National Joint Registry
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NATIONAL JOINT REGISTRY STEERING COMMITTEE

MINUTES

Meeting: Steering Committee meeting 2003/ No. 8 Date: Wednesday 17 December 2003

Location: BOA, The Royal College of Surgeons, 35 – 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)
	Christine Miles	CM	Royal Orthopaedic Hospital (representing NHS Trust management)
	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)
	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
	Mick Borroff	MB	DePuy International Ltd, ABHI (representing the orthopaedic device industry)
	Fiona Davies	FD	AEA Technology (contractor)

The following AEA Technology staff were also present:

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

Apologies Hugh Phillips, British Orthopaedic Association (representing the surgical profession)
Chris Dark, BUPA Hospitals (representing the IHA)
Ken Bateman, Smith & Nephew Healthcare Ltd, ABHI (representing the orthopaedic device industry)
Colin Howie, Scottish Executive (observer status)
David Carter, NJR Project manager, AEA Technology

Item	Welcome and Introductions	Action by
1	The meeting opened at 10.30. BD welcomed Elizabeth Noakes as the Steering Committee member representing Arthritis Care (replacing Neil Betteridge).	
2a	**Progress on actions** Appendix 1 incorporates updates and progress on actions. The following actions were discussed. Action 2003 / 116 - Further discussion with the European Arthroplasty Register (EAR) is required before a decision can be taken on whether the NJR will participate. It was agreed that Dr Gerold Labek, EAR Coordinator, would be invited to the April SC meeting to give a presentation. It was agreed that AEAT would provide SC members with a concise background document ahead of the meeting. Action 2003 / 117 - Lord Warner confirmed that resources for implementing the NJR within individual hospitals needed to come from existing Trust funds. Action 2003 / 126 - The European standard for non-active surgical implants is due to be revised. AC has written to the relevant Commissioner requesting that the NJR's requirements are included in the revised standard. AC agreed to produce a discussion document for the relevant committees. AC has been invited to attend an ABHI – OSIS meeting (January 2004) to discuss barcode requirements and gain supplier feedback.	
2b	**Approval of minutes – NJRSC (03) 41** Minutes were approved. **[Action 2003 /133]** AEAT to make minutes available on the NJR website.	**AEAT**
3	**Update on Progress (non IT)** FD provided and update on progress on the following. **Regional Participation Co-ordinators (RPCs)** • Positions were advertised in the Health Services Journal, Nursing Times and on the Monster job website, as well as via the RCC network • 12 people invited to an NJR presentation day • 3 posts have been offered • Staff induction due to commence 19 January 2004 • 1 full-time (or 2 part-time) vacancies still exist to cover London /SE /East Anglia **Future Events** The NJR Centre will be present at the following: • Welsh Quality Forum, 17 January 2004 • National Patient Safety Agency (NPSA) Conference, 24-25 February 2004 • BHS AGM, 4 – 5 March 2004 • BASK AGM, 2 April 2004 • BOA, September 2004	

	Joint Approach - Newsletter • Issue 4 of the newsletter (December / January) has been drafted and will be forwarded for approval • BD suggested that NJR-related research be covered in the newsletter. As Chair of the NJR Research subcommittee, JM agreed but suggested this as a topic for issue 5 (March). **[Action 2003 /134]** JM to provide SH with an article on NJR research in time for the next issue of the newsletter (end of February 2004). **Trusts with nil returns on the NJR** It has been recognised that not all the Trusts on the current NJR nil-returns list are undertaking orthopaedic procedures, and that approximately only 40 of the trusts listed should be participating. It was suggested that the listed Trusts that do not need to participate should be deleted from the NJR. FD reported that some surgeons have registered themselves to some of these hospitals and some of the Trusts on the list are known by another name. The NJR Centre is making further enquiries. **[Action 2003 /135]** AEAT to continue to follow-up, and delete from the NJR, all the Trusts that do not need to comply with the NJR. CM has contacted the Chief Executives (CExecs) from 6 of the larger non-participating Trusts directly. This involved a phone-call pointing out some of the potential problems and how they can be addressed, followed by a letter. All the CExecs fed back that they did not know of the NJR, despite five NJR-related announcements in the NHS Chief Executive bulletins. CM will continue to contact those CEs from the hospitals not yet participating. It was agreed that Trusts should be contacted once more by directing nil-return notification letters to the hospital's Medical Director. If no response is received further follow-up action should include the NJR Centre making contact with the appropriate Strategic Health Authorities. MB felt that his company's sales managers could quickly identify if a particular trust carries out hip/knee joint replacement procedures. MB agreed to liase with the NJR Centre outside the meeting to obtain electronic copies of the current nil-return listing. **[Action 2003 /136]** AEAT to direct nil-return notification letters to the non-participating hospital's Medical Director.	**JM** **AEAT** **AEAT**
4	**IT update and data reporting** **NJR statistics** • More than 35,000 operations (completed records) have been recorded on the database to date. • The number of NJR participating hospitals continues to increase. DP asked whether the SC would like any further data included in the NJR statistics report. He also queried whether any of the current reporting was	

