

## NATIONAL JOINT REGISTRY STEERING COMMITTEE

## MINUTES

Meeting: Steering Committee meeting 2002/ No. 2 Date: Monday 18 November 2002

Location: Olivier Room, Wellington House, 133-155 Waterloo Road, London

Present:

Bill Darling	BD	Chair
Paul Gregg	PG	Vice chair
Jan van der Meulen	JM	Royal College of Surgeons (representing the surgical profession)
Hugh Phillips	HP	British Orthopaedic Association (representing the surgical profession)
Christine Miles	CM	Royal Orthopaedic Hospital (representing NHS trust management)
Alex MacGregor	AM	St Thomas' Hospital (representing public health and epidemiology)
Ken Bateman	KB	Smith & Nephew Healthcare Ltd, ABHI (representing the orthopaedic device industry)
David Forsythe	DF	Stryker, ABHI (representing the orthopaedic device industry)
Chris Dark	CD	Director of Clinical Services, BUPA Hospitals (representing IHA)
Paul Woods	PW	Department of Health
Shaun Chainey	ShC	National Assembly for Wales
Andy Smallwood	AS	NHS Purchasing and Supplies Agency
Andy Crosbie	AC	Medical Devices Agency
Fiona Davies	FD	AEA Technology (representing the contractor)
Rod Muir	RM	Representing the Scottish Executive (observer status)

The following AEA Technology staff were also present:

David Carter	DC	NJR Project manager
David Pegg	DP	NJR IT manager
Sandra Hasler	SH	NJR Communications manager
Martin Pickford	MP	Orthopaedic adviser

Apologies Apologies were received from:

Neil Betteridge, Arthritis Care (patient group representative)  
Mick Borroff, DePuy International Ltd, ABHI (orthopaedic device industry)

Item	Welcome and Introductions	Action by
1	The meeting opened at 10.30. Round the table introductions were made by Bill Darling.	
2	<p><b>Minutes of Steering Committee 2002/ No. 1 - NJRSC(02)10</b></p> <p>The minutes were accepted with the following amendments:</p> <ul style="list-style-type: none"> <li>- the date of the meeting should be added</li> <li>- Item 6, with reference to the Oxford Hip and Knee Scores. These are not the only validated scoring systems. Remove 'only' and add in a reference to the WOMAC scoring system.</li> </ul> <p><b>[Action 2002 / 23]</b> The amended minutes should be posted to the NJR web site.</p>	<b>AEAT</b>

2a	<b>Progress on actions placed in Steering Committee meeting 2002/ No.1</b>	
2a (i)	<p><b>Terms of Reference - NJRSC(02)02</b>  <b>[Action 2002 / 01]</b> The Terms of Reference were revised by PW in line with changes agreed at SC meeting No.1, then issued as NJRSC (02) 02 revised. The revised version was accepted.  <b>[Action 2002 / 01a]</b> The Terms of Reference are to be posted to the NJR web site.</p>	AEAT
2a (ii)	<p><b>Activity to date</b>  FD reported the following progress on actions to build relevant communication routes with the health sector.</p> <p><b>[Action 2002 / 02] Obtain names and contact details of StHA Chief Information Officers</b>  Due to provisions of the Data Protection Act (DPA), the DoH was unable to provide AEAT with contact details for the StHA Chief Information Officers. However, DoH Information Policy Unit distributed the Healthcheck questionnaire to all StHA CIOs on behalf of AEAT.</p>	AEAT
	<p><b>[Action 2002 / 03] Investigate whether NHS Confederation publications and electronic bulletins can be used as a route for promoting NJR awareness and disseminating information</b>  The NHS Confederation produces Interchange News, a regular newsletter and Interchange Alert, a weekly email update, both for members. Interchange News usually only includes items where joint working is evident, or where members can directly participate.  <b>[Action 2002 / 03a]</b> AEAT to follow-up.</p>	AEAT
	<p><b>[Action 2002 / 04] Investigate whether British Association of Medical Managers (BAMM) electronic bulletins could be used to inform Medical Directors and Clinical Directors of NHS Trusts and independent units about the NJR</b>  Initial contact indicates this would be possible although there be a charge attached.  <b>[Action 2002 / 04a]</b> AEAT to follow-up.</p>	AEAT
	<p><b>[Action 2002 / 05] Investigate whether use of IHA monthly bulletins would be sufficient as a route for disseminating NJR information to the independent sector</b>  Independent Healthcare Association (IHA) electronic bulletins are a good route to communicate with IHA members within the independent sector. The IHA is also a route for distributing to non-IHA members.  <b>[Action 2002 / 05a]</b> CD to check with IHA that non-IHA members have been included in relevant e-mailings.</p>	CD
	<p><b>[Action 2002 / 06] Consider using the Health Service Journal as a dissemination route for capturing large audiences later in the project</b>  The Health Service Journal publishes about 10% of articles received. AEAT were advised that inclusion of an item on the NJR would probably be in the form of an editorial article. FD suggested an item to coincide with going live, i.e. April / May 2003.  <b>[Action 2002 / 06a]</b> AEAT to prepare the ground in late Feb/ March.  <b>[Action 2002 / 06b]</b> BD and PW to approach Lord Hunt to provide some quotes about the NJR.</p>	AEAT BD & PW
	<p><b>[Action 2002 / 07] Contact David Adams (BOA) to obtain a list of linkmen</b>  There are not linkmen in every orthopaedic unit and the network does not cover the independent sector. Due to provisions of the DPA, the BOA was unable to provide AEAT with a list of the Linkmen contact details. However, they distributed an email message on behalf of the NJR Centre. Linkmen were asked to pass on the message to the manager of their orthopaedic unit/ hospital and ask that the manager make direct contact with the NJR Centre to provide their full contact details. This information had started to come in from units. [Note that the IHA distributed a version of the "Linkmen" message to the independent sector.]  <b>[Action 2002 / 07a]</b> AEAT to continue to pursue obtaining contact details for each unit / hospital.</p>	AEAT
2a (iii)	<p><b>Work Programme and the Levy</b>  <b>[Action 2002 / 08] Suggestions for Year 1 work</b>  Paper NJRSC (02) 04b was circulated. SC members were asked to consider the summarised work programme and put forward any other suggestions. The work programme for Year 1 was discussed later under Item 5.</p>	

