Your Health – Your Decision

Evaluation & Output Report of the AQuA Workstream within the National Shared Decision Making Programme
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Mid Cheshire Hospitals NHS Foundation Trust
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NHS Cumbria Clinical Commissioning Group
NHS Trafford
North Bristol NHS Trust
North Cumbria University Hospitals NHS Trust
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Foreword

Shared Decision Making should no longer be considered an option for patient care in the NHS but a basic requirement. There is a wealth of evidence that diagnosing patients’ preferences is of vital importance in delivering effective, patient centered care, yet there is evidence that the NHS is failing to deliver this. Implementing Shared Decision Making requires several key steps:

- Crucially a shift in clinical attitude from a paternalistic model of care to one where the patient is seen as an equal partner
- Organisational changes so Shared Decision Making is seen as a basic requirement, and provider boards, commissioners and primary care have plans for its implementation
- Commissioning levers that require providers of NHS care to deliver Shared Decision Making
- Infrastructure changes that embed Shared Decision Making in NHS Information Technology and clinical record systems
- Tools for patient empowerment such as “Ask Three Questions”
- Tools for clinical use such as Patient Decision Aids (PDAs)
- The ability to measure decision making in a manner that drives continuous quality improvement

AQuA was delighted to win part of the Department of Health QIPP Right Care National tender for Shared Decision Making in the crucial area of culture change. The programme has been very successful in delivering culture change, patient empowerment and tools to measure Shared Decision Making in everyday clinical practice, in a range of settings and clinical pathways.

This report tells the story of AQuA’s work over the past year and we hope it incentivises readers to implement Shared Decision Making in their own practice and organisations.

Dr Alan Nye, Clinical Lead for AQuA Shared Decision Making Programme

Tools and resources can be found at:
http://www.advancingqualityalliance.nhs.uk/sdm/
The AQuA workstream for the National Shared Decision Making programme 2011/12 has achieved a number of outcomes:

- 699 health professionals were trained in Shared Decision Making through 60 training sessions
- 33 clinical teams in England participated in training
- 100% of Cohort 2 2012/13 programme participants are new clinical teams encouraged by the resources and results of the National Shared Decision Making programme 2011/12
- 33% (n=9) of Cohort 1 organisations will actively participate on Cohort 2 2012/13. Remaining teams are continuing with spread and sustainability and remain in contact with AQuA
- Measurement of 2,617 SURE scores collated 351 SHARED scores
- The AQuA programme target was met, 80% of patients across the identified clinical pathways (MSK, renal and maternity) will have been fully involved in their care through either the use of Patient Decision Aids, Shared Decision Making or Ask 3 Questions
- 81% of Maternity teams met the 80% target
- 80% of MSK teams met the 80% target
- 86% of Renal teams met the 80% target
- Over 480,000 Ask 3 Questions leaflets have so far been distributed to patients and carers
- 212 downloads of the Shared Decision Making Train the Trainer resource have taken place in three months from academic, NHS and voluntary organisations including downloads from Canada, India and New Zealand.
Introduction

Over the last couple of years, the concept of Shared Decision Making as a way to increase patient involvement and autonomy has become more popular across the NHS and has been gaining traction across a range of specialties and clinical professions.

The aim of this publication is to spread the learning and the results from the AQuA workstream of the National QIPP Right Care Shared Decision Making Programme and to complement the wide range of resources that have been developed to support the continued embedding of Shared Decision Making so that more patients can benefit.

AQuA would strongly encourage you to review the lessons and resources from this work and to consider the implications for your own services.

Successive legislation for years has highlighted the need to engage patients in their healthcare and to provide services that are truly patient centred. Domain 4 of the NHS Outcomes Framework 2013/2014 “Ensuring that people have a positive experience of care” emphasises the importance of promoting patient experience.

Not only are commissioners required to demonstrate that they have patient engagement at the heart of what they do, but since the Mid Staffordshire NHS Foundation Trust Public Inquiry, the NHS has a mandate to listen to patients even more. This needs to go beyond the recommendations to ensure that patients, families and citizens can be involved in real decisions about their own health and health care. We all have an obligation to seek out best practice from elsewhere and implement it locally. AQuA hopes that this document supports you in meeting that challenge.

“In the past we would often have known the patient’s preferences, circumstances or values because we had worked with them over a long period of time as their GP. Nowadays however, patients do not always see the same clinician because the practices are so large or because there are trainee GPs in the practice, so perhaps we do need to be asking them what their preferences and values are.” General Practitioner, NHS Trafford.
Background

During 2012, the Department of Health Right Care Team funded three workstreams to embed Shared Decision Making in routine NHS care. This programme was part of the Quality, Innovation, Productivity and Prevention (QIPP) Right Care programme. These three workstreams aimed to embed Shared Decision Making among patients, those who support them, and among health professionals and their educators.