	considered to be of limited value and could be removed from the template. It was agreed that: ▪ the % of incomplete records on the NJR for each hospital should be included (i.e. records that have been entered but not yet submitted) ▪ the level of patient consent obtained for each hospital should be included ▪ the statistics report should be circulated in advance of the SC meetings. **[Action 2003 /137]** AEAT to include the % of records remaining in the edit stack and level of patient consent obtained for each hospital and circulate NJR statistics reports in advance of SC meetings. All Treatment Centres (TCs) are associated with NHS trusts (plus one independent) and have been given unique NJR codes to segregate their data from the parent trust data. As yet, no data has been submitted under the identity of the TCs. This means for those TCs that are open (undertaking orthopaedic procedures) and complying with the NJR the data is being submitted under the parent trust. It was noted that there are some unexpectedly high submission rates for some trusts; this could be due to the submission of TC data. It was agreed that where this appeared to be the case the TC should be informed of the need to submit data separately. **[Action 2003 /138]** AEAT to contact the TCs that are undertaking orthopaedic procedures and encourage them to enter data as the TC rather than the parent trust. **MDS v2 progress** • It was agreed that AEAT would resolve any coding issues for MDS v2 data fields and use OPCS codes where they are appropriate. AEAT will report back on actions taken at the next SC meeting in January 2004. • The data entry of MDS v1 and MDS v2 was discussed, and in particular the length of time the NJR system should allow both datasets to be entered. It was agreed that the NJR system should allow MDS v1 and MDS v2 data to be entered in parallel for a period of two months, i.e. from 1 April until 31 May 2004 (subject to the launch of MDS v2 on 1 April 2004). Hospitals need to be encouraged to enter any backlog of data from MDS v1 (i.e. data collected on paper proformas only) as soon as possible. Post 31 May 2004, hospitals that wish to retrospectively enter MDS v1 data will need to contact the NJR Centre to request access to the MDS v1 data entry screen. • It was accepted that there would be no bulk upload facility for MDS v1 data. • The launch date of MDS v2 is 1 April 2004 (subject to ROCR approval). It will be essential for hospitals to collect the MDS v2 on revised proformas from 1 April. • The pilot of the MDS v2 paper proforma is underway. Various communication routes for raising awareness of the need for hospitals to complete revised proformas for MDS v2 were discussed, including: • Messages on the data entry system itself • Newsletter and website articles • The RCCs and RPCs as conduits	**AEAT** **AEAT**

	• Direct mail It was pointed out that the paper proformas are often provided in a surgeon's notes 4 - 6 weeks prior to the operation (i.e. at the time of the pre-operative assessment) so it would be critical for the MDS v2 proforma to be made available to hospitals in mid-February 2004. It was agreed that hospitals would be more likely to respond to NJR communications if the NJR formed part of the hospital's star-rating (under good medical care). **[Action 2003 /139]** BD and PG to raise the issue of NJR potentially forming part of a hospital's star-rating with Lord Warner.	**BD & PG**
5	**Feedback from the RCC network** It was agreed that the SC should receive the draft minutes from the last RCC meeting (October 2003). It was also agreed that the SC should receive the minutes from future RCC meetings. **[Action 2003 /140]** AEAT to circulate draft RCC meeting minutes to the SC. PG introduced the following: It was understood that BASK had nominated TW to be the BASK representative on the NJR Research subcommittee. **[Action 2003 /141]** TW to confirm with Neil Thomas, BASK President, that this was acceptable. The RCCs had suggested that the clinical members of the NJR Research sub-committee be in position for a maximum of 3 years. It was recommended that the BASK and BHS places on the sub-committee should remain. The SC agreed to consider this suggestion. RCC feedback also included the following: • Non-compliance issues appeared to be resource related. PG offered his support and asked for RCCs to direct letters detailing hospitals issues directly to him. To date PG has received no letters. • The development of a barcode reader system was seen as essential to increase and speed-up compliance. • The SC should be more proactive in follow-up action with the non-complying hospitals. • Sight of the draft annual report was requested for RCC comment. It was suggested that an RCC be included on the annual report editorial board. It was agreed that the constitution of the Research subcommittee be addressed at the next SC meeting (15 January 2004). BD requested a note for the record of the Research subcommittee constitution for the next SC meeting. **[Action 2003 /142]** JM to provide a note for the record of the Research	**AEAT** **TW** **JM**

