National Joint Registry
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NATIONAL JOINT REGISTRY STEERING COMMITTEE (NJRSC)

MINUTES

Meeting: NJR Steering Committee **Date:** Tuesday 25th October 2011
Location: Epworth Room, MIC, 81-103 Euston St, London, NW1 2EZ

Members Present:	Laurel Powers-Freeling	LPF	Chair
	Prof Paul Gregg	PG	Vice Chair / Orthopaedic Surgeon
	Mary Cowern	MC	Patient Representative
	Prof Alex Macgregor	AM	Public Health & Epidemiology
	Sue Musson	SM	Patient Representative
	Carolyn Naisby	CNa	Practitioner with Special Interest in Orthopaedics
	Dean Sleigh	DS	Orthopaedic Device Industry Representative
	Andy Smallwood	AS	NHS Procurement Representative
	Keith Tucker	KT	Orthopaedic Surgeon
	Andrew Woodhead	AW	NHS Management Member
Attendees:	Richard Armstrong	RA	Programme Director, Northgate
	Robin Burgess	RB	Chief Executive Officer, Healthcare Quality Improvement Partnership (HQIP)
	Alex Henderson	AH	Committee Administrator, HQIP
	Peter Howard	PH	Chair, NJR Regional Clinical Co-ordinators' Network
	Dr Khalid Razak	CC	Medicines & Healthcare Products Regulatory Agency (MHRA)
	Robin Rice	RR	Welsh Government Representative
	Mike Robinson	MR	Research Officer (NJR), HQIP
	Mike Swanson	MS	NJR Principal Consultant, Northgate
	James Thornton	JT	Communications Manager, HQIP
	Melissa Wright	MW	Development Officer (NJR), HQIP
	Elaine Young	EY	National Development Lead, HQIP
Apologies:	Ashley Blom	AB	Bristol
	Mick Borroff	MB	Orthopaedic Device Industry Representative
	Dr Crina Cacou	CC	MHRA
	Martyn Porter	MPo	Orthopaedic Surgeon

REF	ITEM	ACTION
1.	**Welcome and Apologies for Absence** LPF opened the meeting and welcomed Sue Musson, Patient Representative, and James Thornton, HQIP Communications Manager and NJR Lot 3 contract lead, to their first meeting. Apologies were noted.	
2.	**Minutes of the previous meeting held 26th July 2011** The minutes were accepted as a true and correct record.	
3.	**Matters Arising (not appearing elsewhere on the agenda)**	
	3.1. NJR Appointments [previous minute ref: 3.4] The following appointments were confirmed: a) NJRSC Patient Representative: Sue Musson. b) NJRSC Independent Healthcare Sector Representative: Dr Jean-Jacques De Gorter, Director of Clinical Services, Spire Healthcare. c) NJR Communications Officer, HQIP: Rebecca Beaumont.	
	3.2. NJRSC minutes correction: 28th October 2010, item 8.5 [previous minute ref 3.1] MR requested that the minute be amended further to reflect that the misuse of the data in the two papers presented at the BOA conference of 2010, related to a member of Avon Orthopaedic Centre Knee Group and not the University of Bristol. It was agreed that an apology be extended to the University of Bristol for any previous misrepresentation.	**MR**
	3.3. Access to HES Data: NJR and Information Centre (IC) [previous minute ref: 3.5] It was noted that EY, PG, RA and MR had met with the IC to discuss data access issues and the possibility of agreeing a streamlined process for the NJR which would encompass all the recurring requirements for HES linked data. The IC had agreed in principle to establishing an umbrella agreement and work was ongoing to agree terms.	**HQIP** **Northgate**
	3.4. Incorporation of Elbow and Shoulder joints [previous minute ref: 4] It was noted that HQIP had received permission from ROCR to start collecting data on elbow and shoulder joint replacements, but implementation was now reliant on the completion of the component management system due in November. A meeting was being arranged with BESS to discuss progress, and to notify them that approval had not been given to develop shoulder PROMs initially due to cost implications.	**MW** **Northgate**
	3.5. NJR Data for Care Quality Commission (CQC) Quality and Risk profile (QRP) [previous minute ref: 5] It was noted that EY, PG and RA had met with the CQC and that the following indicators had been agreed in principle subject to NJRSC approval: a) Compliance by Trust with a benchmark set at 100% to reflect mandation. b) Revision Rates by Trust, noting crude data, without adjustment for case mix, would not be relevant to the CQC but would be shared at 1, 3, and 5 years. c) Volume by Unit although not a useful indicator of quality would give a more complete view. d) Thromboprophylaxis. In addition the following potential indicators had been discussed with a view to sharing information with the CQC so that their relevance to the QRP could be assessed: a) 90-Day Mortality. b) ODEP Ratings (hips). The CQC would make a formal data sharing request to the NJR prior to the release of any of the above information. Also while some indicators were ready for use, others required additional consideration and the CQC would work with the NJR to finalise how all the indicators would be presented on the NHS Choices website. It was felt that it would be useful to communicate these indicators to Trusts, and that RC's should be provided with information to assist with this. **Agreed:**	