The three workstreams were:

1. Developing tools which support Shared Decision Making, and the provision of decision coaching. This workstream created 36 Patient Decision Aids (PDAs), to help patients understand and consider the pros and cons of possible treatment options and encourage communication with their health professionals. This was delivered by Totally Health PLC

2. Embedding Shared Decision Making in NHS systems and processes. Making Shared Decision Making a reality for patients can only be achieved if it is systematically streamlined into routine NHS processes, steering clear of lengthy bureaucratic processes. This was delivered by Capita

3. Creating a receptive culture for Shared Decision Making. The biggest challenge to embedding Shared Decision Making in routine NHS care is to create a shift where patients expect to be routinely involved in decisions about their care. This required a change so that health professionals encourage and respond to the greater involvement of patients, and patients want to be more involved. AQuA delivered the third workstream which had three sub-workstreams:
   • Training Health Professionals
   • Engaging Patients
   • Promoting the inclusion of Shared Decision Making in to education

This report shares the insight and experience gained through the work of the AQuA Shared Decision Making Workstream. It highlights and promotes the journey taken by the 33 clinical teams participating in a large scale collaborative programme and the work around developing a receptive culture and promoting Shared Decision Making with educators. All those who are involved or interested in improving patient experience through closer involvement will find this report beneficial. It is written with quality and service improvement leads in mind, although it will also be of interest to senior leaders, data analysts and patient support and engagement groups.

To truly embed Shared Decision Making in a sustainable manner is a system-wide, multidisciplinary journey that requires commitment from people across organisations working in collaboration and partnership towards a common goal. AQuA’s aim with this document is to provide a road map for this journey, based on our experience alongside the Train the Trainer Resource Pack and online resources that have been developed.

http://www.advancingqualityalliance.nhs.uk/sdm/
Chapter 1 – collaborative approach

A Breakthrough Series Collaborative starts with a roadmap and an overarching aim. The driver diagram for the first workstream below served as a project framework organising what is known or believed to influence the embedding of Shared Decision Making within a clinical team, and with patients. It articulates the goals, major categories of improvement work (the primary drivers) and more specific ideas about how to improve in each area (the secondary drivers).

Driver diagram

What we planned to achieve

Three clinical areas were identified: renal, musculoskeletal and maternity:

- Renal was chosen because it was an opportunity to explore the use of Shared Decision Making in the context of applicability for people living with a Long Term Condition
- Musculoskeletal (MSK) was a more ‘traditional’ clinical area within which to apply Shared Decision Making and there were a number of decision aids available or being developed
• Maternity was chosen as it covers a population that is young and healthy, and who have to make many preference sensitive decisions over a 9-12 month period. So the conversation is key, rather than a tool for every decision. In addition, if new mothers embrace this approach, then as guardians of their family’s health in the future they will approach it in terms of choices, options and decisions.

The programme goal was to ensure that ‘by 31st March 2013, 80% of patients across the identified clinical pathways (musculoskeletal, renal and maternity) will have been fully involved in their care through either the use of patient decision aids, Shared Decision Making or Ask 3 Questions’.

The primary focus of the Collaborative was to provide skills and resources for health professionals to enable them to engage with and encourage patients to share in their decision-making. Each team was allocated a dedicated Facilitator who trained and supported them during the Collaborative programme.

This Collaborative was about culture change and a commitment was required from each team involved. Through an Expression of Interest document, teams were asked to sign up to the following principles:

• An informed patient is desirable and important to you as a health professional
• Engaging patients in treatment decisions where there are real options is a desired goal and health professionals need to support individuals to achieve this
• A patient who is not informed of the possible consequences of the options is not able to determine what is important to them

To maximise the success of the programme, we asked each team to identify:

• an executive sponsor
• a clinical lead to ensure there was clinical leadership and
• a project lead to push the work forward within the organisation(s)

This tripartite approach is a tested means to managing and driving through change programmes and enabling barriers and obstacles by individuals or groups of individuals within organisations to be overcome.

There was also a need to consider systems and the enabling functions which at times create barriers for change thus de-motivating clinical buy-in. Organisational systems must be responsive and receptive to change i.e. rewording of outpatient appointment letter to include Shared Decision Making. This is where Executive Leadership and support was required to enable improvements to be enacted and sustainability and spread plans enabled.

All participating organisations were required to self-assess their readiness by completing a short questionnaire which sought to highlight any potential pitfalls when introducing system change. Areas of focus were culture, executive support, clinical leadership, patient engagement, measurement and potential resources required. This enabled the teams to focus on areas that required more engagement when introducing change.
What we actually did

Each team chose the area(s) of clinical practice that they felt would lead to the greatest improvement for both patients and benefits for their Service. Many teams over the duration of the Collaborative shared their learning which enabled more learning and spread of ideas.