	subcommittee constitution for the next SC meeting (15 January 2004).	
6	**Briefing on patient consent review – NJRSC (03) 45** SH outlined the following: NJR database statistics show that for the records submitted, 65% indicate that patients have consented to their personal details being recorded on the NJR. There is a need for the NJR patient consent form to be amended to remove any ambiguity arising if the patient had signed the form but there is no tick mark recorded in the 'yes' or 'no' box. **[Action 2003 /143]** AEAT to amend the NJR patient consent form with sentences beginning with 'I consent' and 'I do not consent' with room for the patient signature alongside. At present the data entry system records patient consent as a 'yes' or a 'no'. However, it is suspected that in some hospitals the NJR patient consent form is not available at time of data entry and as a result patient consent is being recorded as a 'no'. To help monitor where this is the case the data entry system needs to be amended. **[Action 2003 /144]** AEAT to develop the NJR data entry system with the capability to record where patient consent is definitely a 'no', a 'yes' and a 'Don't know' (i.e. no form available at time of data entry). It was agreed that an article on 'patient consent' would be included in the next issue of the NJR newsletter (March 2004). It was recognised that both the RCCs and the RPCs would play an important role in establishing what the actual situation is in each hospital.	**AEAT** **AEAT**
7	**Proposed NJR patient feedback process – NJRSC (03) 43** It was noted that the MDS provides 'hard' data, i.e. factual data, whereas the PFQ provides 'soft' data, i.e. what the patient is feeling, for example, the pain associated with the replacement. DP outlined the following on the proposed patient feedback questionnaire (PFQ) process: • PFQs would be distributed at 1, 5 and 10 year intervals post-operatively • The process would aim for 8000 returns for each mailout interval • Oxford hip and knee scores would be used It was agreed that the PFQ should include questions on patient satisfaction but should prompt explicit replies, i.e. if patient dissatisfaction was recorded, it also needed to record what the patient was dissatisfied with. It was accepted that more detailed questioning should be covered in appropriate research studies. It was agreed that a second mailing was essential to achieve a good	

	response rate for each PFQ sendout. The PFQ sample size was discussed. Some members of the SC felt that the whole population (i.e. all patients who had undergone total hip or knee replacements in the time interval) should be sent a questionnaire. Other SC members felt that this would be expensive, logistically difficult and random sampling would be sufficient. CM suggested contacting the Picker Institute for advice. Three additional options to the core process were presented in the PFQ paper, PW asked the SC if any of the options should be adopted. PG proposed using questions 1, 2 and 3 (paper NJRSC (03) 43, Appendix 4) plus EuroQol for 1 year. It was agreed that detailed costings for each of the options were required before a decision could be made at the next SC meeting (15 January 2004). **[Action 2003 /145]** AEAT to provide detailed costings for: – each of the three options presented in the PFQ paper – 100% sample coverage – for allowing responses to be returned electronically.	**AEAT**
8	**NJR first annual report** FD outlined the following for the proposed report format: • The annual report would be divided into three parts. • Part 1 would be reader friendly and suitable for all audiences. It would provide an overview of the NJR and its progress. • Part 2 would provide the data analysis • Part 3 would contain the detail in appendices • The publication date proposed was September 2004, to coincide with the BOA Congress. • An editorial board was proposed. It was agreed that the following should be included in the annual report: • Where it was applicable detail would be provided to make the report as clinically relevant as possible. Care would be taken to ensure that any interpretation would be given in the context of the dataset, i.e. the first year of data would be incomplete since the reporting period was 1 April to 31 December 2003. • Part 1 would include a look to the future • The Swedish registry should be invited to provide endorsement commentary to the annual report. • An explanation of how the levy operates. • An explanation of how NJR research will be undertaken It was agreed that: • FD would be the Editor and own the delivery of the report. • The RCCs should nominate an RCC representative to the Editorial board. • MPo would provide orthopaedic input to the report	

