NATIONAL JOINT REGISTRY STEERING COMMITTEE

MINUTES

Meeting: Steering Committee meeting 2002/ No. 1 Date: Friday 4 October 2002

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

Present: Bill Darling BD Chair

Professor 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)

Mick Borroff MB DePuy International, ABHI (representing the orthopaedic device

industry)

Stuart Simpson SS Stryker, ABHI (representing the orthopaedic device industry)

Dr Chris Dark CD Director of Clinicial 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)

The following AEA Technology staff were also present:

David Carter DC NJR Project manager
David Pegg DP NJR IT manager

Sandra Hasler NJR Communications manager

Apologies Apologies were received from:

Neil Betteridge, Arthritis Care (patient group representative)

Heulwen Blackmore, National Assembly for Wales. Shaun Chainey attended on her behalf.

Sandra Falconer, Scottish Executive (observer status)

Item	Welcome and Introductions	Name/ Date
1	The meeting opened at 10.00 with the Chair welcoming everyone to the first Steering Committee (SC) meeting of the National Joint Registry (NJR). He apologised for the late circulation of the agenda and papers and, on behalf of the SC accepted the reasons given by the Department of Health and AEA Technology. Papers for future meetings would be circulated at least 5 working days in advance of the meeting date.	
	BD reinforced Lord Hunt's words: "The Registry will benefit patients, clinicians, and the orthopaedic implant industry alike." The NJR has a vision and a goal; it will be a beacon for future work.	
	Round table introductions were made.	

2 Terms of Reference

PW presented paper NJRSC(02)02 - Terms of Reference for the Steering Committee. Following discussion, it was agreed that the the ToRs should be revised as follows:

- In point (7), substitute "monitor" for "police", "units" for "hospitals", and add "and manufacturers" to the end of the sentence.
- Wording of point (8) should make it clear that Ministerial approval is required before the annual report is made public. Point (8) should also incorporate the SC advising Ministers on what data should be made publicly available - i.e it should incorporate a modified point (5).
- Add a new point to a cover the SC's responsibility to facilitate use of NJR data for research purposes.

It was noted that the use of the word "development" under point (1) reflects the fact that the Registry will not be implemented and then stand still; its functionality and scope will increase over time. For example, other joints may be added in future years. Further analysis and reporting options may be required in the future that cannot be predicted now. The levy is to be set on an annual basis and this will allow scope for change. As computer-aided technology develops, this is also likely to impact on the NJR.

It was agreed that the version number and date should be added to all issues of ToRs and also to other papers issued to the Steering Committee.

The Steering Committee ToRs are to be redrafted and issued for agreement at the next SC meeting.

PW

3 i NJR Service Specification

The service specification had been circulated ahead of the meeting. There was no related discussion.

3ii & The AEAT Team, the Proposal and Activity to Date

iii

- FD gave a presentation that covered:
- AEA Technology (AEAT) background and relevant skills and experience
- AEAT's partners
- Outline details of the proposed programme of work
- Some key elements of the developmental phase
- An update on the contractual situation
- Key activity to date
- Key activities for October

It was noted that there is a range of training activities related to establishment and ongoing operation of the NJR. Therefore, there must be clarity on what form of training is being referred to at any time. FD confirmed that the cost of the training roadshows (for training unit staff on how to input data into NJR) is included in the price of the NJR development phase. This is for a pre-defined number of roadshows and number of staff to be trained.

Discussion followed on what contact had already been made with Trusts and the private sector and how this could and should be carried forward.

