

**Informed Decision Making (IDM)**  
**for patients considering Knee Replacement Surgery (for OA Knee)**  
**An Exemplar project for the NHS Institute**  
**November 2007 – April 2009**  
website: [www.informeddecisionmaking.org.uk](http://www.informeddecisionmaking.org.uk)

**IDM Steering Group**  
**Meeting 2**  
**14 March 2008, Kings Fund, London**

**Attendees:**

- Dr Steve Laitner - Clinical Lead
- Suzie Normanton - Project Manager
- Michelle Ovenden - Project Administrator
- Sam Hudson – Lead Associate, NHS III
- Ian Bayley – Consultant Orthopaedic Surgeon, Stanmore Orthopaedic Hospital
- Laurence Wood - Academic Physiotherapist, Keele University
- Nick Black – Professor, London School Hygiene & Tropical Medicine
- Paul Dieppe - MRC senior clinical scientist and honorary Professor of Musculoskeletal Sciences, University of Oxford
- Susan Oliver – Consultant Nurse, RCN Rheumatology Forum
- Lynne Newton – RCN Orthopaedic Forum
- Lisa Hollins – Commissioner, NHS London

**Apologies:**

- David Colin-Thome - National Clinical Director for Primary Care/ Medical Adviser, DH
- Julia Taylor – Programme Director, NHS III
- Abigail Page - Head of Public Policy and Campaigns, Arthritis Care
- Angela Coulter - Chief Executive, Picker Institute Europe
- Carolyn Naisby - Consultant Physiotherapist, City Hospitals Sunderland Foundation Trust
- Mary Simpson - Market Research, Public & Patient Involvement, DH
- Richard Carrington – Consultant Orthopaedic Surgeon, Stanmore Orthopaedic Hospital
- Al Mulley – Head of the Medical Division, Foundation for Informed Medical Decision Making
- John Carlisle – Consultant Anaesthetist, Torbay Hospital

		<b>Action</b>
<b>1</b>	<b>Introductions &amp; apologies</b>  Lynne Newton, a committee member of the RCN Orthopaedic Forum was joining the Steering Group for the first time and introductions were made.  Apologies had been received from David Colin – Thome, Al Mulley, Angela	

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	<p>Coulter, Abigail Page, Richard Carrington, Julia Taylor, Mary Simpson, John Carlisle and Carolyn Naisby.</p> <p>SL took the meeting through the minutes that had been previously circulated of the last Steering Group meeting. One amendment was suggested by Nick Black. The minutes were amended and then agreed.</p>	
<b>2</b>	<p><b>Declarations of Interest</b></p> <p>SL asked for any commercial or non commercial declarations of interest to be made by the group.</p> <p>SL declarations of interest were that in addition to employed work as a GP and Public Health Consultant he was a freelance health consultant working mainly for the DH and that he was a partner in a Limited Liability Partnership which had developed a pathway web-tool</p> <p>NB 's interest was in seeing that the KR patient decision aid would be developed and used in conjunction with measures already in existence and use.(i.e. the Oxford Knee Score)</p> <p>PD was working on the development of other measures that would supersede the measures which this project would be using such as the Oxford Knee Score.</p> <p>SO was an Independent Nurse Consultant and runs her own private clinic.</p> <p>SN was also a partner in the same Limited Liability Partnership which had developed a pathway web-tool. She also hoped to use some of the output from this project for her PhD.</p> <p>SL asked that through the minutes all other members of the Steering Group not present at the meeting made any declarations of interest, either commercial or non commercial to him via email before the next meeting. MO was asked to email those not present for their declarations of interest. These would then be collated into a list and dated and circulated to all steering group members.</p>	<b>MO</b>
<b>3</b>	<p><b>Sign off Terms of Reference</b></p> <p>This document was reviewed by the meeting.</p> <p>SN asked if members of the Steering Group were in agreement with having their names as well as organisation and titles left on the document when it was published on the project's website. SN confirmed that no contact details of the steering group members would be published on the website - but doesn't this mean they will be!! The Steering Group agreed they were happy for this to happen and the TOR was signed off.</p>	
<b>4</b>	<p><b>Sign off Project Objectives &amp; Deliverables</b></p> <p>This document was reviewed by the group and a number of amendments were made which are reflected in the revised document attached to these minutes. This amended document would then be re-circulated for any further comments which will need to be sent to MO by 4 April. These will then be included before this document is finalised.</p> <p>A general discussion was held around the need for ongoing refinement and</p>	<b>ALL</b>

