

**NATIONAL JOINT REGISTRY STEERING COMMITTEE (NJRSC)**
**MINUTES**

**Meeting:** NJR Steering Committee **Date:** Tuesday 17<sup>th</sup> April 2012

**Location:** Burroughs Room, Wellcome Collection, 183 Euston Road, London, NW1 2BE

<b>Members Present:</b>	Laurel Powers-Freeling	LPF	Chair
	Prof Paul Gregg	PG	Vice Chair / Orthopaedic Surgeon
	Mick Borroff	MB	Orthopaedic Device Industry Representative
	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
	Andy Smallwood	ASma	NHS Procurement Representative
	Keith Tucker	KT	Orthopaedic Surgeon
	Andrew Woodhead	AW	NHS Management Member
<b>Attendees:</b>	Richard Armstrong	RA	Programme Director, Northgate
	Rebecca Beaumont	RBe	NJR Communications Lead, Healthcare Quality Improvement Partnership (HQIP)
	Dr Crina Cacou	CC	Medicines and Healthcare Products Regulatory Agency (MHRA) Bristol
	Emma Clarke	EC	Bristol
	Alex Henderson	AH	Committee Administrator, HQIP
	Peter Howard	PH	Chair, NJR Regional Clinical Co-ordinators' Network
	Khalid Razak	KR	MHRA
	Robin Rice	RR	Welsh Government Representative
	Mike Swanson	MS	NJR Principal Consultant, Northgate
	John Trimm	JT	Programme Manager, Northgate
	Melissa Wright	MW	Development Officer (NJR), HQIP
	Elaine Young	EY	National Development Lead, HQIP
<b>Apologies:</b>	Ashley Blom	AB	Bristol
	Robin Burgess	RBu	Chief Executive Officer, HQIP
	Dr Jean-Jacques de Gorter	JG	Independent Healthcare Sector Representative
	Martyn Porter	MPo	Orthopaedic Surgeon
	Mike Robinson	MR	Research Officer (NJR), HQIP
	Dean Sleigh	DS	Orthopaedic Device Industry Representative

REF	ITEM	ACTION
1.	<b>Welcome and Apologies for Absence</b> LPF opened the meeting and welcomed John Trimm (Northgate) and Emma Clark (Bristol). Apologies were noted.	
2.	<b>Minutes of the previous meeting held 24<sup>th</sup> January 2012</b> The minutes were accepted as a true and correct record.	
3.	<b>Matters Arising (not appearing elsewhere on the agenda)</b>	
	<b>3.1. Data Sharing with Care Quality Commission [previous minute ref: 3.2]</b> EY reported that a data sharing agreement between the CQC and NJR was currently being finalised, after which NJR data would be forwarded for their use.	HQIP
	<b>3.2. NJR data for publication on NHS Choices [previous min ref: 3.3]</b> EY reported that NHS Choices had now sent draft publication for agreement. Northgate had forwarded related NJR data so that Choices could format this, and a data sharing agreement between the NJR and NHS Choices was being drawn up ahead of publication. <b>Action: EY to arrange sign off of draft text and ensure that appropriate data sharing arrangements were in place.</b>	EY
	<b>3.3. Compliance with NJR vs. HES – private sector issue [previous minute ref: 3.4]</b> Noted that RA and PH had reviewed the indicators related to HES and identified a selection for development. It was felt that it would be valuable to give individual surgeon feedback on compliance, but this would not be straightforward to achieve. <b>Agreed: Northgate would liaise with PH to arrange a pilot study, with results to be reported at July's NJRSC. Northgate would review and report the costs that would be involved.</b>	Northgate
	<b>3.4. National Orthopaedic Research Strategy [previous min ref: 3.5]</b> AM reported that a draft NJR Research Strategy would be circulated to the Research Sub-Committee, ahead of the National Orthopaedics Research Strategy Meeting in May. It was also noted that a final version of the report from the joint NJR/ARUK meeting held 15/16 March 2011 had not yet been received from ARUK. <b>Action: AM to circulate the NJR Research Strategy.</b>	AM
	<b>3.5. Clinician Feedback System [previous min ref: 11]</b> RA confirmed that Northgate had produced a draft service level agreement, which would obligate them to update the data on the Clinician Feedback System on a quarterly basis, within 10 working days of the end of a quarter - next update 13 <sup>th</sup> July - and recognise that they were working towards updating the data on a monthly basis in the future. This would be monitored as part of their monthly contract performance meetings with HQIP. EY confirmed that the SLA was still under consideration and that a penalty would apply if performance fell below the agreed standard. LPF also noted that there had been a level of concern regarding the availability of the Patient Time Incident Rate (PTIR) reports. RA explained that the current issue had related to difficulties replacing the existing outlier methodology with Bristol's new methodology, but the new functionality would be ready by 11 <sup>th</sup> May. PH stated it would be useful to surgeons if the new funnel plots included previous funnel plot positions to enable them to monitor their performance at a glance. <b>Action: Northgate would place an announcement on the system to keep users informed, and would ensure their service desk staff were briefed.</b>	Northgate
	<b>3.6. Data Quality Group [previous min ref: 14.6]</b> PG reported that a letter to Trust CEO's, requesting a nominated data quality lead to work with the NJR to check unit data, would be sent with the Trust data reporting letters [minute 15.2 below refers].	