	<p><b>[Action 2002 / 09] Chief Executives' Bulletin and IHA bulletin</b>          AEAT provided draft items for inclusion in the DoH CE bulletin and IHA emails to members. These related to the launch of the NJR, the Healthcheck questionnaire and the estimated levy.</p> <p><b>[Action 2002 / 10] Provision of number of operations in the independent sector</b>          CD advised that the independent sector does not hold central returns on volumes of hip and knee replacements. Therefore, figures have been estimated based on a study performed by Professor Brian Williams at Nottingham University and also took into consideration the substantial increase in both self-pay and NHS work currently being performed in the independent sector. CD estimated volumes of procedures for the first year as: 25% for THR and 20% for TKR.</p> <p><b>[Action 2002 / 11] Manufacturers from outside the UK</b>          At present, manufacturers/ suppliers outside the UK are not in the levy loop. MB and CD examined the issues of parallel imports and the use of non-UK suppliers of joints. At present, the number of parallel imports and non-UK suppliers are so low that there is not likely to be a significant impact on the NJR.</p>	
<p><b>2a (iv)</b></p>	<p><b>Minimum Dataset and Patient Feedback Questionnaires</b></p> <p><b>[Action 2002 / 12] Provision of draft Minimum Dataset (MDS)</b>          FD circulated a draft minimum dataset (MDS) to all SC members for review (5 Nov). In compiling the MDS, the focus was on making maximum use of existing datasets. In particular, it was expected that the draft MDS would closely mirror the combined MDS within the NJR Invitation to Tender documentation, and the BOA / RCS hip and knee MDS, and taking into account the MDS used successfully by the Trent Arthroplasty Register. The draft MDS was intended to be applicable to both elective Total Hip Replacement (THR) and elective Total Knee Replacement (TKR), although some sections were only applicable to hips or to knees.</p> <p>It was not possible to get a consensus via e-mail on the final MDS and following agreement by the Chair it was added to the agenda, and discussed at item 11.</p> <p><b>[Action 2002 / 13] Data Fields for Patient Feedback Questionnaire (PFQ)</b>          The decision was taken to consider the Patient Feedback Questionnaire at a later meeting.</p> <p><b>[Action 2002 /13a]</b> In reviewing options for a PFQ, FD should consider WOMAC (Western Ontario and McMaster Universities Arthritis index) in addition to the Oxford Hip and Knee Scores.</p> <p><b>[Action 2002 / 14] StHA Chief Information Officer SC representation</b>          PW pursued this as an option. The DoH Information Policy Unit emailed all StHA CIOs for volunteers. There were no responses. There is a significant programme of IT work currently being undertaken by StHAs and this is likely to be the reason for no take-up. Information intended for StHA CIOs will be routed through the Department.</p>	<p><b>AEAT</b></p>
<p><b>2a (v)</b></p>	<p><b>Regional Clinical Co-ordinators</b></p> <p><b>[Action 2002 / 15]</b> FD updated paper NJRSC(02)07 Regional Champions, to reflect all agreed changes and circulated to SC members.</p> <p><b>[Action 2002 / 16] Call for Regional Clinical Co-ordinators</b>          FD drafted an invitation for Regional Clinical Co-ordinators (RCCs). The deadline for applications was 29 November. The intention was for a final list of RCCs to be presented to the 3<sup>rd</sup> SC meeting.</p> <p>The invitation was sent to the following organisations, who were asked to place it on their web sites - BOA, RCS, BASK, BHS, NAFW, HOWIS (Health of Wales Information Service). The document was also placed on the NJR web site.</p> <p><b>[Action 2002 / 16a]</b> PG agreed to check that the relevant email bulletins had been circulated to the BASK and BOA members.</p> <p>FD also handed out several copies to attendees at the Trent Symposium and emailed copies directly to individuals who had expressed interest.</p>	<p><b>PG</b></p>