	• **That the proposed indicators should be developed with the CQC.** • **Consideration should be given to communicating this information to Trusts.** • **Consideration would be given as to how this would apply to Wales.**	**HQIP** **HQIP** **HQIP**
	3.6. NJR data for publication on NHS Choices [previous minute ref: 12] It was noted that EY, PG and RA had met with NHS Choices, and that the following indicators had been agreed in principle for publication on the NHS Choices website, with the proviso that each would be presented with a summary and explanatory text, which would be agreed by the NJR prior to publication. a) Compliance; b) Volume by Unit for NHS and Independent Sector; c) 90 day mortality. In addition the NJR would work with NHS Choices to consider the following potential indicators for future publication: a) Revision Rates; b) ODEP Ratings; c) Data on other joints (ankles, elbows, shoulders) d) PROMs (albeit the volume of data may not be meaningful across all Trusts). NHS Choices had also offered to include NJR articles in their patient newsletters. **Agreed: To support the proposed indicators and work with NHS Choices in respect of web site presentation.**	
	3.7. BMI – The London Independent Hospital [previous minute ref: 3.6] RA reported that since this issue was raised, the data on this hospital had improved, and it was no longer relevant to write to the CEO of BMI.	
4.	**Compliance with NJR vs. HES – private sector issue** Noted by PH, that the problem of patients referred by NHS Trusts for operations in the private sector, being recorded on HES as having their operations in the NHS Trust, had the effect of significantly lowering a Trust's compliance rate and needed to be addressed. Proposed options included: a) Conducting Trust level audits of theatre logs and data submitted to the NJR; b) Altering data entry forms to include a relevant field for this situation; c) Quarterly reconciliation of the additional data field with the independent sector so that the referral point was captured. **Agreed:** • **To refer to the RCC Network meeting in December for consideration.** • **To discuss with the IC.**	**PH** **MS**
5.	**Publication of Trust and Surgeon Level Data** RB reported that as part of the Government's 'transparency and outcomes' agenda, it had been stated that clinical audit data would be published from April 2012 on www.direct.gov.uk. As such HQIP would be agreeing a plan with all national audits for publication of their data. In this context it was noted that the NJR was expected to publish Trust level data by 2012 i.e. in the next Annual Report, and agree a timetable to report surgeon level data as soon as possible thereafter. KT suggested that the NJR would need to liaise with the BOA regarding surgeon level reporting because the NJR had always given assurance to surgeons that their data would not be available in the public domain. PH also pointed out that the difficulty for the NJR to address surgeon level reporting would be the large volume of orthopaedic surgeons compared to clinician numbers in some other specialties. AW's view was that Trust level reporting would not be as useful to patients as Unit level reporting was accepted, as was recognition of the shortfalls with data quality. It was therefore recognised that the NJR would need to plan what data could be presented in the 9th AR, and how it could subsequently be developed in the future.	

