

Informed Decision Making (IDM)
 – for patients considering knee replacement (for OA Knee)
 An NHS Exemplar project with the NHS Institute
 - Project duration November 2007 – April 2009

IDM Steering Group
Meeting 1
 1 February, 2008, The Kings Fund, London

Attendees:

- Dr Steve Laitner - Clinical Lead
- Suzie Normanton - Project Manager
- Michelle Ovenden - Project Administrator
- Sam Hudson – Lead Associate, NHS III
- Julia Taylor – Programme Director, NHS III
- Abigail Page - Head of Public Policy and Campaigns, Arthritis Care
- Al Mulley – Head of the Medical Division, Foundation for Informed Medical Decision Making
- Angela Coulter - Chief Executive, Picker Institute Europe
- Carolyn Naisby - Consultant Physiotherapist
- Ian Bayley – Consultant Orthopaedic Surgeon
- Laurence Wood - Academic Physiotherapist, Keele University
- Mary Simpson - Market Research, Public & Patient Involvement, Department of Health
- Nick Black – Professor, London School Hygiene & Tropical Medicine
- Paul Dieppe - MRC senior clinical scientist and honorary Professor of Musculoskeletal Sciences - University of Oxford
- Richard Carrington – Consultant Orthopaedic Surgeon, Stanmore Hospital
- Susan Oliver – Consultant Nurse, RCN Rheumatology Forum

Apologies:

- David Colin-Thome - National Clinical Director for Primary Care/ Medical Adviser, DH
- Edwin Borman - Consultant Anaesthetist

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1	<p>Introductions</p> <p>Steve Laitner welcomed everyone to the meeting and thanked them for agreeing to join the Steering Group for this IDM Project.</p> <p>SL gave the group some information about his background, namely that he is a part time GP, a Public Health Consultant (mainly concentrating on service redesign), and also works on a consultancy basis, including care pathway development for the DH and on QOL measures, which he thought would help as a bedrock for this project.</p> <p>He then asked the rest of the Steering Group to introduce themselves.</p> <p>Suzie Normanton, Project Manager for this project, said she worked as an independent health consultant, mainly for the NHS. Her other current work is with the DH 18 weeks team.</p> <p>Michelle Ovenden is the Project Administrator. She had previously worked for</p>	

<p>the St Albans Out of Hours GP Service, and was the Project Administrator for the DOAS Initial Assessment Project that Suzie and Steve completed last year.</p> <p>Julia Taylor, Programme Director at the NHS III, headed the team aligned with the 18 Week Wait Team at the Institute.</p> <p>Sam Hudson is the Lead Associate for patient involvement at the Institute who had commissioned the project.</p> <p>Richard Carrington, Consultant Orthopaedic Surgeon at Stanmore Hospital, is also their Clinical Lead for joint reconstruction.</p> <p>Mary Simpson, DH, leads the team responsible for patient healthcare information and empowering patients to make informed decisions.</p> <p>Ian Bayley, Consultant Orthopaedic Surgeon, has a strong interest in outcome measures.</p> <p>Susan Oliver is a Nurse Consultant specialising in Rheumatology. Chair of the Royal College of Nursing Rheumatology Forum and Chief nurse advisor for the National Rheumatoid Arthritis Society a patient organisation. Undertaken a study mapping the real experiences of patients over a 3 year period. Member of the GDG for NICE OA management. Interested in patient focused approach and optimise outcomes.</p> <p>Nick Black, Professor at LSHTM, is involved in research measuring patient outcomes. Currently he has a leading role in a project on clinical audit for DH including the NHS Operating Framework which covers procedures including knee replacement.</p> <p>Al Mulley is a Professor at the Dartmouth Medical School and Head of the Medical Division at the Foundation of Informed Medical Decision Making, Boston</p> <p>Carolyn Naisby is a Consultant Physiotherapist working in an orthopaedic knee service team between primary and secondary care.</p> <p>Laurence Wood is an academic Physiotherapist working at a MSK research Institute in the Midlands.</p> <p>Paul Dieppe is a Professor of Rheumatology involved in health services research and is the lead on a MRC programme grant around outcome measures.</p> <p>Abigail Page is Head of Public Policy and Campaigns for Arthritis Care and was deputising for the Chief Executive, Neil Betteridge who was unable to attend the meeting. Arthritis Care represented all patients who suffered from arthritis.</p> <p>Angela Coulter is Chief Executive for Picker Institute Europe, an organisation that is a research and educational charity which specialises in improving patient outcomes.</p>	
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	SL concluded the introductions by saying how thrilled he was (and slightly anxious!) to be chairing such an eminent group.	
2	Apologies Apologies were noted from David Colin - Thome and Edwin Borman.	
3	<p>Background to this project</p> <p>SL provided the meeting with some background to the project. The project has evolved out of pathways work for both Do Once and Share (CfH) and the Commissioning Pathways for 18 Weeks. As a result of this work it became evident that the process of patient decision making is currently undeveloped. Thresholds were being used in some areas without supporting decision aids, which was of concern.</p> <p>Demand for health should be managed by empowering patients to make rational, appropriate decisions to maximise their health outcomes, using decision support tools and personnel, rather than through commissioner provided thresholds for treatment.</p> <p>The project aims to develop an Informed Decision Making tool using a knee replacement for OA Knee as an initial example. The tool would need to capture measures for the individual to help predict their likely outcome (risks and benefits) from surgery.</p> <p>SL hoped the group would be able to use all the available work around QoL measurement that was available.</p> <p>The aim of the group was to develop a generic tool and map knee replacement onto it for this project. This generic approach would enable other conditions to be applied to the tool in the future.</p> <p>IB said it was essential to retain the overview of the importance of IDM as he was conscious that the DH were looking for thresholds and saw outcomes as a way of developing thresholds. It was important that the context of this project was really about IDM and focused on outcome.</p> <p>AC is also participating in the Urology Project. She felt it was important for this project to build on the mistakes made and lessons learnt from this project.</p> <p>AM said he was very happy to share previous lessons learnt!</p> <p>SN said the links between the Urology Project and this project would be strong so that the project could learn from the Urology experiences. She had met with Jo Finn from the Urology Project.</p> <p>SO said it was important for her that this tool will be useful along a number of parts of the pathway.</p> <p>SL said it would need to be decided where in the pathway the tool started. Was it for a specific point in time i.e. when the patient was considering having a joint replacement. Perhaps ideally the tool would begin when the patient first suffers knee pain - at the start of the care pathway.</p>	
4	NHS III (project commissioner) views and expectations SH felt that the key focus for the Institute for the project was the sustainability	