The project leads, Facilitators and their teams met regularly during the Collaborative as well as at the three ‘Learning Sessions’ to expand their improvements, share results, and plan changes. Between these learning sessions (during Action Periods), emails, WebExs, and regular meetings were used to support their work. Teams were encouraged to use the PDSA (Plan Do Study Act) model to test changes on a small scale and adapt them to local circumstances. This structure is a modification of the Institute for Healthcare Improvement’s (IHI) Breakthrough Series Collaborative Model. For more information on the Collaborative Model explore the IHI Web site:

http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/HowToImprove/

Simultaneously, teams addressed supporting factors (primary and secondary drivers) known to influence the embedding of Shared Decision Making in practice. These included clinical documentation, systems and coding, administrative and support infrastructures for ensuring that patients received information, sharing learning across their organisations and health communities, as well as building organisational capacity for monitoring, analysing, and reporting Shared Decision Making.

“It’s about clinicians “letting go” and allowing patients to make a different choice to the one they may have made.” Chris Goldsmith, Renal Consultant, Aintree Hospital
Lessons learnt

Positive aspects

• Workshops helped to create work plans for the programme
• Specialist WebExs e.g. primary care was helpful
• Tripartite approach worked well to remove organisational obstacles
• Executive Reports, whilst not always popular with teams, ensured the programme kept on track and additional senior support was provided if needed

Points of learning

• Despite measures being put in place to avoid this, where there was no true alignment in thinking across clinical and management staff about the rationale for Shared Decision Making, the programme was very challenging
• The Extranet was not used much – one Trust allocated access to a single individual so that others could not access information, others did not like the American date and found it difficult to make changes.

Top tips

• Allow teams to identify their own clinical areas/pathways. By identifying the area themselves, they are more likely to engage with the work to be done
• Use your Patient and Public Involvement/Patient Experience Committee in your organisation where leads/managers from every directorate meet, link in with these to spread the Shared Decision Making message and share resources
• Give people a chance to take small steps; don’t expect them to be involving every patient fully every time but encourage them to test out new skills
• Look at where learning and development departments can link into training and sharing the Shared Decision Making message e.g. using the online training
• Maintain the ethos of improvement methodology and avoid falling into performance management as this can be a major turn off for clinical teams
Chapter 2 – measurement for improvement

“I feel Shared Decision Making is something we think we have always done, but when considering Shared Decision Making probably we have never shared choices fully. I think this gives a good template to guide discussions. It has improved working together with the vulnerable team. It has improved discussions with the women who have engaged with the Shared Decision Making Project. The women have been really receptive to it. I feel that they have responded well to being involved in decision making. I feel this is particularly positive with the vulnerable women that we work with.” Midwife, Blackpool Maternity Services.

There is on-going debate as to how to effectively measure ‘good’ decision-making (Scholl et al, 2011) as there is currently no definitive validated tool for measuring the success, degree or outcomes of Shared Decision Making in practice. For the purposes of the Collaborative, it was important that a robust measure was agreed to allow teams to measure their improvement, as embedding Shared Decision Making into practice within an organisation is only part of the process.

What we planned to achieve

When considering a suitable measure of Shared Decision Making, AQuA took into account the need to measure both the process of making the decision and the outcome of that decision and drew on the literature review that had been undertaken by Capita as part of the National Right Care Programme commission.

There were three broad schools of thought – Patient Satisfaction with a Decision Measure (Holmes-Rovner, M et al, 1996), Decision Quality Measures (Sepucha et al 2008) and Decision Conflict Measures (O’Connor et al, 1997). AQuA decided to choose a short form decision conflict measure called SURE as it was:

- Only four questions
- Generic across all specialties and pathways
- Simple for patients to complete
- Quick for the service to evaluate
- Validated, having undergone intensive research and testing

What we actually did

Following the completion and analysis of over 1500 SURE scores, there was discussion that the SURE tool (Appendix A) was not sensitive enough or specific enough across all specialties, despite the academic research which appeared to disagree with this viewpoint.

In collaboration with Dr Hilary Bekker at the University of Leeds, the AQuA Shared Decision Making Team developed a new tool called SHARED (Appendix B) to address some of these concerns. This developmental tool incorporated the SURE Tool along with four additional questions which specifically addressed the process of Shared Decision Making. In addition, it used a Likert scale rather than a simple yes/no response. The SHARED tool has been used across 10 sites and is in the process of face validation.