Chief Executives have been informed via the Chief Executives' Bulletin for 20-26 September 2002, Issue 136. A copy is attached as Appendix 1. The main purpose of this contact was to inform the NHS of the award of contract for the NJR work and the establishment of the SC. It also asked for names and contact details of IT managers in NHS Trusts and units, as their co-operation in completing a Hardware Healthcheck questionnaire is needed at an early stage. An equivalent message for the private sector was provided to IHA. Other communications to date are Lord Hunt's press release and a brief Question & Answer paper on AEAT's role. Both are accessible on the NJR web site at http://www.njrcentre.org.uk

The NJR brings major implications for orthopaedic units, particularly in relation to data provision, data analyses that will be available, required training and also levy payments. It was agreed that various "top down" communication routes should be used to ensure that everyone who needs to know about the NJR is informed – from senior management through to those "on the ground" who it will affect. It should also be made clear that the NJR has support from the top, from the Minister, and that there is a strong and representative SC. Details of the SC membership should be included in key communications

The following actions were agreed:

 AEAT to speak to AS outside the meeting regarding names and contact details of StHA Chief Information Officers (as a route to identifying IT managers at Trust/ unit level) AS

- investigate whether NHS Confederation electronic bulletins can be used as a route for early communications. These bulletins and other NHS Confederation publications may be useful dissemination routes further into the NJR project.

AEAT

 investigate whether British Association of Medical Managers (BAMM) electronic bulletins could be used to inform Medical Directors and Clinical Directors of Trusts and private units about the NJR. **AEAT**

- investigate whether use of IHA monthly bulletins will be sufficient for communications specifically with the private sector or if other routes should also be used.

AEAT

 consider use of the Health Services Journal as a dissemination route for capturing large audiences later in the project. ΑII

 contact David Adams at the BOA to obtain a list of linkmen. (The BOA has a "link" contact in every orthopaedic unit.) Linkmail (email) communications can then be used to identify all orthopaedic unit managers in readiness for an introductory mailing on the NJR. **AEAT**

4 Work Programme and the Levy

PW presented paper NJRSC(02)04 - Work Programme and the Levy.

AEAT are to provide a simple summary of envisaged activity for Year 1 of Operations, along with the overall cost. This will be provided to the Department of Health initially. Following approval, it will be circulated to the SC to assist them in determining whether they have additional requirements for Year 1 that will need to be costed into the levy.

AEAT 18.10.02

All SC members are to identify any extra work that they think the Registry should cover in Year 1 of Operations. Details should be provided to FD by 25 October 2002.

AII 25.10.02

CM stressed the importance of getting information on the levy system and its likely level out to PCTs. PCTs have already been provided with planning guidance for determining budgets and will be preparing their budget bids in November. It was agreed that it would be difficult to provide an accurate figure for the Year 1 levy by early November. However, it should be possible to provide a ballpark figure on that timescale. £25-00 (including the manufacturers' administration charge of £2-50 per relevant implant) was suggested as the figure to be communicated. This would include VAT, which applies to the levy. This figure is comparable to the costs attached to participation in the National Pacemaker Database. It should be made clear that the levy is applied on purchase of the relevant implants, irrespective of whether a unit provides data to the NJR.