	<p>development of the KR patient decision aid after it is developed using the data that is collected through the piloting and in its ongoing use. There was general agreement that this project should be focused on individual patient's decision making and using an individual decision aid. It was reiterated that the KR decision aid must be developed to be compatible with other measures available and being used.</p> <p>SH thought that the compatibility of the KR decision aid with other NHS initiatives and alignment with the current context of NHS development should be added to the list of deliverables. She also thought that the generic nature of the process and the sharing of the learning should be added to the deliverables.</p>	
<p><b>5</b></p>	<p><b>Work Programme</b></p> <p><i>Mapping patient information &amp; decision points on a knee pain pathway:</i> SL took the meeting through the DH 18 Week Knee Pain Commissioning Pathway and the various decision points within it.</p> <p><i>KR Patient Decision Aids:</i> SN informed the meeting she had collated a selection of decision aids, patient information and tools such as Oxford Knee, EQ5D and Ottawa, all freely available and took the meeting through these. Whatever was produced by the project would have to be compliant with IPDAS. This information was intended to act as a resource pack to start the process of developing the KR decision aid from.</p> <p>SO commented that the language used in the Healthwise document was very complex for a patient.</p> <p>SN talked about using a more modular approach for the KR decision aid taking the relevant items from other decision aids, patient information and tools (with permission where relevant) and developing missing component parts within this project.</p> <p>NB enquired whether Health Dialog would be prepared to share information about using the Foundations decision support material with patients in this country. SL had asked AM if he would share the Health Dialogue DVD for patients with OA Knee considering KR with the Steering Group. AM would confirm if the FIDM was agreeable and copies would then be circulated. SN agreed to speak with Health Dialog about using the USA version of the DVD with Uk patients.</p> <p>The meeting looked at the information relating to individual prediction of risk of operative death and thought it would be useful if JC could take them through his data and calculation methods at the next meeting as they were not all familiar with it.</p> <p>SL gave a précis of the articles provided by RC to illustrate risks but commented that the project probably needed to revisit information on the mortality rate for KR.</p> <p>A discussion followed around being careful to focus on the major variables rather than veering into marginal areas</p>	<p><b>SN</b></p> <p><b>JC</b></p> <p><b>SL</b></p>

<p>SO said she felt how information relating to risk was presented to patients needed examining.</p> <p>SH said the Urology project had looked at liability issues surrounding recommended clinical decisions.</p> <p>SN thought it would be helpful to look at the output from the Urology project and everyone at the meeting agreed this would be very useful. SN agreed to pursue this and send information out.</p> <p>SH felt it was very important to involve patients early on to help minimise the amount of modifications subsequently needed as a result of lack of patient comment/ involvement early on.</p> <p>A discussion followed around research and practice and what variations actually existed in practice.</p> <p><i>Leads/ work groups:</i>          PD questioned whether the project would be using the Oxford Knee Score totally unchanged as it did not address participation and social role and was very keen to add on these missing factors.</p> <p>NB agreed with adding to the OKS rather than redeveloping this score.</p> <p>SL queried whether the ‘bothersome’ factor was a validated measure.</p> <p>SN wondered whether the Ottawa personal decision guide provided some personal preferences that may be indicative of issues that are bothersome to the patient.</p> <p>NB gave information on what had been added to IPSS to incorporate the bothersome factor which was just one generic question for 7 symptoms. SL thought this should be examined in more detail.</p> <p>SL then took the meeting through the proposed work groups which would look at 4 different areas of work. The groups were agreed as follows:</p> <p><i>1. Risk Prediction group:</i>  <i>John Carlisle, Richard Carrington, Abigail Page/ Neil Betteridge, Lynne Newton and <b>Angela Coulter</b></i>  <i>(It has since been agreed that Neil Betteridge will join the Patient Information &amp; Pathway Group)</i></p> <p><i>2. Benefit Prediction group:</i>  <i>Nick Black, Paul Dieppe, Ian Bayley, , Carolyn Naisby, Lisa Hollins, Al Mulley and <b>Sam Hudson</b></i></p> <p><i>3. Patient Information &amp; Pathway group:</i>  <i>Susan Oliver, ARMA representative – name tbc, Julia Taylor, Mary Simpson and <b>Lawrence Wood</b></i></p> <p><i>4. Generic Decision Making Tool:</i>  <i>Angela Coulter, Sam Hudson and Lawrence Wood</i></p>	<p><b>SN</b></p> <p><b>SL</b></p>
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	<p>SO suggested that because the content for the fourth area of work needed to be gathered from the first three groups as the project progressed, the members of this last group would work alongside the other 3 groups (highlighted in bold type) to gather the relevant material for this fourth area as it was generated. It was agreed that this was a very good idea.</p> <p>There was some general discussion that the project should be concentrating on all knee replacements and not just total knee replacements as many were only partial. Therefore all documents produced to date should be amended accordingly.</p> <p>Lisa Hollins joined the meeting at this point.</p> <p>PD asked for clarification around how SL saw these sub groups functioning. SL said he or SN would be allocated to each group and be present at any meetings and would facilitate their set-up.</p> <p>SN gave an overview of time lines for the subgroups as follows:</p> <ul style="list-style-type: none"> <li>• Sub groups would meet before the next Steering Group meeting in June 08</li> <li>• Subgroups would circulate their work prior to the June meeting</li> <li>• This work would then be refined at the June meeting</li> <li>• The subgroups would then agree how to develop and refine their work further before the next Steering Group meeting in September</li> <li>• The work produced would need to be robust enough for the pilot sites to work with from January to March 2009.</li> <li>• The project deadline for delivery of the KR decision aid was April 2009.</li> </ul> <p>LW asked for clarification of the role of Group 4. SL said that once the KR decision aid was developed - this group would reflect upon the process of development and develop the generic information needed to enable other clinical specialities to develop patient decision aids.</p> <p>PD asked whether the benefit group would take on the area of psychological predictors. it was generally agreed that it should if these are major predictors</p>	<b>MO</b>
<b>6</b>	<p><b>Pilot Sites</b></p> <p>SL took the meeting through the proposals for the pilot sites. IB thought an occupational therapist should be added to the support teams at the pilot sites. It was agreed a patient representative, a preoperative assessment clinician and an occupational therapist should be added to the support teams for the sites.</p> <p>A meeting date of 3 July had been set to bring the 2 pilot site teams together. SN and SL would meet with each pilot site and their teams' individually prior to this.</p> <p>Focus groups may run at the sites to gather information that patients' report they require from a decision aid. SN went through the points for consideration as detailed in the agenda attachment.</p> <p>A discussion was held around the focus groups operating under the umbrella of</p>	