	<p><b>3.7. Action Plan for NJR/HES Audit [previous min ref: 17.2]</b>  RA reported that he and MPo had discussed the NJR Audit of HES Revisions. The purpose of the audit had been to determine whether or not revisions recorded in HES and PEDW, which had no corresponding record in the NJR, were revisions as defined by the NJR. Findings from the audit, which had a response rate of 68%, showed that the vast majority were revisions. RA suggested that as part of the clinical annual report to Trusts, the NJR could also highlight their HES/NJR revision data for review by their NJR nominated data quality leads.</p> <p>PG noted that the current letters that had been drafted did not refer to HES. Further discussion was required for this to be actioned in future reports.</p> <p><b>Agreed that:</b></p> <ul style="list-style-type: none"> <li>• <b>Northgate, HQIP and PG would discuss a process for NJR revisions to be added by hospitals for future Trust Reports.</b></li> <li>• <b>Northgate would circulate a copy of the audit report to Bristol and the NJRSC.</b></li> </ul>	<p><b>Ngate/ HQIP/ PG Ngate</b></p>
<p><b>4.</b></p>	<p><b>NJRSC Structure and Governance Review</b>  LPF presented a revised operating model with the aim of ensuring that the NJR worked as effectively and robustly as it could, reflected its mature status as the largest arthroplasty register in the world and incorporated changing priorities and external pressures that made it fit for the future. The model addressed key internal and external issues and their implications for the NJR, shared values, structure, systems, staffing/skills and working relationships.</p> <p>It was noted that consultants BASIS had undertaken some initial interviews with NJRSC members on behalf of the NJR, but further internal work was required to finalise new NJRSC governance and operating model. AW supported this approach.</p> <p><b>Agreed:</b></p> <ul style="list-style-type: none"> <li>• <b>To organise two ‘Shared Values’ workshops for members.</b></li> <li>• <b>In advance of the workshops, to obtain individual member feedback on the model and prepare a ‘thoughts’ paper which would also be discussed with DH.</b></li> <li>• <b>To draft a revised NJRSC handbook to reflect new operating arrangements.</b></li> <li>• <b>To finalise a draft governance and operating model for review and sign-off at the next meeting of the NJRSC in July.</b></li> </ul>	<p><b>HQIP HQIP  HQIP LPF/EY</b></p>
<p><b>5.</b></p>	<p><b>NJR Economic Model</b>  LPF reported that work was still in progress to develop options for a revised NJR economic model. AM enquired about charges for data access, as the NJR was receiving an increasing number of large data requests i.e. a recent one from Oxford, and it had previously been confirmed that these should incur a cost. It was agreed that proposals for a charging mechanism would be brought to the next meeting for consideration.</p> <p><b>Agreed:</b></p> <ul style="list-style-type: none"> <li>• <b>Northgate would propose a charge for Oxford’s data request and confirm to AM.</b></li> <li>• <b>AM, LPF, Northgate and HQIP would liaise to produce an economic profile on data request charges for the next NJRSC.</b></li> </ul>	<p><b>Ngate LPF/Ngate /HQIP</b></p>
<p><b>6.</b></p>	<p><b>NJR Price Benchmarking Model</b>  EY updated members on work with the DH to develop a system of price benchmarking. A bid for £150,000 of QIPP funding had been submitted to DH but they had asked for reduced costs based on undertaking an initial trial across three Trusts to be followed by a national roll-out only if this was successful.</p> <p><b>Agreed: That if funding was obtained, an NJR working group should oversee system development, including an NJR disclaimer.</b></p>	<p><b>NJRSC</b></p>
<p><b>7.</b></p>	<p><b>NJR Strategic Plan 2012-14</b>  EY presented the latest NJR Strategic Plan which incorporated suggested changes from NJRSC members, and an estimated budget for years 1, 2 and 3. She noted that figures would change as income was only notional pending the introduction of a charging mechanism, projects being costed in greater detail, and resources allocated to reflect the revised operating model.</p>	

