

NATIONAL JOINT REGISTRY STEERING COMMITTEE

MINUTES

Meeting: Steering Committee meeting 2003/ No. 2 Date: Friday 21 February 2003

Location: Room 136B, Skipton House, 80 London Road, London

Present:

Bill Darling	BD	Chair
Paul Gregg	PG	Vice chair
Hugh Phillips	HP	British Orthopaedic Association (surgical profession)
Martyn Porter	MPo	British Hip Society and British Association for Surgery of the Knee
Sally Couzens	SCo	National Association of Theatre Nurses
Neil Betteridge	NB	Arthritis Care (patient group representative)
Ken Bateman	KB	Smith & Nephew Healthcare Ltd, ABHI (representing the orthopaedic device industry)
Mick Borroff	MB	DePuy International Ltd, ABHI (representing the orthopaedic device industry)
Christine Miles	CM	Royal Orthopaedic Hospital (representing NHS trust management)
Chris Dark	CD	Director of Clinical Services, BUPA Hospitals (representing the IHA)
Andy Crosbie	AC	Medical Devices Agency
Paul Woods	PW	Department of Health
Fiona Davies	FD	AEA Technology (representing the contractor)
Colin Howie	CH	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

Apologies were received from:

Andy Smallwood, NHS Purchasing and Supply Agency
 Jan van der Meulen (JM), Royal College of Surgeons (representing the surgical profession)
 Alex MacGregor, St Thomas' Hospital (representing public health and epidemiology)
 Shaun Chainey, National Assembly for Wales

Item	Welcome and Introductions	Action by
1	The meeting opened at 10.30.	
2a	<p>Progress on actions</p> <p>See Appendix 1.</p>	
2b	<p>Approval of minutes – NJRSC (03) 06 Minutes approved subject to the following amendment:</p> <p>Under Section 6 (Access to data and reporting requirements – discussion). In the table, change “reely” to “freely”, and in the paragraph following add “to” after “pertaining”.</p> <p>[Action 2003 /25] AEAT to amend minutes and make available on the NJR website.</p>	AEAT
3	<p>January Management Report – NJRSC (03) 08</p> <p>The January Management Report was adopted.</p>	
4	<p>Memorandum of Understanding – NJRSC (03) 09</p> <p>MB introduced the key issues.</p> <p>The SC agreed that customised knee implants be excluded from the levy collection (though their data will be collected by the Registry) since their total numbers are small.</p> <p>CM raised the issue of large orthopaedic units/ hospitals facing resistance from PCTs in paying the levy and contributing towards the cost of additional administrative effort. The argument put forward by PCTs is that the NJR is not recognised as a national cost pressure, it is a quality issue, and so it is for acute Trusts to fund via efficiency improvements. CM requested that Lord Hunt be advised of the situation.</p> <p>It was agreed that should a Trust refuse to pay levies the ABHI should inform the DoH who will contact the unit within 5 working days. If the issue remained unresolved, it was agreed that it would be taken to Ministerial level and through them to the Chief Executive of the individual Trust within 5 working days.</p> <p>It was agreed that the definition of a knee prosthesis on P5 under paragraph 15 should be amended (see following action). Similarly, the definition of a hip prosthesis on P5 under paragraph 14 should be amended.</p> <p>[Action 2003 /26] The Memorandum of Understanding should be updated to reflect the following amendments and circulated to SC members.</p> <ul style="list-style-type: none"> • 5 working days should be applied to both points raised re Trust refusal to pay the levy (P2, under 3.1) • Definition (P5, paragraph 15) to read ‘It is agreed that the purchase of any knee femoral component (including the metal component of a 	MB