Each team asked an agreed number of patients to complete a SURE or SHARED questionnaire to assess their level of decisional conflict following their consultation. The aggregate results were then used to assess team progress in implementing Shared Decision Making and to identify areas for improvement. In some cases, the questionnaires were incorporated within a bigger audit or adapted to fit a specific patient group’s needs.
The MSK team at University Hospital South Manchester used a tool that included the Oxford Knee Score, the SURE score and a rating for different options to help patients talk through their condition and their choices. Whereas, Salford Royal Foundation Trust’s renal team developed a survey that looked more generically at patient involvement, as their patients may not have made specific decisions at each occasion, but still needed to be involved with their care.

Teams looked at other relevant measures alongside the SURE and SHARED tools, making the evaluation of the programme multi-faceted in relation to outcomes. For example, Pennine Acute Hospitals NHS Trust looked at levels of induction post – spontaneous rupture of membranes - showing a reduction in inductions after introducing paperwork and decision grids with women in their North Manchester delivery suites; Blackpool Hospitals NHS Foundation Trust looked at the uptake of antenatal education, and Bolton Royal NHS Foundation Trust looked at Rhesus negative immunisation uptake. This latter team showed that using Shared Decision Making improved their uptake on Rhesus negative immunisation from 67% (2011) to 87% (2012).

The results from SURE and SHARED surveys for the collaborative as a whole are detailed in chapter 4.

Lessons learnt

Positive aspects

- The need for data to support the teams’ improvement work was understood and committed to by clinical teams. The data collected was well used within clinical teams
- There appeared to be a preference for SURE over SHARED because it was quick to do, easy to understand, simple ‘yes’/’no’ responses and was a validated tool. Data analysis was simple to do in identifying areas for improvement e.g. risk communication, information communication, support needed for the patient
- The process for data collection was initially considered resource intensive but a excellent number of scores across both tools was collected

Points of learning

- SURE data entry when full pathway data was collected was resource intensive due to volume and time needed to enter and analyse such volumes
- SHARED was too long and some questions were ambiguous e.g. questions two and three
- SHARED process was resource intensive in regards to data collection and entry
- It is essential baseline data is collected before the clinical team has received any training to ensure an accurate assessment of current practice
Top tips

• Measures are there to help you improve so if they are not telling you anything, look at how you can refine them to give you more detail; Royal Liverpool and Broadgreen, Aintree University Hospitals NHS Trust and Liverpool Women’s NHS Foundation Trust started using the SURE questionnaire and although it gave them a way to track improvements initially, they decided to switch to the more sensitive SHARED tool so they could be more specific with their focus
• Know what you want to measure as an organisation, look for relevant and already [technology] enabled collection and collation methods so you are not creating extra work to develop something new which could take a long time
• Where possible adapt current audit tools or embed audit questions into assessment documentation so it becomes embedded into everyday practice, rather than being viewed as an additional piece of work
• Collate measures weekly, this way even small improvements can be shared with the team to promote ongoing engagement and encouragement
• Work with information teams to identify how to record Shared Decision Making on the Patient Administration Systems, so monthly reports can be generated. A nominated Information Team member should be encouraged to regularly report on how the recording is progressing
Chapter 3 – training clinical teams

‘It has been established that there is a lack of understanding of the skills needed by professionals to enable Shared Decision Making with patients about their care in practice. Training is essential in enabling the implementation of Shared Decision Making within usual care across services. Professionals need to understand why Shared Decision Making skills are not the same as those exhibited in often good patient-centered care, that engaging patients in Shared Decision Making may result in patients making informed but different decisions from the clinically effective decision and that being a good practitioner means supporting patients in making good rather than clinically effective decisions’. Training needs to help the practitioner identify the exchange of knowledge and values that take place in a Shared Decision Making consultation between patient and professional, the deliberation about the best decision for the patient, and an agreement between the patient and professional about the best course of action for that patient given their values. What is key to the integration of Shared Decision Making in practice, is that the training helps professionals see how to integrate new skills within existing service provision, i.e. that it is about enhancing, rather than replacing, current practices.” Dr Hilary Bekker, Decision Science Advisor, University of Leeds and Clinical Advisor to Totally Health Plc

A key aspect of the programme was to develop a training resource programme to enable spread and sharing of the ethos of Shared Decision Making within the organisations involved in the collaborative; and also the NHS as a broader entity.

What we planned to achieve

The plan was to develop a core training resource building on the learning from the MAGIC Programme (Shared Decision Making Programme funded by the Health Foundation based out of Cardiff and Newcastle universities) and the Collaborative. Training was offered to each team in the Collaborative aiming to draw all the learning together to create a national training resource that organisations could use to implement Shared Decision Making. In addition, a range of case studies and vignettes were developed to help promote Shared Decision Making.

