National Joint Registry
www.njrcentre.org.uk

NATIONAL JOINT REGISTRY STEERING COMMITTEE (NJRSC)

APPROVED MINUTES

Meeting: NJR Steering Committee **Date:** Tuesday 21 October 2008
Location: MLS Venue, 130 Shaftsbury Avenue, London W1D 5EU

Members Present:	Bill Darling	BD	Chair
	Prof Paul Gregg	PG	Vice Chair, Orthopaedic Surgeon
	Mick Borroff	MB	Orthopaedic Device Industry
	Christopher Brittain	CB	MHRA
	Patricia Cassidy	PC	Independent Healthcare Sector
	Peter Howard	PH	Chair, Regional Clinical Coordinators' Network
	Alex Macgregor	AM	Public Health & Epidemiology
	Carolyn Naisby	CN	Practitioner with Special Interest in Orthopaedics
	Martyn Porter	MPo	Orthopaedic Surgeon
	Andrew Smallwood	AS	NHS Supply Chain
	Keith Tucker	KT	Orthopaedic Surgeon
	Andrew Woodhead	AW	NHS Management Member
Regular Attendees:	Elaine Young	EY	NJR Project Manager, Healthcare Quality Improvement Partnership (HQIP)
	Richard Armstrong	RA	NJR Programme Director, Northgate Information Solutions (Northgate)
	Charlotte Humphry	CH	NJR Programme Manager, Northgate
	Martin Pickford	MPi	NJR Orthopaedic Advisor, Northgate
	Mike Swanson	MS	NJR Principal Consultant, Northgate
Meeting Invitees:	Lisa Robinson (Part 1 only)	LR	NHS Choices
	Robin Burgess	RB	Chief Executive, HQIP
Apologies:	Mary Cowern		Patient Representative
	Patricia Durkin		Patient Representative
	Dean Sleigh		Orthopaedic Device Industry

REF	ITEM	Action
	AGENDA: PART 1	
1	**Welcome and Apologies for Absence** The Chair welcomed all attendees, and introduced Robin Burgess, Chief Executive, HQIP. RB stated that he was very pleased to attend the meeting. He advised on the new HQIP management structure, in particular future arrangements to support the NJR. A new 'National Development Team' with responsibility for strategy and policy at national level would include project management and support to the NJR. Following recent interviews for the post of National Development Lead to manage this team, RB confirmed that Elaine Young had been appointed to this position. Further interviews were now planned to complete the team and support Elaine in her new role, and would include the appointment of a dedicated NJR Development Officer. The Chair thanked RB and formally congratulated EY on her new appointment. Apologies were received and noted.	
2	**Minutes of the Previous Meeting** Item 1: The Chair congratulated Andrew Woodhead on his appointment as Chief Executive Officer of Newham University Hospital NHS Trust. Subject to a minor correction on the use of a member's initials, the minutes of the meeting held on the 24th July 2008 were approved as an accurate record. The minutes were to be published on the NJR website once the corrections had been made.	**NJRC**
3	**Matters Arising (not appearing elsewhere on the Agenda)** **3.1 Hip Owner's Manual (HOM) (prev. min ref 3.1)** EY reported that an electronic version of the H.O.M. was now available, and the recommended changes from the working group would now be made when she had obtained details from Anne Macleod, DH, who had led the Group PG enquired about the remit of the HOM working group, and whether it was the intention to bring the revised version of the HOM to the NJRSC for approval before publication. MPo suggested that it would be prudent to gauge the continued value of the HOM before reprinting further copies, and there was support to make the manual available via the NJR website in the first instance. Referring to the previous meeting of the RCC Network, EY mentioned a RC request for production of a Knee Owners' Manual. It was agreed that this may be something for consideration in the future, once the Hip Owners' Manual had been successfully launched and other strategic priorities addressed. **Agreed that: EY would obtain details of proposed changes to the HOM from the DH and circulate an amended copy to the NJRSC for further review,** **That the updated HOM be posted on the NJR Website to gauge interest prior to re-printing and re-launching a revised version.** **That the RCC Network would be advised of the decision regarding a Knee Owner's Manual** **3.2 Metal on Metal (MoM) Study (prev. min ref 3.3)** It was noted by CH that of 560 MoM questionnaires sent out to surgeons, 250 questionnaires had been received, and 100 surgeons were yet to reply. She expressed concern about reported cases of late or non receipt of questionnaires, and confirmed the NJRC were investigating with Royal Mail. BD thanked colleagues for their presentations at the BOA, in particular John Skinner, Chair, MoM Working Group, for his glowing recommendation of the value of NJR data to the MoM study. **3.3 Information Data Sharing Policy: Research Protocol (prev. min ref 3.4)**	**EY** **NJRC**