	AEAT to draft suitable items on the levy for the Chief Executives' Bulletin and the IHA Bulletin. This will be submitted to PW for approval. The text needs to make it clear that: the levy is non-competitive; that full compliance is expected; that the private sector are required to comply by the national minimum standards; and, that the NJR is a nationally driven programme under the auspices of Lord Hunt. For determining the actual levy for Year 1 of Operations, it is necessary to establish volumes of primary and revision Total Hip Replacements (THR) and Total Knee Replacements (TKR) carried out in the public and private sectors. The Department of Health provided the most recent figures they had in the tender documentation. No private sector figures were available at that time.	AEAT
	To provide the most recent figures available for the private sector, if possible at individual unit level.	CD
	At present, manufacturers/ suppliers outside the UK are not in the levy loop – their data is not on the MDA CD ("Listing of hip and knee joint replacements and bone cements, August 2002") and they are not members of ABHI. MB, with input from CD, will examine the implications and how they should be addressed. The results will be presented at the next SC meeting.	MB & CD
5	Identification of Key Inputs and Decision Points DC presented paper NJRSC(02)05 - Identification of Key Inputs and Decision Points. He highlighted the very short timescales on items 3, 4 and 5 (i.e. completion by 28.10.02); these are required if AEAT is to meet the 31 March 2003 developmental deadline.	
6	Minimum Dataset, Patient Feedback Questionnaires and Analyses - Proposed Way Forward FD expanded on the need to agree the minimum dataset (MDS), the dataset for the patient feedback questionnaires and expected analyses in presentation NJRSC(02)06 - Minimum Dataset, Patient Feedback Questionnaires and Analyses – Proposed Way Forward. (Note that no paper was tabled) Discussion led to the following decisions and actions:	
	- The MDS would be for primary procedures only at present to enable required deadlines to be met for development of the IT solution. Consideration of revision data will be postponed until Year 1 of Operation, when it is likely to require amendment of the MDS. The MDS may also be amended in the light of experience.	FD
	- The Oxford Hip and Knee Scores could be used for the Patient Feedback Questionnaires – they are validated scoring systems. FD will consult Professor Ray Fitzpatrick regarding the relevant data fields. MB requested that consideration also be given to use of the only other validated option, the WOMAC (the Western Ontario McMaster Osteoarthritis Index)	FD
	- FD to liaise with members of the SC, representatives of the British Hip Society (BHS), the British Association for Surgery of the Knee (BASK) and those involved with other joint registries. Views to be gathered on the MDS (for primary procedures only at this stage), the expected dataset for the Patient Feedback Questionnaire, and predicted analyses.	FD
	- FD to produce a paper on the findings of this consultation. It should include a table of predicted analyses to cross-check that all required data fields are in the MDS. Paper to be circulated to all SC members by end 21 October.	FD 21.10.02
	- Comments to be provided to FD and forwarded to BD and PG.	AII 24.10.02

	- BD and PG to make decision on MDS by 28 October and feedback to AEAT and the SC.	BD & PG
	PG provided AEAT with copies of the THR and TKR datasets agreed in 1999 and derived from work by the BOA, MDA and ABHI in 1998.	
	In response to a question, PW indicated that, due to workload, the Department of Health's Information Policy Unit was unable to provide a representative to sit on the Steering Committee. However, they will be able to offer ad-hoc advice as and when required. CM suggested that it would be advisable to have a StHA Chief Information Officer on the Steering Committee.	
	PW to pursue this request.	PW
7	Regional Champions FD presented paper NJRSC(02)07 - Regional Champions. The contents were accepted, with the following amendments: - substitute "Regional clinical co-ordinators" for "Regional clinical champions" - at end of Section 3, para 2, remove the sentence "We would aim to ensure that champions received a raised public profile for the valuable role they perform." In their bid, AEAT had proposed Professor David Murray as national clinical co-	FD 18.10.02
	ordinator for the NJR. The SC considered that such a role was already filled by Professor Gregg in his role as President of the BOA and Vice chair of the Steering Committee.	
	It was agreed that English co-ordinators should be selected on the basis of one per StHA (ie 28 co-ordinators), although there may need to be some slight variation. Wales does not have StHAs, but ShC confirmed that 2 or 3 Welsh co-ordinators would be acceptable.	
	In relation to selection of the Regional clinical co-ordinators, the following actions were agreed:	
	- Information should be made available to the widest possible audience.	
	- FD to contact David Adams (Chief Executive, BOA) about "advertising" the coordinator role on the BOA and RCS web sites. She should prepare a brief item asking for applications and pointing out that appointments would be one coordinator per StHA. It would be made clear that the role is unpaid, although agreed travel and subsistence expenses would be met. A list of StHA regions would be provided. A 2 page CV and reasons why they think they are suited to this role would be required from applicants. Applicants would be asked to declare any conflicts of interest. They would be given a month to respond.	FD
	- A related letter would be sent by David Adams to Presidents of the RCS, BASK and BHS and to BOA council members.	DA
	- Applications should be submitted to the NJR Centre. They will be forwarded to BD and PG as a single package.	AEAT
	- Following sifting, a final list of regional co-ordinators will be presented in a paper for the 3rd SC meeting.	BD & PG
	At this point there was some discussion on Intellectual Property Rights (IPR) and where they lie. PW confirmed that IPR rests with the Department of Health. This led to discussion on research, and the SC's "duty to write" and to encourage research related to the NJR, subject to the usual caveats. HP agreed to present a paper to the next SC meeting.	НР
	the next 50 meeting.	