	LPF felt that it would be useful to review other audits, that were either more advanced or most relevant to the NJR, to assess what data they were reporting and to assist the NJR to understand what was acceptable and how it could be publicly portrayed. It was accepted that a planning group be convened to address this matter. KT suggested that this could be discussed at the BHS annual meeting in March 2012 and the BASK annual meeting in April 2012, and also that a pilot exercise could be undertaken to test proposed Trust/Unit level in NJRSC surgeon hospitals. **Agreed: That a working group be convened for this purpose**	**LPF/EY**
6.	**Data Governance: Access, Use and Sharing of NJR data** EY reported on a recent incident whereby data presented by a guest speaker at the BOA conference had resulted in the temporary shut-down of the NJR Supplier Feedback System, and highlighted a need to review the current NJR data access and data sharing protocols. An audit of data request approvals over the last 18 months had indicated that the NJR had fairly robust systems in place, but these were currently being tightened further to ensure that appropriate governance arrangements were in place. **Agreed: That the NJRSC would be kept updated with progress.**	**AM / HQIP**
7.	**NJR Economic Model** Noted by LPF, that the NJR would be reviewing the current funding arrangements, and giving consideration to what alternative funding models may be applicable to support the NJR in the future. The current processes would be audited, and the outcome would inform any future proposals. **Agreed: That the NJRSC would receive a progress report at the next meeting**	**LPF**
8.	**National Orthopaedic Research Strategy** PG outlined previous work that had been undertaken with ARUK, which had resulted in the recent proposal for a joint ARUK/NJR/BOA/DH collaboration to develop a national orthopaedic research strategy. It had been agreed that a working group would be established to take this forward. It was confirmed that the NJR would continue to develop its own research strategy which would be informed by agreed national priorities. **Agreed: That the draft terms of reference and membership of the national research strategy group would be circulated to NJRSC for information**.	**HQIP**
9.	**NJR Strategic Plan (SP) 2011-13** Following previous discussion at the last meeting, EY presented an outline of SP objectives and associated tasks, which AM felt had been very well compiled. She noted that many of the tasks and objectives were interdependent and required prioritisation and a nominated NJRSC 'lead'. RB noted that the governance arrangements and NJRSC sub-committee structure would assist with this, and should be reviewed at the same time. This was accepted. In addition, it was felt that as data quality was a main priority in the SP, a related sub-committee should be included in the structure, and that to alleviate workload, sub-committee membership should be extended to RCCs. It was felt that it would be useful to revisit the original purpose and Terms of Reference of the NJR, as it had evolved dramatically since being established, and also translate what 'improving outcomes' meant for the NJR. MC requested that the objective related to 'Geographical extension of the NJR' be renamed 'Geographical Implications', to emphasise that consideration should always be given to how initiatives may relate to Wales. **Agreed:** • **To amend SP objective to 'Geographical implications'.** • **To review the original aims and objectives of the NJR from the first NJRSC minutes and the original consultation document from the DH.** • **To prioritise a review the NJRSC structure and governance arrangements.**	**EY** **EY** **LPF/HQIP**