	<p>and transferability of the output to other clinical areas. She was keen the project should learn from other work done, not just the Urology Project.</p> <p>The concern was that to try to repeat the process for every condition would be very costly and she believed it was possible to do a generic tool for part of the decision process with the appropriate clinical content added on later.</p> <p>She was very keen to support the project and could do so in the form of communications around the project and its' sustainability.</p> <p>SH showed the Sustainability Guide to the group and explained it could help organisations test the sustainability of the change they wished to make. She thought it would be useful when the pilot sites were ready to be used.</p> <p>SH explained that at the end of the project the tools would be housed with NHS Choices with the clinical content being placed with The National Library for Health. The move to on-line tools was very strong now. This brought the question of how work was to be kept up to date and an online solution would facilitate easier updating.</p>	
<p>5</p>	<p>Introduction to Informed Decision Making</p> <p>SL asked AM if he would kindly take the meeting through a tour of IDM.</p> <p>AM started by saying IDM is an integration of economic thinking and patient sensitivity. There is much evidence of practice variation. Understanding this variation within clinical decision making is necessary. There is a great deal of variation and untested hypothesis. For example within Urinary dysfunction in men – different men feel different things about the same symptoms. Decisions depend on evidence. There is then the probability of different outcomes.</p> <p>Data has shown that patients are capable of making their own treatment decisions. Recognition that clinicians can have the clinical knowledge and patients can have the knowledge of the effect of the condition on their life and their preferences of outcomes.</p> <p>His own view was that IDM development tools made the transfer of this information from clinician to patient more possible.</p> <p>AC said that she felt people often thought that the more information a patient had the more treatment they would want. However evidence showed that once a patient is better informed they usually want more conservative treatment.</p> <p>A decision aid integrated into a clinical process can be very successful as demonstrated in the gynaecology trials that AC had been involved in. Treatment rates do often go down once patients are better informed. Patients can make rational decisions about their treatment. This is also more satisfying from a clinician's point of view.</p> <p>AM then went on to explain his work in prostate disease had then led him on to work in other clinical areas. The Foundation for Informed Medical Decision Making came together out of a generic collaboration of all these clinicians. He finished by saying he felt the argument should be that the only way to get the right treatment rate, was to make the right treatment decision for every</p>	