8i	Badging the NJR - Logos DP presented suggestions for NJR logos and a possible design and layout for the NJR web site (paper NJRSC(02)08). Eight examples of logos were presented, one of which was selected (bottom left of sheet of options).	
8ii	Badging the NJR – Design and Layout of Web Site The current "under construction" web site was shown. This has a simple Department of Health style. An example web site design was included in AEAT's proposal. This was presented and approved by the SC. It was noted that a consistent style should be maintained – i.e avoid changing the look and overall structure of the web site over time.	
	ShC pointed out that the elements of the web site that contain information aimed directly at the public will need to be available in Welsh as well as English.	
	FD will liaise with CHI, NICE and NPSA to determine how they have addressed this requirement. She will also provide the Department of Health with details of estimated cost.	FD 25.10.02
	There was discussion regarding whether agendas and minutes of SC meetings should be placed on the NJR web site. It was agreed that a summary of each meeting – agreed by BD – should be placed on the web site.	
9	Future Meetings Dates were agreed for the next two meetings. They will be held on Monday 18 November and Wednesday 18 December, at Wellington House. The start time will be 10.30am.	
	SC members will be asked for their availability for meetings in January - April 2003.	
10i	AOB – Contacts within Orthopaedic Hospitals This item had been covered earlier in the meeting.	
10ii	AOB – IT Healthcheck Questionnaire This item had been covered earlier in the meeting.	
10iii	AOB – Manufacturers' Day The SC was supportive of a Manufacturers' Day being held. Probably only 2 hours would be required so it could be run on the same day as an ABHI Orthopaedics SIS meeting. MB will raise this proposal at the next SIS meeting, on 17 October, and report back on their views. The only costs that would be incurred by the NJR project would be T&S costs for AEAT staff to attend the meeting. MDA agreed that they could provide a room if necessary.	мв
10iv	National Symposium on Joint Registers For information, members of the AEAT team have been invited to attend and speak at a National Symposium on Joint Registers. This event is being organised by the Trent and Wales Arthroplasty Audit Group (TAAG) and will be held in Leicester on 1 November 2002. PG will also be participating. BD will be able to attend for the afternoon session and PG will introduce him as the Chair of the NJR SC.	
	 Other issues raised In the public sector there is no legislation to make compliance with the NJR mandatory but all Trusts are expected to comply. In the private sector, units should comply with minimum standards defined by the National Care Standards Commission. All SC members were asked to check contact details held and correct where necessary. 	

- AEAT will produce an expenses form and related guidance. Once approved, this will be emailed to all SC members.	AEAT 21.10.02
The meeting closed at 13.45.	

APPENDIX 1

Extract from the Chief Executives' Bulletin, 20-26 September 2002, Issue 136

17. National Joint Registry

The contract to establish the National Joint Registry (NJR) for hip and knee joint implants has been awarded to AEA Technology. Over the next 6 months AEA Technology will develop a database which will be made available to the NHS and private health care providers. The NJR will then begin to collect data from 1 April 2003 and all orthopaedic hospitals will be expected to participate.

The work of the NJR will be overseen by a steering committee. This will be chaired by former chair of the National Association of Health Authorities and Trusts Bill Darling and vice-chaired by British Orthopaedic Association president Professor Paul Gregg. From April 2003, the NJR will be funded by a small levy placed on the sale of hip and knee implants. One of the functions of the committee will be to set this levy.

The NJR will be an electronic system and AEA Technology will be undertaking a health check of computer hardware specifications/capabilities in all NHS trusts. From 30 September for 4 weeks they will be in contact with IT departments to carry out this assessment. To speed the process it would be helpful if you could e-mail contact details (name, phone and email) for your IT department to enquiries@njrcentre.org.uk

Further information about the NJR announcement can be found at http://www.njrcentre.org.uk

You can also contact Paul Woods on 020 7972 4811 or paul.woods@doh.gsi.gov.uk

Fiona Davies
Director, NJR Centre
18 October 2002