	<b>Agreed: By the NJRSC to approve the latest version of the Strategic Plan and the 'operating budget' until further notice/development.</b>	
8.	<p><b>NJRSC Member Remuneration Policy</b>  LPF reported that as DH had approved the principle that NJRSC members receive appropriate NJR funded remuneration for their work, a policy was being drafted for consideration.</p> <p>It was envisaged that members would fall into different categories as follows:  1) surgeons who would gain financial credit for their Trusts  2) volunteers (i.e. those not representing the organisation that employs them); and  3) Individuals representing their organisation and who would be employed in part to do so.</p> <p>PH stated that many NHS Trusts allocated surgeon study days to allow them to undertake this type of work. AW advised that the NJR should consider carefully any system for reimbursing Trusts in this way. KT felt that recommending surgeons for higher financial awards to reflect NJR work, would be worthwhile, given that there was little recognition for those who went above and beyond normal duties to undertake national voluntary work.</p> <p>LPF stated that these points would be noted.</p>	LPF/EY
9.	<p><b>Incorporation of Elbow and Shoulder Joints</b>  Noted that KT, MW and MS had met with representatives from the British Elbow and Shoulder Society (BESS) to discuss how Shoulder PROMs could be implemented. Northgate had identified development costs for shoulder PROMs at £46,750, and postal questionnaire costs between £19,500 and £22,750 based on 3000-3500 procedures/annum @ £6.50/questionnaire. It was noted that BESS had agreed to consider a financial contribution, which the NJRSC considered appropriate, as associated costs were likely to exceed revenue raised from the levy on shoulder and elbow joints.</p> <p>Although supportive of shoulder PROMs, members were concerned about the costs involved, and whether they had been fully assessed. It was agreed that the NJR would offer a pilot project of shoulder PROMs for four years of data collection and reporting – one year of shoulder procedures with three years follow up, on a cost sharing basis that would involve BESS supporting any ongoing costs.</p> <p>Further, KT reported he and PH had been invited to address the BESS Conference in Torquay on 13<sup>th</sup> June and MS would also be attending. He extended an invitation to LPF.</p> <p><b>Agreed that:</b></p> <ul style="list-style-type: none"> <li>• <b>Further work be undertaken on an option appraisal and establishing the total cost of undertaking shoulder PROMs over 3-5 years.</b></li> <li>• <b>KT would inform BESS that the NJRSC were supportive of a pilot project for shoulder PROMs based on a cost sharing arrangement.</b></li> <li>• <b>If BESS were happy to support on-going costs, advice would be sought on intellectual property rights on the data.</b></li> <li>• <b>KT, PH and MS would liaise about preparation for the BESS Conference.</b></li> </ul>	<p>Ngate/  HQIP  KT    HQIP    KT/PH/MS</p>
10.	<p><b>'Beyond Compliance' MHRA Meeting</b>  KT reported the outcome of a meeting held 4<sup>th</sup> April to discuss the establishment of a multidisciplinary assessment committee to address issues of pre and post market implant surveillance. 'Beyond Compliance' referred to a company introducing a new device which already complied with EU regulations but also introduced other checks to ensure maximum safety to patients. It was proposed that a group of experts should be available to manufacturers and Notified Bodies to advise them on issues related to market entry and post market surveillance. It was suggested that a page could be inserted on the NJR database for manufacturers who went 'beyond compliance' to insert extra information about their new device that would be open to all those involved in the surveillance. The process required further development and a cost analysis.</p>	