	• The NJR Centre would write Part 1 • The NJR Centre and JM (and colleagues) would write Part 2 • Draft chapters of the report should be given early circulation for SC comment. It was agreed that the Editorial board would attempt to answer all questions that the SC put forward. **[Action 2003 /146]** SC members to send questions, that they would like analyses to answer, to FD for the first week in January. PG requested FD to send the RCCs the proposed annual report paper (and JM comments) for their information and comment. **[Action 2003 /147]** FD to send the RCCs the proposed annual report documents and add the annual report format as an agenda item to the next RCC meeting (5 February 2004).	**All SC members** **FD**
(i)	**AOB** **Draft statement on hospital resources** FD presented a proposed statement of resources that hospitals would need to implement the NJR. It was agreed that the SC needed to consider the proposed statement. CM pointed out that trusts needed to approach their PCTs for resources in early January. The SC were asked to send their comments to FD for the first week in January 2004. **[Action 2003 /148]** All SC members to send their comments on the proposed statement to FD by 5 January 2004. It was agreed that the revised statement should be mailed to the Clinical Director for each trust (in England only) in mid-January 2004. **[Action 2003 /149]** AEAT to revise the statement in-line with SC comments and following approval by PW/BD and PG, circulate to the Clinical Director for each trust (in England only) in week commencing 5 January 2004.	**All SC members** **AEAT**
(ii)	**Patient representative on the NJR research subcommittee** PG suggested that a patient representative for the research subcommittee could be identified from a BOA Patient Liaison Group that is due to be formed in February 2004. JM as Chairman of the Research subcommittee, and the SC agreed to the proposal.	
(iii)	**Scotland and the NJR** PW and AEAT met with the Scottish Executive to discuss the potential involvement of Scotland with the NJR. Scotland have an MDS in place for the existing Scottish Arthroplasty Project and have proposed a new MDS for the whole of Scotland. They have	

	compared the new MDS for Scotland with the proposed NJR MDS v2 - parts of them are similar but some elements are different, e.g. Scotland intend to collect additional information on grade of anaesthetist. Conversely, NJR MDS v2 includes fields that are not currently included in the planned Scottish dataset. The NJR MDS v2 is to be circulated to Scottish surgeons by the Scottish Executive/ISD. It is known that Scotland is particularly keen to be allowed access to the NJR components database. The SC agreed that for Scotland to use the NJR they would need to implement it in the same way as hospitals in England and Wales, i.e. to join the NJR and participate as a full partner with England and Wales. Selection of only specific elements was not considered to be of benefit to existing participants or the NJR programme as a whole.	
(iv)	**January SC meeting agenda** The next SC meeting is 15 January 2004 The meeting will be held at the BOA, The Royal College of Surgeons, 35 – 43 Lincoln's Inn Fields, London WC2A 3PN, starting at 10:30 am. Agenda items include: • Patient Feedback Questionnaire process (with detailed costings) • Barcoding scooping study (with full costings) • Update on Annual Report process	

Sandra Hasler
Communications Manager, NJR Centre
6 January 2004

APPENDIX 1

Action no.	Progress	Action holder
Actions from January 2003 meeting		
2003 / 16	**Completed** The differences in epidemiological case mix for surgeons and how they may be statistically addressed to ensure balanced reporting were considered by BHS and BASK representatives on the RCC MDS working groups.	
2003 / 20	**On hold** 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 / 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**
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. It was noted that this action would form part of the participation and compliance procedures. This will form part of AEAT's developing verification and validation strategy.	**AEAT**
2003 / 64	**Completed** PW and DC considered the value of using peripatetic nurses (or similar) as part of the participation and compliance procedures.	
Actions from May 2003 meeting		
2003 / 87	**Completed** FD reported feedback (on options for reporting framework) received from the SC and RCCs.	
2003 / 91	**Ongoing** SC members were asked to identify suitable patient and industry representatives for the research subcommittee. It was agreed that patient representatives would be identified from a BOA Patient Liaison Group which is due to be formed in February 2004.	**All SC members**
Actions from July 2003 meeting		
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 in Spring 2004 (subject to ROCR approval).	**AEAT**
2003 / 104	**Completed** At the October 2003 RCC network meeting, AEAT provided RCCs with identifiable data (at the hospital level) for hospitals in their own SHA / Welsh health region.	

