National Joint Registry
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NATIONAL JOINT REGISTRY STEERING COMMITTEE

MINUTES

Meeting: Steering Committee meeting 2003/ No. 4 Date: Wednesday 16 April 2003

Location: Room 416, Hannibal House, Elephant & Castle, London SE1 6TQ

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

The following AEA Technology staff were also present:

David Carter	DC	NJR Project manager
Sandra Hasler	SH	NJR Communications manager

Observer Barry Hassel, Chief Executive of the IHA

Apologies Apologies were received from:

Christine Miles, Royal Orthopaedic Hospital (representing NHS trust management)

Hugh Phillips, British Orthopaedic Association (surgical profession)

Mick Borroff (DePuy International Ltd) / David Forsythe (Stryker), ABHI (representing the orthopaedic device industry)

Colin Howie, representing the Scottish Executive (observer status)

Andy Smallwood, NHS Purchasing and Supply Agency

Item	Welcome and Introductions	Action by
1	The meeting opened at 10.30. BD thanked everyone for what had been achieved in the initial six months of the project and for delivering an operational NJR for 1 April 2003.	
2a	**Progress on actions** See Appendix 1.	
2b	**Approval of minutes – NJRSC (03) 19** Minutes approved subject to the following amendments: P4 - **Reporting back from the regional training events** • Change HER to EHR • Add comment from MPo about the next level of implementation that needed to be considered, i.e. there was a risk that local units would not be provided with adequate assistance to implement the NJR such as clerical support and ongoing advice. P7 - **State of readiness** • Add comment that reads 'no decision was taken at this point with regards to how the Trent Registry would interface with the NJR'. P8 – **Outline of reporting strategy** • Re-word MPo comment on the risk stratification information available from the Swedish Arthroplasty Register, to reflect that it takes account of patient related factors, system technical factors and environmental factors and that these would need to be considered when reports and analyses are constructed. However, this does not include all aspects of case mix complexity which would require ongoing review and discussion. P11 - **Surgeon performance** • Add comment from MPo that reflects that he raised the issue of expenditure monitoring and asked whether the financial framework was in the control of the SC, and that RCC activities may need resources. **[Action 2003 /62]** AEAT to amend minutes and make available on the NJR website.	**AEAT**
3	**March Management Report – NJRSC (03) 21** The March Management Report was accepted without amendment.	
4	**Reporting on take-up of the NJR – NJRSC (03) 22** DC reported the number of current users registered to use the NJR data entry system (as of 7 April 2003). There were over 1100 individuals registered to use the system, of which 291 Surgeons (of all grades) were registered as users. A further 436 surgeons were registered but by proxy, i.e. other hospital staff would be entering data on their behalf.	

	At present, there is no indication of how many hospitals are using paper proformas to collect data. It was noted that the system records both the number of complete and the number of incomplete data records. (An incomplete data record is one that has not been completed due to missing data but is due to be completed as the data becomes available.) Discussion took place on which data should be reported to the SC to monitor NJR usage. It was agreed that the following should be reported at future meetings: • The total number of users registered • The number of users by user type, e.g. surgeons, administrators, suppliers etc. • The number of hospitals registering data This data would be provided to show separate totals for independent/ NHS hospitals and for England and Wales. The number of completed operations recorded on the NJR should be segregated into primary and revision operations for hips and for knees. All data should be presented on a weekly cumulative basis. MPo expressed concern over the potential problem of users sharing user ID and passwords. The NJR Centre has explicitly advised users they should not share user ID and passwords. It is the responsibility of data entry staff within hospitals to ensure that all records are completed. However, there is a risk that some records could be duplicated if a hospital does not have a system in place for recording which records require completion (and by whom). It was agreed that the number of incomplete operations recorded should be monitored closely so that any necessary follow-up action could be taken. AC explained that the use of incomplete records that would subsequently be edited and completed by surgeons, may represent the best use of a surgeon's time. **[Action 2003 /63]** 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 audit and compliance procedures. It was decided that the use of peripatetic nurses as part of the audit and compliance procedure needed to be reconsidered. **[Action 2003 /64]** PW and FD to look at the value of using peripatetic nurses (or similar) as part of the audit and compliance procedure. JM stressed the importance of agreeing an overall NJR reporting structure to ensure that early NJR data does not lead to confusion through misinterpretation.	**AEAT** **PW & FD**