	<p>Very few applications or queries about the RCC role had been received. One query that had been received related to difficulties in units being able to put individuals forward if there was no funding available for this role. PG said that consultants had 3 sessions that were used for non-clinical work such as audit, teaching and research, and that this could be used for the purpose of being a RCC. HP agreed and noted that he did not believe that being a RCC would be too time consuming.</p> <p>It was noted that there was unlikely to be a full response by the deadline. This would have implications for training of unit staff, in terms of potentially not having full RCC representation on the roadshows. Hence, this issue needed to be addressed urgently.</p> <p><b>[Action 2002 / 16b]</b> It was agreed that in light of the invitation having been made available to as wide an audience as possible, it was acceptable for SC members to inform suitable individuals of the availability of the position and encourage them to apply.</p>	
<p><b>2a (vi)</b></p>	<p><b>Research and the NJR</b></p> <p><b>[Action 2002 / 17] <i>Research and the NJR</i></b> This action was discussed later under agenda item 6.</p>	<p><b>All</b></p>
<p><b>2a (vii)</b></p>	<p><b>The NJR Web Site</b></p> <p><b>[Action 2002 / 18] <i>Investigation of the requirements, and costs involved, for public information on web site to be translated into Welsh</i></b> FD checked the CHI, NICE, NHSIA and NPSA web sites to see how they addressed this requirement. CHI, NPSA and the NHSIA do not provide any information in Welsh, whereas, NICE does.</p> <p><b>[Action 2002 / 18a]</b> Contact has been established with the Welsh Language Board and the gatekeeper of the National Assembly of Wales Welsh Language Scheme. ShC will confirm the definitive requirements.</p> <p>Following discussions with PW, no further action is required from AEAT at present.</p>	<p><b>ShC</b></p>
<p><b>2a (viii)</b></p>	<p><b>Future Meetings</b></p> <p><b>[Action 2002 / 19]</b> Dates were agreed for January through to April. The meetings will be held at Wellington House, and start at 10.30am.</p> <p>Jan – Wed 15 January 2003** Feb – Fri 21 February 2003 Mar – Wed 19 March 2003 Apr – Wed 16 April 2003</p> <p>** Note: The January meeting has been rearranged for 20 January 2003.</p>	
<p><b>2a (ix)</b></p>	<p><b>Suppliers' Day</b></p> <p><b>[Action 2002 / 20] <i>Investigation of the feasibility of a Supplier's day to run alongside the next ABHI Orthopaedics SIS meeting</i></b> It has been agreed to hold the Supplier's Day on the afternoon of Thursday 9 January 2003. This will follow the ABHI meeting. The invitation to use the MDA's offices was accepted.</p>	
<p><b>2a (x)</b></p>	<p><b>National Symposium on Joint Registers</b></p> <p><b>[Action 2002 / 21]</b> Unfortunately BD could not attend. FD gave a presentation on the NJR and took questions with PG. MB, AC and HP were also present. The meeting was well attended and very lively.</p> <p>FD received some very positive emails from surgeons present who were very supportive of the aims of the NJR. Some individual orthopaedic units have offered to be pilot sites and are keen for the AEAT team to visit and observe what they do at present.</p> <p><b>[Action 2002 / 21a]</b> AEAT to follow-up requests.</p>	<p><b>AEAT</b></p>