	<p>unicompartmental or patellofemoral joint) or a one piece knee prosthesis will attract a NJR Levy payment for a total knee prosthesis.</p> <ul style="list-style-type: none"> • Definition (P5, paragraph 14) to read 'It is agreed that the purchase of a one piece (monobloc) acetabular cup or a modular metal acetabular cup outer component will attract an NJR levy payment for a total hip prosthesis'. <p>It was noted that 'patella femoral replacement' was excluded from the list of procedures to be included in the NJR. It was agreed that it should be included since this procedure is likely to increase.</p> <p>[Action 2003 /27] AEAT to amend the reference list of operations to be included in/ excluded from the NJR.</p> <p>PW raised the issue of whether trauma prostheses would be covered by the levy. It was noted that whilst these prostheses would not be recorded by the NJR they would have a femoral component and would therefore attract a levy charge.</p>	AEAT
5	<p>Department of Health guidance – NJRSC (03) 10</p> <p>PW introduced the key issues.</p> <p>It was agreed that the following amendments should be made to the paper:</p> <ul style="list-style-type: none"> • Reference to the knee femoral component be updated to reflect the change in the Memorandum of Understanding (Definition P5, paragraph 15). • The opening sentence needs to be updated to reflect that the NHS is <u>expected to participate</u>, rather than them being 'asked to participate'. Note: The Independent health sector has used 'Hospitals are required to comply'. • Where orthopaedic hospitals are referred to, this should be amended to 'orthopaedic units / hospitals'. <p>[Action 2003 /28] PW to update the paper to reflect the amendments outlined above and circulate to all SC members.</p> <p>Separate guidance will be provided for Wales.</p>	PW
6	<p>Patient Consent, an Update – NJRSC (03) 11</p> <p>SH introduced the documents tabled.</p> <p>DoH good practice would be to offer patient opt-out, i.e. to have no details recorded by the NJR (personal or anonymised operation details). The patient consent form was suggested as the vehicle to collect this. The SC agreed that opt-out would not be offered via the patient consent form for the following reasons.</p> <ul style="list-style-type: none"> - It is in the patient's best interest to participate in the NJR, and it would be to their benefit, and to the public good, not to be offered an opt-out clause on the form - The statistical analysis would become seriously undermined if all patients did not participate 	

	<p>- The NJR will make patient follow-up much easier if there is a need for urgent clinical review.</p> <p>The SC wish to emphasise that, where patients have given their consent to their personal details being recorded by the NJR, these details will be encrypted and hence data will be stored on the database in an anonymised format.</p> <p>Where patients withhold their consent, no strong personal identifiers will be entered into the NJR database (i.e. name, date of birth, postcode and NHS number). This prevents subsequent identification of patients who have not given consent.</p> <p>The guidance for hospitals and the accompanying poster were adopted with the following amendments:</p> <ul style="list-style-type: none"> • Remove reference to 'opt-out' in the guidance • Add the number of copies of the patient consent form that should be completed, i.e. two copies, one for the patient and one for the hospital's records. • Remove reference to 'total' as in 'total hip or total knee replacement' • Add a reference to patient feedback questionnaires <p>[Action 2003 /29] AEAT to update guidance and poster and distribute with the patient consent form.</p> <p>NB raised the issue that large print is predominantly used rather than Braille. It was agreed that the consent form should be made available in large print.</p> <p>[Action 2003 /30] AEAT to make the patient consent form available in large print.</p>	<p>AEAT</p> <p>AEAT</p>
<p>7</p>	<p>Draft Patient Consent Form – for approval – NJRSC (03) 11a</p> <p>The design of the patient consent form was discussed and the following amendments were agreed:</p> <ul style="list-style-type: none"> • To remove any reference to 'total' as in 'total knee replacement' • To remove the hyphen in the heading between 'Your participation' and 'is voluntary' • Add a version number and date • Add a reference to patient feedback questionnaires • Make available in 12 pt font size and in Arial font • Move the first bullet point under 'The benefits the NJR will bring to you' to become the third bullet point • Add room for the name of the person accepting patient consent alongside signature <p>[Action 2003 /31] AEAT to make the amendments outlined and make the form available on the NJR website as a locked word document (i.e. to prevent the document from being changed easily once downloaded from the web).</p> <p>It was agreed that the patient consent form should have standardised text that was suitable for both the NHS and the Independent health sector. CD</p>	<p>AEAT</p>

