who expressed an interest in Bulk Upload to confirm that they are required to capture data on paper proformas or submit electronically via the NJR data entry system.	
2003 / 101	**Completed** PG and MDS working groups reported to the SC their suggested amendments to the current NJR MDS.	

2003 / 102	**Ongoing** The MDS has been reviewed and agreed by the NJR SC. AEAT to develop the NJR database to reflect the updated MDS (Version 2.0) ready for general release on 1 April 2004.	**AEAT**
2003 / 103	**Completed** AEAT forwarded a copy of minutes of the meeting with MHRA, PASA and DoH to all SC members.	
2003 / 104	**Ongoing** AEAT to provide RCCs with identifiable data (at the hospital level) for hospitals in their own SHA / Welsh health region for the next RCC meeting (on 27 October 2003).	**AEAT**
2003 / 105	**Completed** AEAT confirmed which Trusts have not submitted any data records. BD and PG wrote to all Chief Executives where no records have been submitted to the NJR.	
2003 / 107	**Completed** CM and DC to liase on job detail and salary for 'participation and compliance network staff'. DC and PW to liase with regard to costs and value for money. See also Action 2003 / 92.	**CM, DC & PW**
2003 / 108	**Ongoing** MDS Working parties (PG) provided feedback on the PFQ process. The Patient Feedback Questionnaire process is under ongoing development, involving liaison with RCCs and others. A paper will be presented to the December SC meeting.	**AEAT**
2003 / 109	**Completed** AEAT conducted a scoping study for the use of barcode readers and reported its outcomes at the September SC meeting.	
2003 / 110	**Completed** AEAT clarified that the NJR gives the Consultant in charge access to the lead surgeon's data.	
2003 / 112	**Completed** An RCC had offered his resignation due to a lack of support from his hospital management. Resignation withdrawn for at least 6 months on the understanding that he would receive support in dealing with issues in his hospital.	
2003 / 113	**Ongoing** JM to write a letter to the BOA requesting members to be put forward to sit on the NJR Research subcommittee. Reply awaited from BOA.	**JM**