	It was noted that this would be incorporated into a later discussion item **3.4 Clinician Feedback (prev. min ref 6)** RA confirmed that the Clinician Feedback System would be launched to all surgeons via the BOA, who had kindly agreed to notify its members on behalf of the NJR. RA offered to demonstrate the system during the lunch break to any NJRSC members who may not yet have seen it. MB mentioned the benefits of the system for suppliers, and outlined the types of information which would be of interest to them e.g. survivorship information, revision rates. It was agreed that he have access to the system to review what was currently available and provide a supplier information summary to the NJRC.KT and PG offered MB use of their personal data for this purpose. RA confirmed that a 'Supplier Day' was due to be arranged, with a view to offering an NJR supplier feedback system in the future. The NJRSC would be notified of feedback from this event. With regard to the process for investigation of implant/device outliers, AW explained that the Non-Disclosure Agreement he had agreed to draft, to enable supplier access to patient records in the event of an implant being identified as a potential outlier, would be circulated to the NJRSC for comment in the next few weeks. PG stated that he felt it important to compare surgeon performance against national average performance for a technique, so that results were not misleading for the surgeon's performance figures. **Agreed that:** **MB would review the clinician feedback system in liaison with the NJRC and notify details of supplier requirements.**	**MB**
	The NJRC would keep the NJRSC informed about the Supplier Day and relevant feedback.	**NJRC**
	AW would circulate a draft Non Disclosure Agreement to the NJRSC for consideration.	**AW**
	3.5 Mr Timperley Research Request (prev. min ref 15.1) MSw advised on discussion with Mr Timperley at the BOA Conference, and reported that a review of his data requirements had been undertaken and an associated work plan was now being finalised for approval by the NJRSC. Mr Timperley had confirmed that his team would do the commentary on the data, and any information would only be published in agreement with the NJRC and NJRSC. With regard to future funding available for research, MPo enquired about the NJR strategy review noted at the previous meeting, which needed to be costed to establish what level of funding had been committed. EY confirmed that the draft strategy needed to be finalised into a detailed costed business plan which would be presented to the NJRSC at their January meeting, together with proposals for the NJR levy. BD reiterated that the NJR draft strategy provided a work focus but needed to be flexible and would be subject to change.	
	Agreed that: A work plan be submitted for NJRSC approval of Mr Timperley's request.	**NJRC**
	The draft Strategic plan be reviewed to provide a detailed and costed business plan for NJRSC consideration	**EY**
4	NJR Collaboration with NHS Choices Lisa Robinson, NHS Choices attended to discuss proposed collaboration with the NJR. She gave a summary about NHS Choices, explaining the key areas of content that could be searched, and the use of comparative indicators/scorecards for a range of different areas of procedures and waiting times. Also NHS Choices had started to present how services performed against national standards/averages, giving the public more information about what to expect, and how care may be organised for them. LR outlined a number of proposed trust-level indicators based upon NJR data, for possible inclusion on the NHS Choices website, and sought NJRSC approval to use NJR data for this purpose. She highlighted that the indicators presented were examples, and that further discussion may be necessary to agree the precise indicator set, in particular where more outcome-based	