The plan also included development of an E-learning Resource for NHS staff to raise awareness, which could also be used for training purposes, and would be freely accessible to the wider NHS – see Chapter 7 for more details.

What we actually did

Although the content was generic, training was tailored to suit individual teams. A comprehensive training programme was developed providing information and opportunities to practice Shared Decision Making and useful support resources were made available. The AQuA Team ran 60 sessions during the Programme and trained 699 health professionals.

“I loved the training video with the patient asking 3 questions of the GP. Really highlighted how focussed a conversation can be”

“It was really useful to see examples of how Shared Decision Making has been embedded in paperwork, also found the video resources useful"
I enjoyed the role play as it made me aware of the difficulties encountered in the process of doing Shared Decision Making.

The collaborative approach encouraged shared learning across as well as within organisations, creating a test bed for innovative approaches. It brought whole clinical pathways and health communities together building relationships and helping to see that they had a common goal – enabling their patients to make the best decision for their own personal circumstances. The approach has also generated further improvement opportunities beyond Shared Decision Making.

“Using Shared Decision Making has changed my practice, I have always suggested what is best for my patients but now I give them the options, we discuss and to come to a decision suited to the patient”, Mr Shahid, Consultant Obstetrician, Wrightington Wigan and Leigh NHS Trust

Although some training sessions were challenging, having evaluated each session, feedback has been positive. Many staff commented that the training would help them improve their care to patients. Some clinicians further acknowledged that even though they believed they were already doing Shared Decision Making, attending the training encouraged them to reflect on their practice; identifying that often they would present information in a biased way. Training, using role play and adopting the COD (Choice – Option – Decision) approach to consultations enabled health professionals to ensure that they were consistently adopting a Shared Decision Making approach.

**COD (Choice – Option – Decision) approach**

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Adapted from The Model for SDM by Elwyn, Thomson et al and MAGIC Programme
“Reflecting on my own behaviours in a clinic consultation, I’m introducing the ‘choice talk’ and presenting ‘options’ more. New patient decision aids are really informative and much better – I am going to really try to promote these to patients.”

Additional complementary training was also developed. ‘Motivational Interviewing’ sessions were researched and commissioned after feedback from teams and have been very successful. Teams indicated that they were unsure how to evolve consultation formats from their current communication style to one which promoted and supported Shared Decision Making. The motivational interviewing approach seeks to empower the patient, through reflective and supportive questioning by the health professional, to feel confident in taking the decision-making role within the consultation.

“The event has given me a good base on which to build when I am developing a new service for my clients in the near future”

“I have found it very useful. This will change my practice”

“Please keep doing this for the sake of all professionals, patients and managers”

Lessons learnt

Positive aspects

- Facilitator input to regular Shared Decision Making operational meetings
- Facilitators providing Shared Decision Making training meant that they really understood the topic and the teams involved
- Onsite training was particularly useful for getting buy in
- Facilitators – described as energetic, good communicators/trainers, initiating ideas, and keeping momentum going

Points of learning

- Difficulties releasing staff for training was highlighted, but online resources seen as a way to overcome this
- More training across whole health economies
- More time up front allocated to look at roll out would have been helpful
- Initial delays in facilitator recruitment, however resources were provided and were helpful
- Facilitators to have more sense of how Shared Decision Making fits into the bigger picture
Top tips

• Involve representatives from all parts of the pathway – all health professionals can benefit from this work and training works best in multidisciplinary groups
• Acknowledge that many health professionals are already trying to do Shared Decision Making to a greater or lesser extent and aim to refine their skills rather than teach new ones
• Resources permitting allocate protected time to enable health professionals to do some back ground reading prior to the training
• Encourage health professionals to reflect upon their clinical practice and consider whether they present information in a truly unbiased way
• Try to get a key leading health professional involved in the work, and to attend the training you plan. Whilst it shouldn’t be the case quite often having a supportive senior clinician can mean the difference between success and an uphill struggle to change attitudes, and paperwork. They can also be a great advocate for encouraging others to attend training.

“Shared Decision Making has provided some structure to the decision-making process.” Phil Wykes, Clinical Lead Orthopaedic Surgery, Bolton
Chapter 4 – results

“Shared Decision Making represents the pinnacle of patient-centred care. It means ensuring that no patient undergoes treatment that hasn’t been properly explained to them, including risks, benefits and alternatives. Listening to patients, eliciting their informed preferences and sharing decisions is a crucially important clinical skill that should be seen as the gold standard for high quality healthcare.” Angela Coulter, Director of Global Initiatives, Informed Medical Decisions Foundation UK.