	<p>was concerned that the text was too long to be accepted by the Independent health sector.</p> <p>[Action 2003 /32] CD to amend the patient consent form in line with what would be acceptable to the Independent health sector and make available to AEAT for distribution.</p> <p>[Action 2003 /33] AEAT to distribute the patient consent form to hospitals.</p>	<p>CD</p> <p>AEAT</p>
8	<p>Progress report on proposals for auditing the functions of the National Joint Registry – NJRSC (03) 12</p> <p>FD introduced the paper and the background that would feed into a more detailed paper to be submitted to the SC in March.</p> <p>FD requested SC comments.</p> <p>[Action 2003 /34] All SC members to pass comments to FD in time for the next SC meeting (Wednesday 19 March).</p>	All
9	<p>Checking and validating encrypted patient details – NJRSC (03) 13</p> <p>DC introduced the key elements of the paper.</p> <p>The paper was adopted.</p>	
10	<p>Initial proposals for analyses – review / feedback</p> <p>FD explained the background to a paper drafted by Jan van de Meulen (Director, Clinical Effectiveness Unit), entitled “Outline of reporting strategy”. FD requested that SC members’ comments be sent to JM and copied to FD.</p> <p>It was noted that the paper formed an excellent foundation document.</p> <p>It was agreed that the paper should be distributed more widely, including to BASK, BHS and ABHI, to seek their views and ascertain what they wanted with regard to analyses to be undertaken.</p> <p>[Action 2003 /35] FD to send the paper to James Nixon (BHS), Neil Thomas (BASK), Keith Tucker (BHS) and Judith Mellis (ABHI), asking for their views.</p>	FD
11	<p>Development of the IT solution – verbal update</p> <p>DP informed the SC that the development of the <i>web browser based forms</i> solution was still on target for 1 April launch, but that recent changes to the Minimum Dataset could result in a 1-2 week delay in the development of the <i>desktop PC</i> solution (the windows client). DP assured the SC that every effort would be made to make this option available for use on 1 April.</p> <p>The first pilot phase was virtually complete. The main issue that had arisen from pilot user feedback was that the speed of download was slow (using the <i>web browser based forms</i>). Where this had been a particular problem, this had been remedied by changing the server that the user accessed.</p>	

	<p>The second pilot phase was due to commence in early March, after comments from the first pilot phase had been addressed.</p> <p>It was agreed that ICD10 / OPCS4 codes should be arranged in alphabetical order in the drop down list. The top five most common codes should be provided first if the length of the list was sufficiently long.</p> <p>[Action 2003 /36] AEAT to develop the IT solution such that the ICD10 / OPCS4 codes are displayed in an alphabetical order in the drop down list.</p>	AEAT
12	<p>March Regional events – update</p> <p>DC updated the SC on progress made with arrangements for the training events.</p> <p>The change in location from the Wirral to the Wrightington Hospital in Wigan on Tuesday 18 March was highlighted.</p> <p>The video featuring BD, PG and DP is now complete.</p> <p>Details of the current number of registrations for each of the events was distributed to SC members. It was noted that the Regional Clinical Co-ordinators had been instrumental in encouraging surgeons to attend the events.</p> <p>BD requested details of the number of units represented by the registrations.</p> <p>[Action 2003 /37] AEAT to provide the details of the number of units represented by the registrations.</p>	AEAT
13	<p>Review of the ‘State of Readiness’</p> <p>BD summarised the recent observations made in relation to orthopaedic unit readiness for 1 April. He noted that communications from the NJR Centre to units had been extensive, and was delighted at the number of event registrations.</p> <p>A questionnaire was sent to each unit (where contact details were known) on 19 February asking for an assessment of their state of readiness for the NJR on 1 April.</p> <p>BD requested suggestions from the SC as to how the commitment to the NJR could be improved.</p> <p>It was agreed that the biggest risk to the successful implementation of the NJR was the lack of local resource commitment for data input. It was vital that each hospital/ unit identify a member of staff to manage the NJR implementation and that appropriate staff for data input were made available.</p> <p>[Action 2003 /38] BD, PW, PG and DC to review this issue and decide what appropriate steps are required.</p>	BD, PW, PG and DC