	• **To finalise the SP.**	**EY**
10.	**Update from the NJR Sub-Committees**	
	10.1. Regional Clinical Co-ordinators Network PH noted that the next RCC Network meeting would be held on 8th December 2011, and that all RCC positions were either filled or in the process of appointment.	
	10.2. Outlier Sub-Committee (Surgeon Data) PG updated members on the outlier surgeon subcommittee of the 12th October, and noted that minutes would be circulated separately. <u>a) Outlier Statistical Methodology:</u> PG thanked Bristol for the excellent work they had undertaken, and reported that Alison Smith had presented a proposal outlining a new outlier statistical methodology which the committee had supported. **Agreed: To support the proposed changes and that PG would notify the BOA.** <u>b) Annual Trust Reporting:</u> PG outlined proposals for annual trust reporting and a draft report format was tabled for information and comment. It was also noted that a letter would be sent to all Trust CEO's ahead of the first report, to outline the new process and highlight the mandatory status of the NJR. <u>c) Surgeon Outlier Progress Report:</u> The new progress report format was reviewed. LPF identified that there may be more consideration required in relation to the criterions attached to the RAG ratings. **Agreed:** • **A final draft of the Trust report and copies of supporting communication documents, would be circulated to the NJRSC for information.** • **That the surgeon report presentation required further review before it was finalised, particularly in respect of the criterion attached to the RAG ratings and appropriate colour coding.**	**PG** **Northgate/ HQIP MW**
	10.3. Implant Performance Sub-Committee KT updated members on the Scrutiny Group of 17th August 2011as follows: • 6 implants were rated 'red', and details had been forwarded to the MHRA. • 8 implants were rated 'amber' and the NJR would alert the relevant companies. • That future consideration should be given to advising other international registries of any NJR concern about an implants performance. <u>MHRA/BOA/NJR Workshop:</u> KT advised that the MHRA/BOA had organised a workshop for 4th November to consider the pre and post market regulation and surveillance of new implants. He felt that the NJR Implant Performance sub-committee should be involved in any process. PG expressed concern that while the NJR should participate in any agreed process, it should not assume any 'regulatory' responsibility, which was the remit of the MHRA. LPF envisaged that the NJR could provide the data that would support the MHRA and implant companies, but this would require an assessment of the workload and any associated funding implications. **Agreed: That the NJRSC would be kept updated.**	**KT**
	10.4. Editorial Board (EB) - 21st October 2011 **a) BOA/IOA Conference/NJR Session, Dublin (13th to 16th September 2011)** EY reported that the NJR session, and presentation of the 8th Annual Report (AR), had been extremely successful. The number of people attending the session had exceeded the room capacity, an issue that would be addressed with the BOA for next year, and all 150 copies of the report, and USB memory stick versions, were given out. It was noted that a different approach had been taken this year to launching the AR, with external speakers invited to present. One such presentation, which had reached	

	conclusions using NJR data, had highlighted the need to review NJR data access policies, and necessity to have advance notification of any 'external' presentations, should a similar approach be repeated. Noting a high level of associated press interest, JT confirmed that a media strategy would be in place ahead of the next conference. **Agreed: That a media and communication strategy would be finalised to support the EB with facilitation of the launch of the 9th AR (item 14.1 below refers).** **b) Annual Report: Patient and Public Guide (PPG)** It was noted that the PPG had been circulated to the RCC's for comment by 31st October. When published, 500 copies would be distributed via RC's, RCC's and the HQIP Patient Network, and be available as a free download on the internet. Members noted amendments which would be incorporated into the PPG, and were supportive of a patient event being organised to launch the PPG particularly as it was noted that the NJR was a good example of how national audits should be communicating with patients. **Agreed:** • **Further comments on the PPG should be emailed to MW by 31st October 2011.** • **Suggestions about communication of the PPG should be emailed to JT.**	**JT** **All** **All**
	10.5 Research Sub-Committee (RSC) - 21st October 2011 <u>a) BOA speaker data:</u> AM noted that NJR data used for presentation at the BOA, had been approved through the NJR data request process, but should have been referred to the RSC where it would have been rejected on the grounds of a conflict of interest. <u>b) Research requests:</u> It was noted that MR was maintaining a log of all work/publications using NJR data. 6 requests had been reviewed at the last RSC, one of which would link the NJR to a cancer audit. As the RSC workload had increased, the panel of reviewers would be increased to include those with areas of specialist expertise. Currently this was being piloted with RCCs. AM assured members that the RSC were confident that the all research requests were self funded and would not incur NJR costs. <u>c) General Practice Research Data Base (GPRD):</u> AM noted that the NJR were developing a linked process with the GPRD, who would be providing the funding. <u>d) DNA Biobank:</u> Noted that the pilot study had been set up with Sheffield University, and associated contracts were being finalised. The study was due to run for one year in the first instance with continuation for a second year dependent on an evaluation. <u>e) NJR PROMs:</u> AM noted that the one-year cohort had been increased to 50,000 with excellent response.	
11.	**NJR Finance Report: Q2 (2011/12)** The Q2 finance report was received and noted. Referring to the way that income/expenditure was recorded, LPF felt that greater clarity was required. **Agreed: To re-format the finance report.**	**HQIP**
12.	**Quarterly Statistics Report (QSR) Q2 (2011/12)** The Q2 QSR was received and the following points highlighted by RA: • Of 45,615 data submissions over Q2, 43,314 had an associated NHS number. • 89.9% of those records agreed for their data to be stored on the NJR.	