In delivering this programme we have tested and shown the potential for large scale improvement in patient experience, but there is still much work to be learnt in terms of measuring and monitoring Shared Decision Making. The summative result for all teams participating was 82% of patients across the identified clinical pathways have been ‘fully involved in their care through either the use of patient decision aids, Shared Decision Making or Ask 3 Questions’. The results by specialty against the 80% aim within the Driver Diagram are as follows:

- 81% of maternity teams were meeting the 80% target
- 80% of MSK teams were meeting the 80% target
- 86% of renal teams were meeting the 80% target

What we planned to achieve

The original goal within the Driver Diagram was that:

‘By 31st March 2013, 80% of patients across the identified clinical pathways (musculoskeletal, renal and maternity) will have been fully involved in their care through either the use of patient decision aids, Shared Decision Making or Ask 3 Questions’.

AQuA approached Dr Hilary Bekker at the University of Leeds to provide guidance on developing a measure to assess the impact of training staff in Shared Decision Making on patients’ experiences of care. The aim was to use a measure that helped staff see the impact of their training on the quality of the decisions patients were making. Most measures at the time assessed either staff skills in Shared Decision Making, measures assessing patients’ quality of decision making and/or measures assessing patients’ preferences for involvement; there were no patient reported outcome measure of Shared Decision Making (Capita Literature Review for the Right Care Shared Decision Making Programme).

The decisional conflict scale (O’Connor 1995) was the most appropriate measure assessing the effectiveness of a patient’s decision, i.e. an informed decision made in accordance with their values. A refinement of the Decisional Conflict Scale is the four-item SURE measure (O’Connor and Legare). It was developed to screen patients for decisional conflict, rather than to be used as a measure to assess changes in effective decision making. Together it was felt that the SURE measure was the closest validated measure for the purposes of AQuA's evaluation. We reviewed AQuA's piloting of this tool within services who had received the AQuA training.

The results provided by AQuA indicated it was easy to implement into practice, staff were able to include the measure to assess patient experiences in a range of services and patients were able to complete the measure. Generally during the course of training, and its use, SURE scores improved, illustrating that levels of decisional conflict within services were decreasing.
However, although SURE scores may be improving because staff’s Shared Decision Making skills were improving; there was still a need for a patient reported outcome of Shared Decision Making. Based on the literature and AQuA’s experience of implementing SURE in practice, AQuA and Dr Bekker developed an eight item measure SHARED to assess patients’ experience of Shared Decision Making.

The measure operationalises the components of Shared Decision Making from the patients’ perspective: the options provided by the professional, the experiences of importance mentioned by the patient, and beliefs about the best decision for the patient. AQuA piloted the acceptability of SHARED. Although some staff would have liked a shorter questionnaire, patients understood the items and found SHARED easy to complete. A formal validation of SHARED is required but preliminary analyses suggest it is a useful measure of patients’ experiences of Shared Decision Making in services within the UK.

What we actually did

The measurements collected using the SURE and SHARED tools provided teams with timely data, tracked over the programme (as more data points were collected) enabling, in most cases, teams to use the data to effect changes in practice to enable implementation of Shared Decision Making and to allow assessment against the original programme goal.

In addition to the collection of SURE and SHARED data, the teams carried out a ‘snap shot’ survey during the last quarter of the Collaborative to get additional insight into how aware patients were of the Ask 3 Questions campaign and about how involved they felt with their care. Representative samples were agreed with the teams and data was collected directly from patients. Sample sizes varied enormously due to the nature of the pathway chosen and the number of patients attending who had decisions to make. Teams were awarded points against the number of patients sampled being aware of the following:

- Ask 3 Questions – leaflet/poster/ within Trust documentation
- Given a decision grid or directed to a decision aid
- Asked to complete a SHARED or SURE tool
- Felt that they were able to discuss their options with their health professional
- Felt they could share their decision about their care with the clinical team. 100 points for 80-100% 50 points 60-79% and 0 points for 59% and below

The SURE and SHARED results have shown a marked improvement in patient experience for those teams working on the Collaborative. In some cases the baseline data was already very high, revealing that there were already great efforts being made to implement Shared Decision Making in practice. Aggregate data for the whole Collaborative and a range of results showcasing the work of a number of teams across the three clinical pathways – musculoskeletal, renal and maternity are illustrated below.

The nature of SURE allows an overall percentage to be calculated, based on how many patients answered ‘Yes’ to all four questions. The SHARED survey does not include a similar overarching figure, hence no percentages are included on the SHARED Graphs.
Aggregated baseline comparison (SURE) (ALL)

Aggregated baseline comparison (SHARED) (ALL)

Aggregated baseline comparison (SURE) MSK teams
Aggregated baseline comparison (SHARED) MSK teams

SHARED was introduced as more sensitive to SURE to highlight areas for improvement. Although not validated, the data appears to show an improvement in patient experience over the course of the programme. However the numbers are low.