<p>14 (i)</p>	<p>AOB</p> <p>Third party software vendors</p> <p>The possibility of allowing third party software providers to submit data to the NJR was discussed.</p> <p>It was recognised that some systems were already collecting implant data, and in effect some hospitals were being asked to input data twice.</p> <p>At present third parties are not collecting the full MDS, although some current datasets are similar. DP explained that all third parties would need to agree to provide data to satisfy the approved Minimum Dataset (MDS), and would need to adhere to any future updates to the MDS. This in turn would attract two sets of costs:</p> <ul style="list-style-type: none"> • initial setting-up of third party systems • updating third party systems to comply with future changes of the MDS <p>It was agreed that no decision, on whether third party software could be used, should be made until the scale of the situation had been ascertained. The events are expected to provide some valuable feedback from hospitals.</p> <p>[Action 2003 /39] AEAT to provide indicative costs of using third party systems to submit data to the NJR and estimate how many units would benefit from this investment.</p>	<p>AEAT</p>
	<p>Response to editorial article on the NJR</p> <p>An editorial article on the NJR had appeared in the Journal of Bone and Joint Surgery, Volume 85-B No.1 January 2003.</p> <p>It was noted that this article contained many factual inaccuracies.</p> <p>It was agreed that a written response should concentrate on the achievements of the NJR and the SC to date.</p> <p>[Action 2003 /40] CH and FD to draft a response to the article. BD and PG to sign the response on behalf of the SC.</p>	<p>CH, FD, BD and PG</p>
	<p>Steering Committee representation</p> <p>MPO raised the issue that orthopaedic surgeons in general are concerned that there remains insufficient representation of the surgical profession on the NJR SC. Of particular concern to them was the lack of individual representation from the British Association for Surgery of the Knee (BASK).</p> <p>HP explained that whilst the work of the NJR does not pose any actual threat to the orthopaedic surgical profession, many individual surgeons perceive it to and are concerned that NJR data will be used to compile surgeon league tables.</p> <p>BD assured members that the functioning of the NJR would be kept under review to ensure it continues to achieve its aims and SC representation will be considered as part of this process. No changes to the SC representation were anticipated prior to 1 April.</p>	

	It was noted that considerable input from orthopaedic surgeons had been given to the Minimum Dataset.	
14 (ii)	<p>Agenda items for February 2003 Steering Committee meeting</p> <p>It was agreed that AEAT would bring forward agenda items for the next meeting.</p> <p>=</p>	
14 (iii)	<p>Venue and format for March 2003 Steering Committee meeting</p> <p>The March SC meeting will be held in Birmingham on 19 March.</p> <p>The venue for 19 March is:</p> <p>Dollond & Aitchison Group Training and Conference Centre 50 Rocky Lane Aston Waterlinks Birmingham B6 5RQ</p> <p>A buffet lunch will be available from 12.30, with the meeting starting at 13.00 and due to finish by 16.30 at the latest.</p> <p>SC members may wish to consider staying in Birmingham on the night of 19 March so that they can visit the training event on the morning of 20 March.</p>	