	<p>service redesign or obtaining MREC approval. It was agreed that ethical approval would be necessary.</p> <p>The size of the pilot was discussed. Patient throughput figures needed to be obtained in order to calculate potential patient figures for the trial period and estimate the percentage of patients that would be likely to consent to participate in the pilot.</p> <p>SH thought the project could engage with some patients who had already been through the decision making process of KR to appraise the KR decision aid.. However these patients may then regret that they had not had access to such an aid to assist their decision making.</p> <p>SO reminded the group of the need to consider the actual process of collecting the data from an IT perspective as this could bring its' own complications.</p>	
<p><b>7</b></p>	<p><b>Publicising the project (via an event)</b></p> <p>SN gave the meeting an overview of the purpose of holding an event in November 2008 to publicise the project. SH offered the NHS III as a venue to hold the event. It could cater for up to 50 attendees.</p> <p>NB asked for clarification around the purpose of such an event before the output of work was produced from the pilot sites. He felt the timing would be too late to influence the project and therefore would not be very satisfying from an attendee's perspective. It was generally agreed that the event should come after the learning from the pilot sites. This would lead to a more attractive event from a delegate's perspective.</p> <p>It was agreed the event would be held after the pilot sites had finished – probably in April 2009.</p> <p>Consideration would also be given as to whether a face to face meeting with the reference group would be worthwhile.</p> <p>SH suggested that in the meantime the project could be publicised via literature and a presence at the events of the national societies.</p>	
<p><b>8</b></p>	<p><b>Bibliography</b></p> <p>SN thanked everyone who had sent her papers to date. Her aim was to keep the bibliography broad up until the end of the project and then distil it down at the end into the key papers relating to the project.</p>	
<p><b>9</b></p>	<p><b>Membership Groups/ IDM reference group</b></p> <p>SO suggested inviting ARMA to be on the Steering Group which SN agreed to action.</p> <p>PD agreed to ask Diane Dickson and Jeremy Horwood to join the reference group</p>	<p><b>SN</b></p> <p><b>PD</b></p>

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	SN would ask Denis Gizzi for PCT commissioner representation for the reference group	<b>SN</b>
	LH would ask for PCT commissioner representation from Barnet PCT for the reference group	<b>LH</b>
	PD would ask Ray Fitzpatrick to join the reference group	<b>PD</b>
	NB would contact the surgical group in The Netherlands	<b>NB</b>
	IB suggested the reference group needed representation from BODS, Orthopaedic Professors and the Chairman of Board of Specialist Societies. He would provide some contact details	<b>IB</b>
	RC needed to forward the details on the nursing association who collected data on outcome measures that he mentioned in the last meeting	<b>RC</b>
	SO suggested that more social and voluntary sector representation was needed for the reference group	<b>SO</b>
	PD thought NICE representation (? Gillian Leng) should be pursued	<b>PD</b>
	LN agreed to approach the Advanced Nursing Practitioner Group for representation for the reference group	<b>LN</b>
	SO suggested obtaining a representative from NRAS (National Rheumatoid Arthritis Society)	<b>SO</b>
<b>10</b>	<b>Website</b>  Once the documents produced to date had been revised following this meeting they would be placed on the projects website which would also be used to publish papers for comment on by the reference group.	
<b>11</b>	<b>Date &amp; Time of next meeting</b>  The next Steering Group meeting would be Friday 20 <sup>th</sup> June 2008 at the Kings Fund.  The September meeting was also booked. Consideration would be given whether it would be worthwhile for the steering group to meet in November.	<b>ALL</b>
<b>12</b>	<b>AOB</b>  None SL thanked everyone for what had been a very productive and useful meeting.	