<p>individual patient.</p> <p>NB questioned the concept of ‘informed’. A common reaction is that doctors are withholding information from a patient but this is not the case. Doctors do not always have the information. Sharing uncertainty with a patient can help to make the exchange between the two transparent.</p> <p>AM said GPs were generalists and willing to recognise they did not always have the knowledge and therefore would readily refer. Specialists had the clinical expertise but were often less aware of the context of the decision for the patient compared to their GP.</p> <p>NB then talked about the dimensions of health which were impairment (e.g. loss of limb), which could be measured objectively, disability or functional status (difficulty with certain daily tasks), which could be measured objectively or subjectively and QoL / well being (the overall effect on an individual life). The degree disability affected QoL depended on individual lifestyle. There was a correlation between the first area (Impairment) and the last area (Quality of life) of only 0.25 which is why sometimes surgeons can be frustrated that the operation was “successful” but the patient was made no more content for it.</p> <p>PD questioned what was actually meant by QoL. He thought there was not a good theoretical QoL framework underpinning QoL. He talked about the International Classification of Function (ICF) – the patient is concerned with the ‘participation’ aspect. How do we measure participation in life? This is the key element to measure. For this work he felt a theoretical structure was needed for QoL. He also asked whether the project wanted economic assessment included and was it to be at individual patient level or societal level.</p> <p>AM said using an average could result in increasing treatment levels from an economic perspective. To match treatment to patient would manage treatment levels most economically.</p> <p>AC said she felt it was essential for there to be meaningfulness to the tool. This was crucial to IDM. Some of the QoL measures are not meaningful from a patient perspective – too many figures for example.</p> <p>AM said to collate collective experiences would be a great opportunity for the project. He also wanted to make the group aware of a possible declaration of interest on his part as Health Dialogue, part of the FIMDM, now owned by BUPA.</p> <p>SL thanked him for this information and said that he would ensure everyone had an opportunity to make any declarations of interest before the next meeting.</p> <p>RC returned to the previous point about ‘participation’. He said patients were aware of how they wanted this improved. Clinicians were also aware of this and it was a crucial factor to take into account. Patients reported different outcomes. He carried out standard hip and knee evaluations using the Oxford, WOMAC and Harris Scales.</p> <p>PD felt using a number of scores could muddy the water.</p>	<p>SL</p>
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	<p>SL asked if outcomes were fed back to the patient.</p> <p>RC said they were not but patients were given satisfaction rates and infection rates.</p> <p>PD said 15-20% patients were disappointed with the result of their knee replacement.</p> <p>RC said that the evidence suggested the additional mortality attributed to a Total Knee Replacement was 1% at 6 months. He also stated that the risk of thrombolism (DVT or OE) was 42% at 6 months.</p> <p>CN asked how the likely outcome is communicated to a patient as the expectations of patients are very varied.</p> <p>SO said that IDM should be mindful of not giving patient's economic screening of why they should have treatment. Most patients do not go to their GP until the pain they are suffering is extreme. Therefore IDM needs to be in place early on.</p> <p>AC felt risk communication was very difficult to do. Communicating uncertainty is important so patients are not disappointed post op. Techniques were available for conveying this information.</p> <p>Ian Bayley left the meeting at this point.</p>	
<p>6</p>	<p>Discuss and agree aims and deliverables of project</p> <p>The meeting reviewed the attachment detailing both these areas.</p> <p><i>Project objective -</i></p> <p>NB said he agreed with PD's comment on validating the QoL measure and participation. The Oxford knee score and WOMAC measures pain and mobility but does not score participation. The main reason for using EQ5D is that it enables economic factors and utilities to be included.</p> <p>AM suggested adding on a 'bothersome' index which would be 2 further questions on the Oxford knee score</p> <p>PD said he had been including 'bothersome' on the knee pain work he is involved in. It was generally agreed this would be a good way forward and the wording of the project objective would be amended to - 'to select and modify a patient reported outcome measure for knee pain....'</p> <p><i>Project deliverables –</i></p> <p>It was important to look at the risk as robustly as the outcome. AC asked how much was known about the risks and benefits of knee surgery.</p> <p>RC said there was huge variation in the risk figures quoted e.g. Mortality and infection rates varied enormously. Patients tended to focus on the positive things they were told.</p> <p>PD said there was data lacking in the area of what is the risk of the patient staying in pain and not getting better. Patient related outcomes are missing. Literature on co morbidities is scarce in relation to patient benefit and lack of benefit.</p>	