**Sandra Hasler
Communications Manager, NJR Centre
28 February 2003**

APPENDIX 1

Action no.	Progress	Action holder
2002 / 06a and 06b	<p>Reopened 21 Feb 2003 Follow up of the prospect of an editorial article in the Health Services Journal to coincide with the launch of the NJR should go ahead. Following discussion, it was agreed that a request will be made for a small paragraph to be included.</p>	AEAT
2002 / 07a	<p>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.</p> <p>The Regional Clinical Co-ordinators have been supplied with a list of contacts (including NHS and Independent contacts) in their areas and have been asked to identify any existing units that are not included on the list. AEAT is awaiting replies.</p> <p>The events will be used as another means of trying to capture the details of any 'missing' units by asking delegates to share their local knowledge.</p> <p>Note: All MOD hospitals are linked to an NHS Trust and should be included on the Registry.</p>	AEAT
2002 / 35	<p>Ongoing Need to confirm how many BUPA hospitals and units carry out orthopaedic procedures. CD and DP to check list provided by CD.</p>	CD / DP
2002 / 18a	<p>Ongoing Material to be translated into Welsh has been identified. AEAT are obtaining cost estimates and turnaround times from several organisations.</p>	AEAT
Report on hardware healthcheck - NJRSC(02)13		
2002 / 26	<p>Completed AEAT is no longer actively pursuing contact details for the IT Managers at orthopaedic hospitals/ units. Where new contact is established, replies are scanned to ascertain whether there may be significant IT issues within a unit / hospital. Where this appears to be the case, details will be forwarded to the Department.</p>	AEAT
2002 / 27	<p>Ongoing A draft paper proforma has been designed. This will be updated to reflect the final version of the MDS.</p>	AEAT
2002 / 28	<p>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 by AEAT to populate the NJR prior to its launch.</p> <p>This activity has been helped greatly by gaining access to a Binley's dataset. A database of hospital personnel with orthopaedic specialities has been purchased. All contacts are in the process of being written to personally. [Organisation Codes Service (OCS) lists of hospitals were split into Strategic Health Authority groupings and those hospitals known to carry out hip and knee procedures were flagged. Each list was then distributed to the relevant RCC for review to determine which other hospitals have orthopaedic units].</p>	RCCs / AEAT

Research and the NJR – NJRSC(02)15																																						
2002 / 30	<p>Ongoing The SC agreed that the draft guidance on 'How to apply to use the NJR for research' would be reviewed in March.</p> <p>The guidance should not be placed on the NJR website until fully reviewed.</p>	AEAT																																				
NJR Newsletter - NJRSC(02)18																																						
2002 / 31	<p>Completed The first NJR Newsletter has been finalised. It has been posted on the NJR website and circulation initiated via email. Printed (colour) copies would be available in w/c 24 February.</p>																																					
Minimum Data Set																																						
2002 / 41	<p>Completed Final actions – related to selection of relevant OPCS4 and ICD10 codes - completed immediately following main SC meeting on 21 February.</p>																																					
November management report - NJRSC(02)21																																						
2002 / 43	<p>Ongoing The DoH to pursue the cost of using the National Strategic Tracing Service (NSTS) for the purpose of the NJR.</p>	PW																																				
Memorandum of Understanding - NJRSC(02)23																																						
2002 / 44	<p>Completed ABHI comments have been reported to PW.</p>																																					
NJR national training events – scoping paper NJRSC(02)24																																						
2002 / 45	<p>Completed AEAT made clear on the invitations to training events how long the training would be expected to take.</p>																																					
2002 / 46	<p>Completed. Current Senior consultant representation at each training event is:</p> <table border="0"> <tr> <td>3 March</td> <td>London South</td> <td>Hugh Phillips</td> </tr> <tr> <td>4 March</td> <td>London North</td> <td>None</td> </tr> <tr> <td>5 March</td> <td>East Anglia</td> <td>Keith Tucker</td> </tr> <tr> <td>6 March</td> <td>Oxford</td> <td>None</td> </tr> <tr> <td>7 March</td> <td>Exeter</td> <td>None</td> </tr> <tr> <td>10 March</td> <td>Gwent</td> <td>None</td> </tr> <tr> <td>11 March</td> <td>Basingstoke</td> <td>None</td> </tr> <tr> <td>12 March</td> <td>Leicester</td> <td>Paul Gregg</td> </tr> <tr> <td>17 March</td> <td>Newcastle</td> <td>Paul Gregg</td> </tr> <tr> <td>18 March</td> <td>Wrightington</td> <td>Martyn Porter</td> </tr> <tr> <td>20 March</td> <td>Birmingham</td> <td>Paul Gregg</td> </tr> <tr> <td>21 March</td> <td>Leeds</td> <td>Paul Gregg</td> </tr> </table>	3 March	London South	Hugh Phillips	4 March	London North	None	5 March	East Anglia	Keith Tucker	6 March	Oxford	None	7 March	Exeter	None	10 March	Gwent	None	11 March	Basingstoke	None	12 March	Leicester	Paul Gregg	17 March	Newcastle	Paul Gregg	18 March	Wrightington	Martyn Porter	20 March	Birmingham	Paul Gregg	21 March	Leeds	Paul Gregg	
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2002 / 47	<p>Completed AEAT has devised a system to manage the PC training, e.g. appointment slots.</p>																																					