	It was agreed that DC, JM and AM should discuss the reporting structure and its logistics separately. **[Action 2003 /65]** DC, JM and AM to discuss developing a suitable team for analysing the NJR data for SC consideration. Building on the outline reporting strategy prepared by JM, was discussed further under Agenda item 9. MPo reported that he had experienced problems using the data entry system for the first time, i.e. that the system had locked him out several times. DC agreed to pursue this issue urgently. NB requested that consideration be given to the potential issue of patients refusing to allow their personal details to be recorded by the NJR, and how it might be monitored to ensure that communications are being effective. FD reported that some hospitals / surgeons, that had attended the regional training events, had indicated that they would not be asking for patient consent in the early operational days of the NJR. The reason given was that they would normally introduce NJR consent at the pre-operative assessment, which would have occurred before 1 April for those patients having operations in April. The hospitals / surgeons were advised that they should put interim measures in place to ensure that all patients having operations from 1 April pass through the NJR consent process. The SC endorsed this action.	**DC, JM & AM**
5	**IT update** No technical problems have been experienced with the IT system since the 1 April launch. However, users may have issues using local hospital internet connections if these have not been optimised. DC reported on progress of development of the windows-based client, and that it would be ready for use on the 1 May.	
6	**Bulk upload of data – NJRSC (03) 23** DC gave a summary of the paper that identified the benefits of providing a bulk data upload facility to those hospitals that were already using electronic data collection systems (databases) before the introduction of the NJR. The main benefits are: • manual data entry would occur once • it would help preserve data quality • it would encourage compliance with the NJR FD pointed out that some hospitals had informed the NJR Centre that they would not submit data to the NJR until such a facility was made available. Others have indicated that they are only prepared to manually enter data in the NJR in addition to their own system for a short period of time until the facility is offered. Discussion took place on the merits and reservations of such a facility, the main points include:	

	• it would provide an incentive to some of the larger hospitals that currently have their own electronic data collection systems in place to comply with the NJR • the data would need to be standardised, i.e. the hospital database would need to collect the NJR core data fields (the MDS) • each hospital system would be different and there would be a risk of hospitals returning with queries on a regular basis (FD pointed out that the NJR Centre is already aware of the systems that the main future users have in place) • the NJR Centre would need to manage any data errors produced The SC also looked at the affordability of this facility within current resources. The SC agreed to the bulk upload option. FD requested that "inclusion of Reoperations" be made prior to the development of the bulk upload facility so that disruption to the NJR database is minimised, i.e. the number of changes to the system. The changes to the MDS require consultation with members of the SC and RCCs. **[Action 2003 /66]** AEAT to contact RCCs to gain their final suggestions on what should be included in the MDS in relation to Re-operations. A deadline of two weeks should be given. The SC agreed that the database should incorporate the changes in the MDS **prior** to development of the bulk upload option. The bulk upload facility will take two months to develop following changes to the MDS. Total development time for the bulk upload and the incorporation of Reoperations would be approximately 3 months. **[Action 2003 /67]** AEAT to update the NJR system to incorporate the amended MDS and to develop the bulk upload facility. **[Action 2003 /68]** AEAT to inform hospitals that the bulk update facility is being developed, when its launch is anticipated, and to ensure that hospitals are aware of what they will be required to do in-house to comply with NJR bulk upload requirements.	**AEAT** **AEAT** **AEAT**
7	**Reporting back from the 2nd RCC Network meeting** It was agreed that minutes from the RCC network meetings should be circulated to all SC members. FD pointed out that these documents should be treated as confidential to the RCC network and the NJR SC. **[Action 2003 /69]** AEAT to circulate the draft minutes from the 2nd RCC network meeting to all SC members. PG and FD provided a summary of the key issues that were raised by the RCCs at the March network meeting. • There was a consensus view amongst the RCCs that the use of	**AEAT**

	barcoding in NJR data gathering merited serious consideration. RCCs wished to be involved in any review of this topic, and saw this as essential to obtaining compliance in hospitals.
	
	• RCCs agreed to write to PG / FD detailing any procedures that they considered should be included in the NJR that are either not currently included or require separating out from more generic descriptors.
	
	• RCCs requested that there be no serious interrogation of the NJR database until its overall completeness and accuracy could be determined. Although it was difficult to specify a timescale the expectation seemed to be that a bedding in period of at least 6 months would be required.
	