	<p>SL felt the group needed to use what was available to develop the best tool they could. He did not think they could afford to wait for a better decision aid to be developed before the tool was produced.</p> <p>AC felt the key was to communicate any uncertainty to the patient.</p> <p>The meeting then went on to talk about the importance of involving the pilot sites early on. AC said this had been learnt in the Urology Project. They should be brought into the extended reference group as early as possible.</p> <p>AM said he felt it was important to involve the clinicians on the ground that were actually using the tool on a day to day basis and not just the Team Lead.</p> <p>AC said also to involve patients and specialist societies early on.</p> <p>PD thought ICATS should be one target group for pilot sites.</p> <p>AC felt it would be important to convey that economics are not driving treatment decisions. Patients need to feel empowered to decide and she felt SO's point about having tool early in pathway was crucial to facilitate this.</p> <p>SO felt the value of having the tool early on in the pathway was that information could be 'tailored' to the patient's position and social consequences.</p> <p>AM said for information to be useful to a patient the information needed to be available at specific 'crossroad' points. It was worth thinking about what the significant decision points/ crossroads were in the patient pathway.</p> <p>MS said that 'capturing generic QoL' should be added as a deliverable.</p> <p>AM said there were different decision types because something is reducing a patients' QoL and it gets to a point where they feel forced to take action. From a patients' perspective these decisions are very generic.</p> <p>SN then talked about gathering the key papers for the project including those mentioned so far at the meeting in order to start a bibliography. She would contact individuals to follow this up.</p> <p>AC mentioned some information available on the Picker Institute website.</p>	<p>SN</p>
<p>7 & 8</p>	<p>Supporting group membership and steering group membership</p> <p>SN said there was a need to draw on the international experience available for this project. She told the meeting the intention was to run the extended groups via the website in a 'virtual' way. Also on the website information relating to the project would be available such as the bibliography. In order to protect identity, roles and organisations would be published but not names.</p> <p>Proposed membership was reviewed by the meeting.</p> <p><i>Steering Group -</i></p> <p>SO suggested the Chief Executive of ARMA to represent the patient's point of view. She agreed to follow this up.</p>	<p>SO</p>

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SH said she would have patients involved in the steering group but not to represent patient's views but to remind the group that they need to be focused on patients needs.	
CN wondered whether there should be any psychological input and the group agreed. She suggested Kate Kendal who currently works in Cancer Care and agreed to follow this up with her.	CN
PD said he could also offer psychological contacts.	PD
NB said he felt people should not be burdened with representing societies but should come with their personal interest and experience to the project.	
SN acknowledged this point but wanted to have representation from nationally recognised societies to help gain national consensus at the end of the project.	
SL would approach the Head of Commissioning for NHS London, who had also been working on the QoL measures for 18 Week Commissioning Pathways	SL
<i>Extended Groups -</i> AP suggested a representative from ARMA as they were already engaged in local groups that could be used as pilot sites.	AP
SO suggested an advanced practitioner group in primary care.	
JT agreed to source a PCT Director of Commissioning.	JT
MS agreed to source a DH Commissioner	MS
PD thought orthopaedic outcomes needed more representation. He agreed to approach Ray Fitzpatrick.	PD
RC suggested orthopaedic representation from Newcastle, Oxford and Bristol as they were major orthopaedic centres.	
LW thought a GP should be included.	
Everyone agreed pilot sites should be identified and included.	
NB said he would approach a surgical group in The Netherlands and pass these details on.	NB
SL suggested that based on the strong feeling that the pilot sites should be included very early on perhaps the two extended groups should be the pilot sites and one reference group. This was agreed by the meeting.	
SH mentioned that in the NHS III Sustainability Guide there was a section on devising job briefs for engaging wider groups that could be useful for this area of work.	
RC mentioned a nursing association that collected data on patient outcomes nationally. He would come back with details on this.	RC

<p>9</p>	<p>Discuss and agree TOR of steering group SL took the meeting through this attachment. It was agreed that pilot sites should be added to the responsibilities of the steering group.</p> <p>SL raised the point again relating to what point the tool should be applied within the pathway. A discussion followed on this subject. SH said she felt alright that it was not resolved at this point in time as it would become more apparent as the project progressed. SL thanked her for this clarification and said he could sense that the feeling within the group was that it should be applied as early as possible within the pathway.</p> <p>AM said it was possible for the same decision aid to be used in a general and specialist setting.</p> <p>JT reiterated the importance of referring to generic within the TOR as the tool would be used to map other clinical areas.</p> <p>SH reiterated the project was around the process / decision made rather than the actual clinical decision. The support part of the tool would be generic.</p> <p>AM sought clarification about whether decision aids represent evidence available internationally or whether it is at local national level.</p> <p>JT said the responsibility of supporting the successful spread and adoption of the tool should be added to the steering groups' responsibilities.</p> <p>NB said the group should ensure the outcome is compatible with other NHS initiatives and aligned with the current context of NHS development.</p> <p>On a separate point PD mentioned another dimension of outcome to consider - the impact on other people around the patient e.g. carers. If this could be factored into the tool it would be useful.</p>	
<p>10</p>	<p>Agree dates of future meetings It was agreed that future meetings would be held on 20 June and 19 September 2008.</p>	<p>All</p>
<p>11</p>	<p>Date and time of next meeting The next meeting would be held on 14 March at The Kings Fund again. It was agreed this was a suitable venue for future meetings.</p>	<p>All</p>
<p>12</p>	<p>AOB None was raised. SL closed the meeting just after 12.30 and thanked everyone for a very productive first Steering Group meeting.</p>	