	measures were recommended. The Chair thanked LR. He stated that when this was initially discussed, a main concern had been sensitivity of the data, but the level of public interest in the effectiveness of individual hospitals and surgeons had been acknowledged. LR confirmed that surgeon level data was not currently published on the Choices website, but acknowledged there was interest in this. The NJRSC commented as follows: a. AW supported what had been presented but confirmed he would like to see more information on hospital outcomes from a patient's point of view, such as infection rates. He believed that successful hospitals with good results relevant to patients, sometimes failed on indicators such as access times due to the demand that is placed on them. Results would be balanced with a greater emphasis on outcomes data. PG stated that he would support hospital and unit outcome rate information, but not at surgeon level. b. PG asked about hospital-level MRSA rates and queried whether there were future plans to publish this information at directorate level. MPo felt that re-emphasising the importance of the MRSA indicators was a good solid starting point. c. PG also suggested that publication of information relating to individual hospital NJR compliance rates would be a welcome first step, and MPo suggested some form of star banding on this. LR agreed to examine the possibility of publishing this information. d. AM had concern about some figures being presented as a very minor fraction (e.g. 0.4%) and how meaningful this would be to a patient. LR explained that at present these were only indicative figures, and further work was required to ensure that presented information was of most value to patients. e. AM felt it would be useful to have a descriptor of each unit to provide an indication of the area of specialism, as well as clarification around the term 'revision' to ensure that patients understood what this meant. f. MPo warned that one patient could skew the figures for average length of stay within a hospital and asked how that indicator was calculated. LR undertook to find out. g. KT enquired about the level of GP involvement in the website content and GP and patient involvement in the decision-making, as he considered it vital that data was accurate and not misleading for patients. LR explained that GP and patient input was being sought, together with all users of the site, to establish what was working well. **Agreed that: The NJRSC feedback be considered further by NHS Choices and the NJRC and the outcome be discussed further at the next meeting.**	**HQIP/LR**
5	**PROMS** Discussion ensued on the summary of NJRSC feedback on the national PROMs, and the DH response document, which had been previously circulated. The NJRSC queried how NJR funding would be used within the PROMS. MPo asked what data would be provided, and questioned whether value for money for the NJR would be gained. He maintained that the requirements of the NJR had not been acknowledged by the DH. He felt the original NJR PROMS was clear in identifying what the NJR was trying to achieve, but the national PROMs did not match this. RA queried the DH licensing proposal and whether there would be any restrictions, within the T&Cs that would be imposed on the use of the data. EY agreed to explore this with the DH. KT asked which orthopaedic advisors provided input into the DH PROMS. EY agreed to ask DH. PH reiterated NJR concern that a six month follow-up on a sample was not an adequate time period and should be undertaken at twelve months. This was supported by PG. However AM suggested that the NJRSC should accept that the DH PROMS was already defined, and that the NJR had committed funds. Whilst the national study would not meet all the NJR's specific needs, there would be benefits and the NJRSC could still focus on their own requirements such as a longitudinal study, and begin to move these forward. AM offered his time to begin to define what	**EY** **EY** **AM**

	was required from a longitudinal study, which could then feed into the strategy discussion at the January Committee meeting. KT enquired whether collaboration with the DH PROMS prevented the NJR from undertaking its own study, PG stated not, referring to encouragement from Paul Lelliot at the previous meeting, for the NJR to drive forward future developments. RB agreed with this view, and clarified that the national study formed part of a large programme of work which could benefit the NJR. He acknowledged NJRSC concern that this study would not provide the NJR with exactly what it required, but suggested that it be accepted, and the NJRSC then look to influence the outputs from the national PROMS to ensure the study provided the closest fit possible given the accepted constraints. He acknowledged that in order to achieve what the NJRSC wanted for NJR PROMS, additional funding may be required at a later date. MB queried whether patient consent given for the DH PROMs study would cover future studies that the NJR may wish to undertake i.e. a longitudinal study. RB confirmed this would be the case. **Agreed that: The next step was to finalise a contract/SLA between the DH and the NJR which would formalise arrangements and that EY would liaise with David Nuttall regarding this, and highlight the NJRSC concerns expressed at the meeting.**	**EY**
6	**6.1 Outlier Procedure (Surgeon): Stakeholder Communication** EY confirmed that the NJR outlier procedure had been communicated to the profession by the BOA President Steve Cannon. **6.2 MHRA Update on Recent Outlier Scenario** CB provided an update on the recent MHRA investigation, stating that this had taken longer than anticipated to process. He confirmed that the information the MHRA had felt manufacturers needed, had now been communicated, and replies had been requested as soon as possible. AS queried whether lessons learned on the time taken for MHRA to investigate had been identified, especially as the required response time for the investigation of outlier surgeons was much shorter. CB confirmed this was the case and that steps had been taken to improve the MHRA response time in future. MPo suggested that an SLA be set for the response times of such investigations. BD felt that NJRSC concerns should be communicated to the MHRA, with a request for a formal response regarding the delay with the outlier investigation, and a proposed action plan to ensure improved turnaround times in future. **Agreed that: BD/EY draft a letter to the MHRA regarding this**. **6.3 RCC Network Feedback on Communications with Outlier Surgeons** PH reported strong support for RCCs to be involved in communication with potential outlying surgeons, but it was felt that confidentiality should be carefully considered, before any approach was made. The RCCs had concluded that they would be happy to handle any informal discussions only if they knew the surgeon in question personally. **Agreed that: The outlier process should be amended to reflect this.**	**BD/EY** **EY**
7	**MDSv3 Dataset Review** PH explained the proposed dataset changes that had been discussed at the last RCC meeting. The NJRC confirmed that the proposed changes would be assessed in terms of operational and cost implications, and submitted to the January NJRSC meeting with a view to implementation on the 1st April 2009. The amended data entry forms, when available, would also be circulated to the RCCs for comment. Acknowledging concern from MS that communicating with surgeons was difficult, MPo offered to take this to the next BOA council meeting to request access to the BOA mailing list, and to report back to the Committee. It was agreed that there should be further discussion on the associate surgeon grade amendment at the next meeting. PG felt it appropriate to discuss this issue further with the surgeon who felt	**PG**