2003 / 108	**Completed** MDS Working parties (PG) and the NJR research subcommittee (JM) provided feedback on the PFQ process. The Patient Feedback Questionnaire process is discussed under agenda item 7.	
2003 / 109	**Ongoing** AEAT conducted an initial scoping study for the use of barcode readers. The draft report was discussed at the September 2003 SC meeting. The final report, including costings, will be presented at the January 2004 SC meeting.	**AEAT**
2003 / 113	**Completed** The BOA Council via liaison with relevant specialist societies and APOS have provided details of members representing the orthopaedic profession to sit on the NJR Research subcommittee.	
Actions from September 2003 meeting		
2003 / 114	**Completed** AEAT have made minutes of the July 2003 SC meeting available on the NJR website.	
2003 / 115	**Ongoing** The National Pacemaker Database has links into a European database. The NJR could potentially learn from their experience. AEAT have contacted the National Pacemaker Database and DC is due to visit in mid January 2004**.**	**AEAT**
2003 / 116	**Ongoing** Further discussion with the European Arthroplasty Register (EAR) is required before a decision can be taken on whether the NJR will participate. It was agreed that Dr Gerold Labek, EAR Coordinator, would be invited to the April SC meeting to give a presentation.	**AEAT**
2003 / 117	**Completed** Lord Warner confirmed that resources for implementing the NJR within individual hospitals needed to come from existing Trust funds.	
2003 / 118	**Ongoing** Models of good practice, i.e. demonstrations of how hospitals have implemented the NJR within their local systems, should be made available on the NJR website.	**AEAT**
2003 / 119	**Completed** NJR statistics reports for the Steering Committee now include separate totals for the NHS and Independent hospitals.	
2003 / 120	**Ongoing** Southport and Ormskirk Hospital have been contacted to ensure overseas orthopaedic surgical teams are capturing NJR data. Mr Alan Stephenson (Director of Surgery) confirmed that operations are being entered against the parent NHS trust. NJR users have been registered and resource has been made available for data entry. This has been done on paper proformas but has not been submitted electronically.	**PG**
2003 / 121	**Completed** AEAT have found that Treatment Centres do not have OCS codes assigned. The NJR Centre has generated and allocated unique IDs for the purpose of the NJR.	
2003 / 122	**Completed** AEAT have contacted all Treatment Centres and obtained key contact	

	details. Two Centres have registered surgeons with the NJR under their parent Trusts. The appropriate Strategic Health Authorities have been contacted. All Treatment Centres (TCs) are associated with NHS trusts (plus one independent) and have been given unique NJR codes to segregate their data from the parent trust data. As yet, no data has been submitted under the identity of the TCs. See related action 2003 /138.	
2003 / 123	**Ongoing** 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. This will form part of AEAT's developing verification and validation strategy.	**AEAT**
2003 / 124	**Ongoing** The first year's Annual Report format and content were presented in a paper and is discussed under agenda item 8.	**JM & AEAT**
2003 / 125	**Completed** AEAT have confirmed with PW that the NJR annual reporting cycle should be 1 January to 31 December.	
2003 / 126	**Completed** The European standard for non-active surgical implants is due to be revised. AC has written to the relevant Commissioner requesting that the NJR's requirements are included in the revised standard.	
2003 / 127	**Ongoing** 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. This action is due to be discussed at the January 2004 SC meeting	**AEAT**
2003 / 128	**Ongoing** A draft statement on the hospital resources required to implement the NJR has been drafted ready for SC comments. The approved statement will be mailed to all trusts in January.	**AEAT**
2003 / 129	**Ongoing** AEAT to place the statement above on the NJR website and to make it available to the RCCs and BOA Clinical Director / Lead Clinician Network website.	**AEAT**
2003 / 130	**Completed** AEAT has updated the programme plan to reflect all the activities related to the implementation of MDS v2, which is discussed under agenda item 4.	
2003 / 131	**Completed** AEAT amended the MDS documents to reflect SC discussion / decision and provided copies to BD, PG and the members of the MDS working groups for review. MDS v2 is discussed under agenda item 4.	
2003 / 132	**Completed** JM and AM provided advice to AEAT on the sample size required by the Patient Feedback Questionnaire process. The proposed NJR Patient Feedback Process is discussed under agenda item 7	