Aggregated baseline comparison (SHARED) 5 Boroughs partnership NHS Foundation Trust - MSK

North Cumbria University Hospitals Trust tested Shared Decision Making in one consultant clinic for patients listed for surgery at Workington Outpatients. Using SHARED for question 3 only 60% of patients felt it was ok to choose an option that was different from the consultant after implementation compared to 72% of patient at baseline. In question 8 a further increase of 4% shows patients feel sure the option chosen to be the best for them.

Aggregated baseline comparison (SHARED) NHS Cumbria Clinical Commissioning Group
Aggregated baseline comparison (SURE) Aintree University Hospital NHS Foundation Trust - MSK (OA Hip)

Aintree University Hospitals FT initially tested SURE on OA hip triage patients and rolled-out to knee and upper limb 120+. As the structure of triage entails detailed discussions about options, risks and benefits, the team did not anticipate any change in scores. The whole triage department was tested for one month sampling 80% of patients. There was an increase of between 4 to 7% overall. This is attributed to all patients receiving the ‘Ask 3 Questions’ information and raised staff awareness of SDM.

Aggregated baseline comparison (SURE) renal teams

Aggregated baseline comparison (SHARED) renal teams
Aggregated baseline comparison (SHARED) Kings Health Partners - Renal

SHARED was introduced as this was considered more sensitive to SURE to highlight areas for improvement. Although not validated, the data appears to show an improvement in patient experience over the course of the programme. However the numbers are low.

Aggregated baseline comparison (SURE) WMRN and Heartlands (Unit)

Heart of England NHS FT worked with patients who were looking to self-dialyse either in the unit or at home. SURE data was collected monthly as their numbers were small, but the results showed consistent improvement during the Collaborative. The dip between 31-60 days and 61-90 days may reflect a greater expectation from patients as staff members were getting better at encouraging their involvement but still refining their skills.

Aggregated baseline comparison (SURE) maternity teams
Aggregated baseline comparison (SHARED) maternity teams

Aggregated baseline comparison (SURE) Wrightington, Wigan and Leigh Foundation Trust - maternity

Wigan Maternity Department used SURE to test SDM in 3 areas: (1) infant feeding (2) place of birth and (3) vaginal birth after caesarean. In comparison to the baseline, understanding of information has increased by over 50% with an increase of 30% of mothers sure of the decisions they have made.

Aggregated baseline comparison (SURE) Pennine Acute Hospital NHS Trust - maternity

The team consistently and reliably collected data from their specific clinics allowing an analysis of the SDM work throughout the whole time span of the collaborative. This has enabled the team to identify any specific areas which needed more input i.e. information, risks vs benefits, encouragement or support in making decisions.
“A challenge faced by practitioners can be that they can see more potential for recovery than the patient wishes to achieve. Often a patient would not be allowed to go home unless they could mobilise the “length of the ward”. However, at home the patient only wanted, and needed, to be able to walk a few yards from living room to kitchen! Shared Decision Making will put the patient in the driving seat and practitioners will learn to understand that ‘relevant’ is more important than ‘possible’.” Norah Flood, Professional Lead for AHPs, 5 Borough Partnership

“I love Shared Decision Making. In the past I felt like I was persuading people and if they opted for a home birth I was worried, because if something went wrong you feel responsible that you persuaded them to take that option. Now I feel much more that it is the patient’s choice and I’m happy with that. It’s informed choice.” Diane Davis, Midwife Central Manchester Foundation Trust

Lessons learnt

Positive aspects

• Measurement acts as a tool for change in its own right, the act of measuring changes behavior
• The SURE and SHARED tools enabled teams to identify areas for improvement and continuously strive for excellence
• The flexibility of different measures was useful for those teams who found the SURE tool was not sensitive enough

Points of learning

• Some teams felt that the SHARED tool was confusing to patients – it is in the process of validation to help ensure it is a useful tool
• The greater sensitivity of the SHARED tool was countered by its increased complexity and this was seen as a negative by some teams

Top tips

• Measures need to be easy to use for both professionals administering them and patients completing them or data collection will be too challenging
• It is important to look at not only the quality of decision-making but also the process and the outcomes. Consider the ‘so what’ – for example, patients felt they were more sure of their options, but what did that mean for their outcomes?
• Measures can often act as interventions in their own right, so also think about the affect a measure can have on the result you want to see
Chapter 5 – spread and sustainability

“We now have a conceptual framework that means everybody is singing from the same hymn sheet, shared understanding of vision, and a way of translating what we are doing across different audiences. It means I can go into groups of patients, clinicians or managers confident that we are pulling in the same directions. This has only been possible through working with inspiring Patient Leaders… the result of this collaboration has profoundly changed the way I work. More importantly patients, and healthcare professionals now have the right words, the tools and the measures to really offer healthcare choices” Dr Donal O’Donoghue, National Clinical Director for Kidney Care.