	strongly about it at the BOA Congress to understand what was prompting the request. KT asked if it would be possible to build a portfolio for surgeons, which included details of all procedures they had been involved with, across all units. RA confirmed that this was feasible and that the NJRC would evaluate the requirement and report back to the Committee on this. Agreed that: The NJRC would assess the operational and cost implications associated with the proposed data set changes, find out more information about the request to include the associate surgeon grade, evaluate whether individual surgeon portfolios with details of procedures across units could be established, and report back on all items to the next NJRSC meeting in January. **MPo would investigate whether the BOA mailing list could be used for communicating this information to surgeons**	**NJRC** **NJRC** **MPo**
8	**US Food & Drugs Administration (FDA)** MPi provided a background summary on the FDA request for NJR data. He quantified the advantages in establishing the NJR position within the orthopaedic world; and areas for consideration in relation to control over the FDA and what they do with any data they may be sent. MB requested more detail into their research strategy and what different methodologies they were looking to research. **Agreed that: Further discussions would take place with the FDA, particularly in relation to the value of the intellectual property.**	**HQIP**
9	**Glasgow BOA 2010 & Other Orthopaedic Association Meetings** KT informed the meeting that Mr Mike Bell was President Elect of the Orthopaedic Association of the English Speaking World and that its 2010 meeting was to be held in Glasgow. There was an opportunity for the NJR to present at that meeting. The NJRSC welcomed this opportunity but felt that, with six other registries scheduled to present in 90 minutes, the time allocation was insufficient. It was noted that as the meeting was scheduled to take place after the BOA Congress, also in Glasgow, the key findings of the 6th NJR Annual Report could be presented. **Agreed that: KT would see if it was possible to increase the amount of time available.**	**KT**
10	**US Registry Barcode Interest** KT provided the meeting with a summary of this request and the interest from Henrik Malchau to come from America to see the work of the NJR, in particular how the barcode system is used. It was noted that Mr Malchau was responsible for the establishment of the Swedish Registry, and was now looking to set up an arthroplasty register in the US. KT had emailed him to find out what he would like to see and was currently awaiting a response, but it was noted that Mr Malchau's visit was recognition of the work of the NJR, and would be an ideal opportunity to demonstrate what the NJR does. The NJRSC supported the visit, and HQIP expressed interest in being represented at the meeting. RA confirmed that Northgate would be delighted to host the visit, but would require confirmation of the objectives, date and time. The NJRSC also supported MPo suggestion that there was value in hosting a regular UK Registries meeting to facilitate learning and sharing of information. **Agreed that:** **The date and objectives for the visit be confirmed and circulated for information and further discussion.** **The idea of hosting a UK registries meeting be pursued.**	**KT**
11	**11.1 NJR Data Survivorship Analysis; Validation Study** MPo stated the two concerns that he had over the (a) accuracy of the data and (b) having confidence in the accuracy of the survivorship figures. He explained that he had been in discussion with the Royal College of Surgeons, who had been looking at potential under-reporting	