	• PG requested that RCCs write to him with estimates of the implementation costs within hospitals so that he could inform the Steering Committee. To date he has not received any feedback.
	
	• The RCCs agreed to the following forming the basis of their Terms of Reference.
	
	- Providing support to the initial set-up of the NJR
	- Facilitating feedback to orthopaedic surgeons
	- Communicating between the regionally based hospitals / units and the NJR Centre and NJR Steering Committee
	- Representation on organising committees for NJR-related events
	- Hosting training roadshows and regional seminars
	- Providing input to determining appropriate reporting, analysis and interpretation of NJR data
	
	• In relation to the NJR reporting strategy, RCCs emphasised that:
	
	- It is important that orthopaedic consultants have a significant input into determining what should be analysed and subsequent data interpretation
	- The RCC network as a whole, and perhaps a subgroup of their members, would wish to contribute to
	  - any advisory group set up to develop reporting and analyses
	  - determining protocols for addressing problems related to apparently underperforming hospitals or individual surgeons
	  - reviewing any papers or presentations using NJR-related data prior to their submission to journals or conferences
	- Any group developing reporting and analyses would require BASK representation. (It was noted that at present there is not clear BASK representation within the RCC network, or on the Steering Committee other than a joint BASK/BHS representative).	

8	**Audit and compliance framework – an update – NJRSC (03) 23** It was agreed that the developing framework would need to be reviewed to consider the potential inclusion of a peripatetic nurse (or similar) role, possibly incorporating support to RCCs. **[Action 2003 /70]** All SC members to provide FD with their relevant comments and experiences on audit and compliance.	**All SC members**

9	**Informing the surgical profession – reporting and procedures** An informal discussion between BD and a number of members of the SC, took place to ascertain which information reported from the NJR surgeons would find most helpful (15 April). BD indicated that he would be meeting with the President of BASK on 22 April. It was agreed that no decisions would be made at this point but the main feedback is as follows: • The BHS, BASK and BOA conferences were considered to be relevant routes for sharing NJR information with the surgical profession. • Reports should be relevant and robust, using high quality data and were requested on a 6 monthly basis. • Consideration should be given to information being shared at a surgeon's appraisal with their approval. • A procedure for approving research projects would be welcomed. Discussion took place about how issues arising from hospital / surgeon performance data could be managed. BD suggested that this issue be one of the areas covered in a paper by PW and FD that would be presented to the SC at the next meeting. **[Action 2003 /71]** All SC members to provide FD with relevant experience / information. **[Action 2003 /72]** BD, PW, PG and FD to meet at the BOA offices on 14 May to further develop approaches to reporting and procedures. **[Action 2003 /73]** Following the 14 May meeting, PW and FD to prepare a related paper for the May SC meeting. MPo requested that an article outlining relevant SC discussion in relation to the surgical profession be included in the NJR newsletter. **[Action 2003 /74]** AEAT to draft an article to provide feedback to the surgical profession. [This will be for inclusion in the September issue of the NJR Newsletter to allow SC discussions to have reached an appropriate stage.]	**All SC members** **BD, PW, PG & FD** **PW & FD** **AEAT**
10 **(i)**	**AOB** **Frequency and format of Steering Committee meetings** The dates for the next two meetings were suggested as follows: 29 May, London – Please note that the 27 May was announced in the meeting but was subsequently changed to the 29 May due to the late May Bank Holiday. The venue will be Partnership House, 157 Waterloo Road, London. This is next door to the Department of Health's offices. 1 July, London – Venue is to be confirmed.	

(ii)	**Invitation to co-operate in the European Arthroplasty Register (EAR)** PG was sent a letter from the EAR inviting the NJR to participate. It was agreed that the letter did not provide enough information for a decision to be made as to whether or not the NJR should be involved, e.g. there was no indication of what costs were involved. It was noted that there were advantages of participation, e.g. sharing of data, the potential size of the EAR database. It was agreed that PG contact EAR for more information. **[Action 2003 /75]** PG to contact EAR for more information on the programme.	**PG**
(iii)	**Operations to be included in the MDS** FD requested agreement from the SC to put the updated list of 'operations to be included in the NJR' on the website. This listing now includes Revision operations. This was agreed.	
(iv)	**Steering Committee Representation** MPo reopened the issue of SC representation. BD repeated that he was due to have a meeting with the President of BASK. The NJR is moving into a new phase and the function of the SC and the representation on it are evolving to reflect this.	
(iv)	**Feedback from ABHI members** KB reported that there was still some confusion in hospital supply departments as to which components attract the levy. It was noted that many of the ABHI members had issued letters to their customers informing them of the details of the levy. **[Action 2003 /76]** PW to discuss the ABHI feedback with AS (PASA), who was unable to attend the April SC meeting.	**PW**