	The NJRSC were supportive of the 'Beyond Compliance' proposal and looked forward to receiving further information.	KT
11.	<p><b>MHRA/NJR Collaboration</b></p> <p>EY reported that she and LPF had met with the MHRA to discuss how the NJR could facilitate ad hoc data requests that would overcome problems recently experienced with timescales, data sharing arrangements and costs. It was agreed that an MOU would be drawn up between the NJR and the MHRA to address these issues.</p>	HQIP/ MHRA
12.	<p><b>Geographical Extension of the NJR</b></p>	
	<p><b>12.1. Northern Ireland (NI) / Guernsey / Jersey / Isle of Man</b></p> <p>EY reported that work was ongoing to incorporate NI into the NJR from July 2012. The business plan to develop the NJR system for this purpose also included the facility to incorporate Guernsey, Jersey and the Isle of Man at a later date. The estimated number of procedures for all locations was under review to ensure that annual levy income for the NJR covered the costs of providing a service to these locations.</p>	
	<p><b>12.2. Republic of Ireland (ROI)</b></p> <p>Noted that discussions with the ROI were ongoing but were complicated as they did not use NHS numbers and operated different systems. RA reported that the following two options were being explored:</p> <p>1) To incorporate changes to the current NJR system to accommodate the lack of postcode and NHS number.</p> <p>2) At the request of the ROI, to establish a system that would incorporate their own PROMs programme linked to patient records.</p> <p><b>Noted: Concern by the NJRSC about pursuing Option 2. Agreed that Option 1 was the favoured option.</b></p> <p><b>Scotland:</b></p> <p>MB noted that Paddy Ashcroft, Chair of The Scottish Arthroplasty Project, had contacted him regarding sharing data with the NJR, although EY had not heard anything from him. The Project still did not wish to come on board the NJR.</p>	
13.	<p><b>NJR Finance Report (1<sup>st</sup> April 2011 to 29<sup>th</sup> February 2012)</b></p> <p>The finance report was received and noted.</p>	
14.	<p><b>NJR Research Fellows</b></p> <p>EY noted that the NJR Research Fellow appointments were due to expire and consideration needed to be given to whether the NJR wished to recruit again to these positions. It was felt that as the Fellows had been very successful, and their work beneficial to the NJR, they should be replaced. Members agreed with CNA suggestion that future posts should be available to all relevant clinicians, and not restricted to doctors.</p> <p>AM reported that he had attended the Arthritis Research UK (ARUK) Research and Academic Capacity Committee on 15<sup>th</sup> March to discuss whether one or both of the NJR fellowships could be managed through ARUK. The idea was for the NJR to provide the funding and ARUK to use their admin protocol. This was supported.</p> <p><b>Agreed that:</b></p> <ul style="list-style-type: none"> <li>• <b>Two Research Fellows would be appointed: one an NJR/ARUK fellowship for 2-3 years, and the second an NJR post, possibly for one year with an option to extend for a further year.</b></li> <li>• <b>AM would produce a paper for the next NJRSC outlining job descriptions, costs, timings and next steps for the NJR/ARUK Fellowship, and would check if the NJR/ARUK Fellow had to be a medical doctor.</b></li> </ul>	AM
15.	<p><b>Updates from the NJR Sub-Committees</b></p>	
	<p><b>15.1. Regional Clinical Co-ordinators Network</b></p> <p>PH highlighted two issues from the minutes of the RCC meeting held 27<sup>th</sup> March 2012:</p> <ul style="list-style-type: none"> <li>• RCC's felt it would be worthwhile examining the possibility of reporting on compliance</li> </ul>	