<p>2a (xi)</p>	<p><b>Other issues raised</b></p> <p><b>[Action 2002 / 22] Expenses claim form and related guidance.</b> An expense form and guidance was approved and circulated to SC members. Since the previous meeting KB, RM and DF have joined the SC.</p> <p><b>[Action 2002 / 22a]</b> AEAT to send form and guidance to KB, RM and DF.</p>	<p><b>AEAT</b></p>
<p>3</p>	<p><b>Summary of October management report - NJRSC(02)12</b></p> <p>DC presented a summary of the key points. It was recognised that one of the main risks to the success of the NJR, was the possibility of some units not providing data since participation in the NJR is not mandatory.</p> <p><b>[Action 2002 / 24]</b> There was a general agreement that SC members should follow-up positive contacts and encourage units to be pilot sites where relevant.</p>	<p><b>All</b></p>
<p>4</p>	<p><b>Report on hardware healthcheck - NJRSC(02)13</b></p> <p>DP presented a summary of the key points of the report and important IT-related issues.</p> <p>(a) <u>Responses</u> 130 responses to the Hardware Healthcheck questionnaire had been received when the report was written. This represents about 200 individual units as an IT Manager may be responsible for more than one hospital. Responses continued to be received.</p> <p>There were no lists available with contact details for IT Managers for the NHS and Independent health sector. Requests for IT Managers to complete a questionnaire were made via the CE bulletin, the StHA Information Officers, the NJR web site and the IHA bulletin. In addition, the AEAT team is “cold calling” Trusts and independent healthcare providers to obtain relevant contact details to enable the project to run to schedule.</p> <p>(b) <u>IT solution</u> The response rate has allowed the recommendation of the desktop based client (ASP.NET and VB.NET clients) to be used as the IT solution. This recommendation was accepted by the SC.</p> <p>Units/ hospitals need to consider what steps they will need to take to ensure the IT system is capable of connecting to the NJR database. <b>[Action 2002 / 25]</b> AEAT to highlight this via the orthopaedic unit information package currently being compiled.</p> <p>(c) <u>IT upgrade</u> The response rate has not allowed a full determination of the IT upgrades required for every hospital. CM pointed out that PCs and modems are not necessarily available either in or very close to operating theatres. <b>[Action 2002 / 26]</b> AEAT to follow-up as a matter of urgency by continuing to collect returns from the Healthcheck questionnaire and following up contact with IT Managers.</p> <p>Discussion indicated a need for a paper proforma to be designed. This will provide a means for capturing data for database input in the event of a PC not being accessible at the time of operation or in the event of the hospital’s system failure. It was noted that although it was acceptable that data could be collected on a paper form initially it was essential that all data should be transferred electronically to the NJR. Postal submission of forms would not be an option.</p>	<p><b>AEAT</b></p> <p><b>AEAT</b></p>

	<p><b>[Action 2002 / 27]</b> AEAT to design a proforma and inform units/ hospitals that this will be supplied.</p> <p>CM raised concern over the potential to lose data should a computer be stolen. Data is not stored locally on the computer used for data input; all data is transferred to the NJR database daily.</p> <p>(d) <u>Data printout</u> Data printouts from the NJR database will not include the details that identify the patient. This ensures patient anonymity and meets requirements of specific contract conditions.</p> <p>(e) <u>Hospital and surgeon details</u> The NJR database needs to be populated with complete sets of hospital and surgeon details ahead of 1 April 2003 to ensure a smooth start-up and obtain unit/hospital "buy in". It will be essential for the AEAT team to have complete lists of all NHS and independent sector units/ hospitals and of all surgeons to ease user operation. At present these lists either do not appear to exist or access is being prevented due to concerns that this may contravene provisions of the DPA.</p> <p><b>[Action 2002 / 28]</b> Action on all SC members to investigate urgently how this might be resolved – e.g. so that the BOA can provide full sets of surgeon details to AEAT solely for the purposes of populating the NJR database ahead of going live.</p>	<p><b>AEAT</b></p> <p><b>All</b></p>
<p><b>5</b></p>	<p><b>Work programme – Year 1 - NJRSC (02) 14</b></p> <p>A supplementary paper (NJRSC (02) 04(b) - Estimated Stage 3 (Year 1 of Operations) costs - was circulated to the SC on 24 October 2002. Paper NJRSC (02) 14 is a revised version of NJRSC (02) 04b, incorporating the comments received from the SC. No disagreements were received.</p> <p>CM raised a preference for the launch of the NJR to be in pilot units rather than in all units on 1 April 2003. The IT system will be tested in some pilot units prior to April 2003. It was agreed that the preparation for the launch should continue as originally planned. However, the situation would be kept under review, particularly during February/ March 2003.</p> <p>The Work Programme for Year 1 was adopted.</p> <p><b>[Action 2002 / 29]</b> PW to provide a paper on levy costs for the next SC meeting.</p>	<p><b>PW</b></p>
<p><b>6</b></p>	<p><b>Research and the NJR – NJRSC(02)15</b></p> <p>HP noted that the NJR will be the biggest database of its kind in the world.</p> <p>The mechanism for granting permission to use the NJR for collecting data for research purposes was agreed.</p> <p>Anyone can apply through the SC. The SC will seek peer review for research requests where applicable. Applicants will need to arrange funding for any research to be undertaken, including the costs of any SC activity and adding extra data fields to the NJR database. The research purpose should provide significant benefits to stakeholders. Any research undertaken should not hinder data collection at units or the NJR's overall aims.</p> <p><b>[Action 2002 / 30]</b> FD to draft brief guidance on 'How to apply to use the NJR for research', which should be made available on the NJR web site, following SC approval.</p>	<p><b>AEAT</b></p>