	of revisions in both the NJR and HES. RA stated that the Regional Coordinators (RCs) role was to work with units to improve their data quality. The wider issue of HES data was not currently within the remit of RCs and that it was only when increased HES-linked data was published that they may be involved at a local level. PG questioned the accuracy of HES data relating to hip and knee replacement surgery, suggesting that in some cases revisions may be 50% under reported in HES. RA stated that due to the high tariff associated with hip and knee procedures, providers were incentivised to ensure that HES records were submitted for this activity. He acknowledged, however, that this would not assure the quality of data contained within the record, or the availability of patient linkable data items that would support HES / NJR linkage. **Agreed that: RCs continue to address the issue of data quality at local level.** **Further study be undertaken on data quality** 11.2 NJR Revision Study MPo presented a paper proposing a study into NJR revisions. It was agreed that this be discussed in detail at the research meeting to be held after the NJRSC meeting. 11.3 Scottish Registry Component Information Request MSw provided some background on this request and the potential considerations for the NJR, in particular the cost of NJR investment to build the component database up over the years and whether this should be provided to another registry. He also raised concern that there appeared to be potential, hidden commercial interests involved in the request. MB stated that the orthopaedic industry would rather have a single national system to upload codes into rather than separate systems to keep up-to-date. **Agreed that: Further information was required before any further decision could take place. There was a need to understand the outcomes and whether patient safety, in particular, was the priority in this request, or whether its focus was that of a commercial venture.** 11.4 Nuffield Othopaedic Centre Data Request MSw provided a summary of this request which was to examine the impact of training and volume on the outcomes of unicondylar knee replacement. Whilst there were concerns over some of the ethics, there was general support for the study. The NJR would require assurance that those surgeons whose identity would be known by those undertaking the study had all consented to their data being used. The study needed MREC approval and, once it had been obtained, a full study proposal should be submitted to the NJRSC for consideration. **Agreed that: Further discussion was required to clarify the requirement and ethics**	**NJRSC** **HQIP** **NJRC**
12	**Quarterly Statistics Report Q1 (July - September 2008)** The Quarterly Statistics Report Q1 (July – September 2008) was received and noted.	
13	**Quarterly Management Report Q1 (July - September 2008)** The Quarterly Management Report Q1 (July - September 2008) was received and noted.	
14	**NJR Finance Report (July - September 2008)** EY provided the NJR finance figures for the reporting period, which were duly received and noted.	
	The Chair informed the meeting that the intention for Agenda Part 2, was to enable the NJRSC to discuss the Annual Report process. Northgate would leave the meeting for this item. He explained that considerable time and discussion had already taken place to establish reasons for the delay in the production of the 5th Annual Report and how this could be avoided in the future, and he hoped for constructive feedback from members on the way forward.	

	AGENDA: PART 2	
15	**Any Other Business** **15.1 Business Case: Extension to the Performance Management System** Members discussed a business case from RA, Northgate, for extension to the existing performance management system. It was noted that the current system was developed in 2006 when Northgate took over the NJR contract, and was designed to meet the reporting requirements at that time. Since then the volume and complexity of NJR reporting requirements had expanded significantly and there was a need to extend the system in a number of key areas to meet the needs of stakeholders. Main improvements were noted as the inclusion of ODEP ratings to allow routine monitoring and performance of ODEP rated products and importantly those without ODEP ratings, agreed as a significant benefit, reduction in time taken to prepare data for the Annual Report without creating 'one-off' data set, and improvement to overall data security. **Agreed that: This development should be approved pending confirmation of costs.**	**EY/RA**
16	**Annual Report Process** It was noted that the process for the 6th Annual Report needed to commence with immediate effect as it was acknowledged that a major problem this year had been the delay with sub contracting for data analysis resource. Given the urgency to commence work, and the length of time required to sub contract for an analytical resource, RB confirmed that the tendering process could be waived for the coming year, and that HQIP would contract directly with the RCS to provide this service for a period of up to a year. The service would continue to be competitively tendered in subsequent years, through the NJR contractor. It was agreed that an Editorial Board should be established as a sub group of the NJRSC to oversee production of the 6th Annual Report and monitor the work of the RCS. Membership and terms of reference for this group needed to be established **Agreed that:** **HQIP would notify Northgate of the agreed contract arrangements for the 6th Annual Report and liaise with the RCS about contracting for this service for the coming year.** **That an Editorial Board would be established, and that NJRSC members would be kept informed about arrangements for the Chair, membership and terms of reference of the group.**	**EY**
17	The Chair closed the meeting at 15:10 hours	