	• 52,674 levies were collected which was the highest volume in a quarter.	
13.	**Quarterly Management Report (QMR) Q2 (2011/12)** The Q2 QMR was received and the following points highlighted by RA: • 1,271 service desk calls were received during Q2. 75% from patients following the Channel 4 programme on 'Metal on Metal', and the BBC's One Show on the ASR implant. • 2 technical incidents had occurred during Q2. One related to the crash of the NJR website due to the high volume of users downloading the annual report when it was launched. • Charlotte Humphry had replaced Nicky Pearson as NJR Programme Manager. PG requested Northgate to break down the Regional Performance table by Unit, as it would be useful to review Unit performance. **Agreed: That Northgate would circulate NJR website statistics and a unit performance table for information.**	**Northgate**
14.	**Any Other Business**	
	14.1. Annual Report JT distributed a draft communication plan to support the process of presentation and launch of the NJR Annual Report. He drew attention to the importance of having a timetable which facilitated staged editorial review, and that EB meetings should be scheduled to coincide with key dates in the publication process. It was noted that this required liaison with MPo who was already scheduling EB meeting dates. **Agreed:** • **To email the Annual Report communication plan to EB and NJRSC.** • **To liaise with MPo regarding timelines for scheduling EB meetings.**	**JT** **HQIP**
	14.2. Hip Replacement Conference EY notified members that PG had been invited to speak at a national conference on hip replacement on 2nd February 2012, and that NJR members/associates would be entitled to a 15% discount on the booking fee. Details would be circulated	**HQIP**
	14.3. British Hip Society (BHS): Femoracetabular Impingement (FAI) Register KT reported that the BHS had established a registry with Bluespier (paid for out of their own funds) for registering patients who had undergone FAI surgery. NICE had stipulated that surgeons would have to register all their FAI cases with the BHS registry to fulfil their guidelines. It was planned that the registry would eventually capture all non replacement hip surgery, possibly including surgery for developmental dysplasia of the hip and Perthe's disease. It was envisaged that in the future, the BHS would request a link to the NJR so as to note the final end point when the joint was replaced. It was thought that once set up, a "pop up box" would appear on the NJR upload when the patient had been entered onto the NJR with their joint replacement. The registry would monitor the effectiveness of all non THR surgery.	
	14.4. Minimum Dataset (MDS) PH reported since the MDS review was last presented to the NRJSC, the following two changes had been requested which had a strong case for inclusion: • On the Hip (H1) form, 'SUFE', 'Perthes', and 'Skeletal Dysplasia' for inclusion under Reasons for Implantation. • For all MDS forms, 'Direct, Local Anaesthesia Infiltrations for inclusion as an additional anaesthetic type. **Agreed: To approve the recommended MDS changes pending review by RCCs.**	**PH**
15.	**Next meeting** Tuesday 24th January, 10.30 am – 4 pm.	