7	<p><b>Patient confidentiality - NJRSC(02)16</b></p> <p>It was agreed that the patient be asked for consent for personal details to be added to the NJR. If it is found that significant problems are experienced in receiving patient's consent then an application for exemption, under Section 60 of the Health and Social Care Act, could be explored.</p>	
8	<p><b>Proposal for categorisation of implant types to be included within the NJR database - NJRSC(02)17</b></p> <p>MP proposed setting up a method of identifying incompatible datasets at the time that implant details are entered into the NJR database. Attempts to enter such data would produce an error message that would advise that such a combination should be checked before being entered into the system. This would assist in maximising the accuracy of data entry and therefore help minimise the need for subsequent correction of erroneous data.</p> <p>This topic has been discussed with suppliers present at the meeting of the Association of British Healthcare Industries (ABHI) Orthopaedic Interest Section on 17 October 2002. All suppliers represented readily agreed to undertake the work necessary to upgrade their in-house databases with a system of product categorisation codes designed to meet the needs of the proposed NJR validation requirements. Based upon this meeting and further discussions with each supplier, a list of classification codes was compiled. This list was submitted to the Steering Committee for approval.</p> <p>The proposal and list of classification codes were adopted.</p>	
9	<p><b>NJR Newsletter - NJRSC(02)18</b></p> <p>FD presented some ideas on what the first NJR Newsletter could contain. The SC agreed the following content:</p> <ul style="list-style-type: none"> <li>- introduce the NJR – what is it, where has it come from, what progress has been made to date, how it will operate, the NJR web site and Helpline number</li> <li>- introduce the Steering Committee and include pen portraits</li> <li>- key FAQs</li> <li>- interview with a patient who has positive experience of a THR or TKR</li> <li>- patient confidentiality and consent</li> <li>- how the levy will work</li> <li>- how to apply to use the NJR for academic research</li> <li>- the benefits other registries have given</li> <li>- the fact that the NJR will be the largest database of its kind in the world</li> <li>- the benefits to patients and practitioners</li> </ul> <p><b>[Action 2002 / 31]</b> AEAT to compile the first Newsletter and make available electronically on the web site and in paper form to distribute at exhibitions and conferences.</p>	<b>AEAT</b>
10	<p><b>AOB</b></p> <p><b>10i Position with Wales</b> Wales has joined the NJR. FD had received contact details for all Welsh unit IT managers.</p> <p><b>10ii Agenda items for December meeting</b> It was agreed that the agenda should include the following items:</p> <ul style="list-style-type: none"> <li>- Minutes of Steering Committee meeting No.2</li> <li>- Summary of November management report</li> <li>- Proposals for March 2003 roadshows</li> </ul>	

	<ul style="list-style-type: none"> <li>- IT specification</li> <li>- Proposals for the auditing aspects of the NJR</li> <li>- List of proposed Regional Clinical Co-ordinators - for endorsement</li> <li>- Units / hospitals that have volunteered to be early pilot sites</li> <li>- Memoranda of Understanding</li> <li>- Levy costs</li> </ul>	
<b>10iii</b>	<p><b>Patient representation</b>  <b>[Action 2002 / 32]</b> ShC was to identify a Welsh patient representative.</p>	<b>ShC</b>
<b>10iv</b>	<p>BD requested a list of the proposed pilot units that will be used to test the NJR database.  <b>[Action 2002 / 33]</b> AEAT to compile the listing.</p>	<b>AEAT</b>
<b>11</b>	<p><b>Minimum dataset</b></p> <p>The minimum dataset was agreed.  <b>[Action 2002 / 34]</b> AEAT to prepare a final document for circulation to the SC.</p>	<b>AEAT</b>

**Sandra Hasler**  
**Communications Manager, NJR Centre**  
**4 December 2002**