NJR IT system specification - NJRSC(02)25		
2002 / 50	Completed AEAT have made the NJR system available to SC members to trial data input.	
2002 / 51	Completed Information regarding the free text fields in the NJR database is being disseminated via the first Newsletter.	
Proposed Regional Clinical Co-ordinators (RCC) - NJRSC(02)27		
2002 / 54	Completed Unsuccessful applicants have been contacted.	
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. Letters will also be sent to unsuccessful candidates, following initial contact by PG or HP. Note: Terms of reference would be discussed with RCCs at the next RCC network meeting on 25 March.	FD / PG / BD
Potential pilot sites - NJRSC(02)28		
2002 / 59	Completed Trial of data input (online) was undertaken by PG and DP.	
Actions from January 2003 SC meeting (SC meeting No.4)		
2003 / 01	Completed AEAT will provide a separate summary listing of outstanding actions to all SC members at future meetings.	
2003 / 02	Completed A list of appointed Regional Clinical Co-ordinators, and the minutes of the first RCC network meeting has been provided to SC members. The list of RCC names is also available on the NJR Centre website.	
2003 / 03	Withdrawn Action was superseded by provision of a letter from Bill Darling to Chief Executives of NHS Trusts and Primary Care Trusts.	
2003 / 04	Completed Minutes for SC meeting No. 3 (with minor amendment) have been posted on the NJR Centre website.	
2003 / 05	Ongoing Costs for translating the patient consent form into Welsh are being pursued. It was agreed by the SC that the form also be made available in large text.	AEAT
2003 / 06	Completed AEAT will make the 'patient consent form' available in an electronic format which can be printed as required.	
2003 / 07	Completed The patient consent form has been revised in line with SC comments, except where subsequent advice indicated otherwise.	

2003 / 08	Ongoing AEAT are liaising with Neil Betteridge on appropriate communication routes for disseminating the patient consent form to raise awareness with patients and public.	AEAT
2003 / 09	Completed MREC requirements and how they relate to the NJR have been investigated.	
2003 / 10	Completed PW has rechecked that data from operations (excluding strong personal identifiers) can be entered into the NJR database without patient consent.	
2003 / 11	Ongoing The revised patient consent form should be distributed to the NHS for use. The revised form acceptable to the Independent sector should also be distributed.	AEAT
2003 / 12	Completed SC members have provided information to AEAT to support further development of the patient consent form and associated guidance.	
2003 / 13	Completed The NJR IT system is being developed to include an audit trail function that will record all data amendments.	
2003 / 14	Modified action Jan van der Meulen has produced a short paper titled "Outline of reporting strategy".	
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 / 17	Completed The training events schedule was referred to (and its URL provided) in Bill Darling's letter to Chief Executives, dated 31 January.	
2003 / 18	Ongoing All required modifications to the MDS are being enacted. The identification of relevant OPCS4 and ICD10 codes has now been finalised with a subset of SC members.	AEAT
2003 / 19	Completed AEAT has circulated the paper NJRSC (03) 13 Checking and validating encrypted patient details.	
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
2003 / 21	Closed No advice on how the auditing and compliance element of the NJR should function was received.	All
2003 / 22	Completed Nominations from independent sector hospitals to pilot the IT solution were	

	forwarded to AEAT.	
2003 / 23	Ongoing Nominations for smaller hospitals to pilot the IT solution are required.	All
2003 / 24	Completed The NJR will be launched on 1 April by the DoH in England and by the Welsh Assembly Government in Wales.	