	<p>by primary and revision procedures using HES and PEDW data. This would not be overly complicated and could be piloted through the RCCs. This was supported by the NJRSC.</p> <ul style="list-style-type: none"> <li>• One RCC had queried letters sent from the Implant Performance Group to two suppliers regarding potential outlier status of their products. This had been referred to the Implant Group to follow up.</li> </ul>	
	<p><b>15.2 Outlier Sub-Committee (Surgeon Data)</b>  PG reported that letters to Trust CEO's informing them of the Trust Data Reporting process had been drafted and would be sent out within the next 6-12 weeks. Northgate would plot data from September 2011 for the first report.</p>	
	<p><b>15.3. Implant Performance Sub-Committee</b>  KT reported that further analysis was required into the following areas of 'Mixing and Matching' components:  <u>Mixing Brands</u> : A possible topic for the Research Fellows or a Senior Registrar.  <u>Trunnions and ODEP</u>: Bristol would undertake.  <u>Size mix-match</u>: Northgate had conducted initial analysis.  <b>Agreed: That the NJRSC would support further analysis into the mixing and matching issues and keep the MHRA informed.</b></p>	
	<p><b>15.4. Editorial Board</b>  a) <u>Editorial Board teleconference, held 3<sup>rd</sup> April 2012 - MW reported:</u></p> <ul style="list-style-type: none"> <li>• Part 1 would be edited to exclude some information which would be incorporated as appendices and include updates from the NJR sub-committees.</li> <li>• Part 2 would include less tables and figures.</li> <li>• Part 3 would focus on NJR linked data rather than HES linked data.</li> <li>• Part 4 (new section) would be introduced for Trust Level Reporting.</li> <li>• The NJR session at the BOA Conference would be held 8 – 10 am on Thursday 13<sup>th</sup> September.</li> </ul> <p>b) <u>NJR Patient Focus Conference, held 28<sup>th</sup> February 2012</u>  RBe reported excellent feedback especially related to the Patient and Public Guide to the Annual Report, and thanked all members for their support. Smaller patient events would be organised in future with consideration of staging them out of London.</p>	
	<p><b>15.5. Research Sub-Committee (RSC)</b>  a) <u>Research Sub-Committee teleconference, held 28<sup>th</sup> February 2012-AM reported:</u></p> <ul style="list-style-type: none"> <li>• The DNA BioBank project received ethical approval and was due to commence.</li> <li>• AM had possession of the one-year NJR PROMs data and was in the process of developing analysis plans for agreement at the NJR PROMs project board. Once analysis plans and structure were in place, AM would lead work to analyse the results.</li> <li>• All publications were updated on the NJR website. An easily-accessible log would be investigated and developed for NJRSC members to access.</li> <li>• The RSC had reviewed seven publications since the previous NJRSC. Participation of RCCs in these review process had been successful and would continue. Five publications had been accepted for publication, including two papers from Bristol for the BMJ and the Lancet.</li> <li>• A study using NJR data linkage to the National Cancer Registry was being undertaken by Prof. Henrik Möller and should be completed within 4-6 months.</li> <li>• A study using NJR data linked to the General Practice Research Database (GPRD) was being undertaken by GPRD and should be completed within 3-4 months.</li> </ul> <p>b) <u>Alignment of NJR papers and abstracts</u>  Following instances of overlapping work between the Research Fellows and Bristol, Bristol had now been requested to log their paper information, including title and authors, before the manuscripts were written.</p>	
<b>16.</b>	<p><b>International Collaboration</b>  a) <u>International Society of Arthroplasty Registers (ISAR)</u></p>	

	<p>Noted that KT had attended the ISAR general meeting on 9<sup>th</sup> February in San Francisco to present on the NJR. ISAR, in collaboration with ICOR, had organised the '1<sup>st</sup> International Congress of Arthroplasty Registries' to be held in Bergen in May, where the next President Elect for ISAR would be elected. Past President, Ove Furnes, had asked MPo if he would like to stand for the role, and the NJRSC were fully supportive of this.</p> <p><u>b) International Consortium of Orthopaedic Registries (ICOR)</u>  ICOR, established by the Food and Drug Administration (FDA), also met in San Francisco in February. They wished to collaborate with the NJR on a few projects and would make any relevant data requests in due course. They had requested an NJR representative for the committee which KT was willing to undertake.  <b>Agreed: That KT to represent the NJR at the ICOR committee meeting in May.</b></p> <p><u>c) Orthopaedic and Rehabilitation Devices Panel of the Medical Devices Advisory Committee</u>  CC reported that the FDA had scheduled a public meeting for 27<sup>th</sup> – 28<sup>th</sup> June, location tbc, and recommended that the NJR should be represented at the meeting.</p>	KT
17.	<p><b>Quarterly Statistics Report (QSR): Q4 2011/12</b>  The QSR for Q4 was received and noted with the following amendment:  Page 4-line 5 to read '% of <u>NJR</u> data on Hip Replacements'.</p>	
18.	<p><b>Quarterly Management Report (QMR): Q4 2011/12</b>  The QMR for Q4 was received and noted.  MS reported that a new functionality that enabled users to go back into a record and enter an NHS number (where it was not previously possible to trace one) has enabled an additional 7,000 linkable records. Also that data requests from patients had increased from 0 in 2008 to over 800 requests to date.</p>	
19.	<p><b>Any Other Business</b></p>	
	<p><b>19.1 Succession Planning</b>  PG noted that his final term of office for the NJRSC expired in September 2012, but he had offered an extra year of service to facilitate succession planning. LPF stated that the process of succession was being considered as part of the governance review and would be confirmed in the near future.</p>	
18.	<p><b>Next meeting</b>  Tuesday 24<sup>th</sup> July, 10.30 am – 4 pm.</p>	