Sandra Hasler
Communications Manager, NJR Centre
1 May 2003

APPENDIX 1

Action no.	Progress	Action holder
Actions from December 2002 meeting		
2002 / 07a	**Ongoing** A definitive list of orthopaedic units in England is not available and not all units have supplied contact details. There is a continuing need to pursue contact details for each orthopaedic hospital / unit on an urgent basis. Additional units / hospitals are being identified via: contact with RCCs; contact with the compilers of HES; continued awareness raising in the orthopaedic community; surgeons notifying the NJR Centre of all units / hospitals at which they work. Once units / hospitals are identified, contact details of NJR unit managers / responsible persons, surgeons and others who need access to the NJR system can then be pursued.	**AEAT**
2002 / 27	**Completed** The Hip and Knee proformas for use from 1 April 2003 are available via the NJR web site.	
2002 / 28	**Ongoing** A complete set of hospital and surgeon details (including names and GMC codes) for all orthopaedic hospitals and units in England and Wales are required to populate the NJR database. See response under Action 2002/07a.	**RCCs / AEAT**
2002 / 30	**Ongoing** Draft 3 of "Research and the National Joint Registry" has been prepared in line with discussions at the March SC meeting. It was agreed that final queries would be discussed with M Porter following the April SC meeting before placing the text on the NJR website.	**AEAT**
2002 / 43	**Ongoing** The DoH has enquired about the cost of using the National Strategic Tracing Service (NSTS) for the NJR. A revised costing was not realised. A formal letter should be sent to reinforce PW's telephone conversation with the NSTS.	**PW**
2002 / 57	**Ongoing** Letters of appointment will be drawn-up and signed by BD and PG. They will also contain the RCCs terms of reference. Unsuccessful candidates were notified earlier in the year. Terms of reference were discussed with RCCs at the RCC network meeting on 25 March 2003.	**FD / PG / BD**
Actions from January 2003 SC meeting		
2003 / 05	**Completed** The patient consent form has been translated into Welsh and has been made available on the NJR website. The form is also being made available in large text.	
2003 / 08	**Ongoing** AEAT are liasing with Neil Betteridge and others on appropriate communication routes for disseminating the patient consent form to raise awareness with patients and public.	**AEAT**
2003 / 11	**Completed** The final version of the consent form, associated guidance and poster are	

	available on the NJR web site. Large numbers have been distributed at training events. See also Actions 2003/29, 30 & 33.	
2003 / 15	**Ongoing** To date no requests related to data analysis have been received from SC members.	**All**
2003 / 16	**Ongoing** The BHS are currently discussing how differences in epidemiological case mix for surgeons may be statistically addressed to ensure balanced reporting.	**MPo**
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 February 2003 SC meeting		
2003 / 28	**Completed** Paper NJRSC (03) 10 – Department of Health Guidance – has been updated to reflect amendments agreed.	
2003 / 29 & 30	**Completed** The final version of the consent form, associated guidance and poster are available on the NJR web site. Large numbers have been distributed at training events. See also Actions 2003/11 & 33.	
2003 / 31 & 32	**Completed** The consent form, guidance and poster are on the website. CD contributed to the consent form text so that it became suitable for both the NHS and independent sectors.	
2003 / 33	**Completed** The final version of the consent form, associated guidance and poster are available on the NJR web site.	
2003 / 34	**Ongoing** To date, SC members have not provided any comments on proposals for auditing the functions of the NJR.	**All SC members**
2003 / 39	**Superseded by Action 2003 / 48**	
2003 / 40	**Completed** A response has been sent to the editor of the Journal of Bone and Joint Surgery. It will be published in the next appropriate edition of the Journal.	
Actions from March SC meeting		
2003 / 41	**Completed** The Chief Medical Officer was unable to attend the London launch on 1 April. However, he provided suitable quotes for the Department of Health's press release.	
2003 / 42	**Completed** PW issued invitations to clinicians on the Steering Committee and BHS / BASK representatives to attend an informal meeting on 15 April.	
2003 / 43	**Completed** Minutes for the February SC meeting have been amended and made available on the NJR web site.	

2003 / 44	**Ongoing** ABHI OSIS has requested a central contact for each supplier. Once received KB will send on contact details to AEAT.	**KB**
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. This issue currently resides with Custom and Excise.	**PW**
2003 / 46	**Completed** PW amended and issued the Department of Health guidance via the Chief Executive's bulletin with a link to the actual guidance paper on the NJR web site.	
2003 / 47	**Ongoing** AEAT provided the SC with a listing of queries and issues raised by the NJR training event delegates. Issues 1-5 were currently being addressed. Issues 6 – 13 required further consideration.	**All SC members**
2003 / 48	**Completed** AEAT prepared a paper outlining an implementation plan for bulk data upload and the associated costs. The paper was addressed under agenda item (6) at the April SC meeting.	
2003 / 49	**Completed** Contact with the "Patients Owner Manual" project with regards to NJR involvement has resulted in the following. M Pickford attended an Owners' Manual editorial board meeting on 11 April (as an ABHI representative). Key points from the meeting include: the first 3-4 pages of the manual had been allocated to record patient, surgeon and operation details. The board agreed to use a printed copy of the NJR data input instead. Piloting of the manual starts at the end of May in two orthopaedic hospitals (Glenfield Hopsital, Leicester and Pilgrims Hospital, Boston). The pilot ends in October. The Owners' Manual project manager is keen to avoid unnecessary duplication between the NHSIA project and the NJR. AC reported separately, details were broadly in line with the above.	
2003 / 50	**Completed** Consultants would like to see a system put in place that would allow them to retrieve raw data for all operations where they are the Consultant in charge (although they may not actually be present during all operations). AEAT were asked to check how this issue affects surgeon consent. The system allows the Consultant in charge to view information on all operations carried out in his name, regardless of whether he is present. This means that a lead surgeon who withholds their consent for their management to have access to their identifiable data cannot withhold access for the Consultant in charge.	
2003 / 51	**Completed** RCCs were informed at the 2nd RCC network meeting that the speed of the web-based client is dependent on the speed of the hospital server. Therefore, users may experience a slower system at their hospitals (as compared with the demonstrations at the training events) and perhaps become frustrated with the speed of download.	

2002 / 52	**Ongoing** AEAT to present a proposed system for reporting back to the SC on progress relating to the extent of data submission to the NJR. This action was covered under agenda item (4).	**DC**
2003 / 53	**Ongoing** From May, AEAT to start using agreed reporting system (for progress on data submission to the NJR).	**AEAT**
2003 / 54	**Completed** The PASA letter (to NHS supplies departments within Trusts) has been made available on the NJR website.	
2003 / 55	**Completed** PG appraised Colin Esler of the discussions at the March SC meeting related to the Trent Registry and whether or not it would be possible for units to send completed NJR papers proformas to Trent and for Trent to carry out the electronic data submission.	
2003 / 56	**Ongoing** AEAT to investigate the method employed by the CCAD to gain entry to hospital records for audit and compliance purposes. FD awaiting reply to initial contact.	**AEAT**
2003 / 57	**Ongoing** PW to write to the Chief Executives of CHI and CHAI on behalf of the SC and bring to their attention the potential need for them to assess hospitals' compliance with the NJR.	**PW**
2003 / 58	**Ongoing** The outline reporting strategy (12 March version) was circulated to the RCCs at the 25.03.03 network meeting. It is also being circulated with the minutes of the network meeting. All RCCs have been asked to provide comments direct to JvdM (copied to FD).	**AEAT**
2003 / 59	**Ongoing** Draft 3 of "Research and the National Joint Registry" has been prepared in line with discussions at the March SC meeting. Final queries will be discussed with M Porter ahead of the text being placed on the NJR website. (see also Action 2003 / 30).	**AEAT**
2003 / 60	**Ongoing** All members of the SC to submit a list of website links that they feel is representative of their stakeholder group needs.	**All SC members**
2003 / 61	**Ongoing** AEAT has updated the "Operations to be included / excluded from the NJR" document and placed it on the NJR website. Subsequently it has been pointed out that only primary operations are listed. List to be reviewed, amended and placed on website in place of the current version.	**FD**