It is fundamentally important that after making improvements they are sustained and built upon. This is a real challenge in the NHS, but it is important that we share our learning with other areas to maximise the benefits and learning. Typically, staff make major efforts to achieve improvement – only to discover later, perhaps for a variety of reasons, that there has been slippage or decay in maintaining the approved process or the outcomes achieved. Another major frustration can be that great improvements occur in parts of the organisation, and the learning does not spread naturally.

What we planned to achieve

Each team was encouraged to take steps to ensure the effects of their work so far are sustained and to look at how to stretch these effects beyond that of their immediate team. This issue was addressed at the first Learning Event when teams were asked to consider how they would be promoting Shared Decision Making in a month, 6 months and a year’s time. To augment this planning a Sustainability and Spread Template was developed to encourage teams to think widely about their next steps. A copy can be found on the AQuA Shared Decision Making website.

How widespread is Shared Decision Making within your Organisation? Where do you want to spread it to next?
What we actually did

The plans that teams made included embedding Shared Decision Making principles into their patient literature, conducting an ongoing audit to monitor levels of Shared Decision Making in their clinical area and including awareness training related to Shared Decision Making in inductions for all new staff, including those beyond the clinical areas where Shared Decision Making was initially piloted.

Looking at organic growth from one area to another i.e. linked areas/departments, can make for easier spread and sustainability as teams who work closely together mutually support embedding Shared Decision Making principles and the culture change is then more widely supported. Barts Health NHS Trust has looked at spreading the principles of Shared Decision Making into their transplantation pathways and Royal Free Hampstead NHS Trust has considered spreading horizontally into the Diabetes service due to the links with renal and diabetes.

The physiotherapy team working with West Cheshire CCG were keen to spread Shared Decision Making along the pathway to GPs to ensure that a Shared Decision Making approach began when the patient first accessed healthcare. Blackpool Teaching Hospitals FT maternity team has looked at links into paediatric wards and special baby care as these are staff they work with regularly; and Wrightington, Wigan and Leigh NHS Foundation Trust, maternity services has, as a result of a Trust Board presentation, created interest in Urology, Gynaecology and Cancer services.

The 23 midwives who attended the Train the Trainer session are currently planning how this will be cascaded to ward and community staff. Lancashire CCGs engagement enabled our clinical lead and facilitator to host a learning session for over 90 GPs and practice staff from Blackburn with Darwen and East Lancashire.

“When I had my first child, there were a few complications and I ended up having to have a forceps delivery. At the time I didn’t know what was happening to me and I just felt like I was being talked to. This time, again there were difficulties and I once again found myself in a situation where I was having to have a forceps delivery, however this time the Doctor fully explained to me what was happening and explained the different options to me. This meant that my partner and I were able to make a decision and we felt fully informed about what was happening to me and our baby.”

A woman’s experience of being involved with Shared Decision Making during the birth of her second child – Liverpool Women’s Hospital NHS Foundation Trust
Lessons learnt

Positive aspects

• Useful to have a sustainability and spread action template/plan to focus the next steps
• The action plan prompted the teams to look at other areas for spreading Shared Decision Making
• Having access to facilitators in the future gave the teams confidence to sustain and spread Shared Decision Making

Points of learning

• Sustainability and spread needs to be considered up front, including new starters working with the training and human resources department
• The role of patient champion needs to be much more developed within all organisations and teams if there is to be a real commitment to Shared Decision Making

Top tips

• Plan several training sessions and follow up training for all levels of staff
• Look at embedding Shared Decision Making within routine practices – patient letters or audit reports for example, so that even if you don’t remember to practice Shared Decision Making in every consultation, there is still a drive in the background
• When Shared Decision Making has been implemented at a specific decision point, the next step is to spread it to all points along the pathway so that Shared Decision Making is reinforced at every consultation and patient interaction
• Develop a time limited action plan with identified names which includes spread and sustainability at the start of the programme – it is never too early to plan for spread (see the AQuA website for resources)
• Factor in regular updates in meetings already taking place. That way Shared Decision Making reviews will always be part of your agenda

“*It’s about clinicians “letting go” and allowing patients to make a different choice to the one they may have made*” Christopher Goldsmith, Nephrology Consultant, Aintree University NHS Foundation Trust
Chapter 6 – creating a receptive culture

"There is no doubt that AQUA stands out as an organisation that has understood why 'diagnosing' patient's preferences and priorities, after they have had a chance to consider good information, is not only the right thing to do, that it is an ethical gold standard, but that it also leads to improvement, less waste, less complaints and patients that feel respected and valued. It remains a puzzle to me why more organisations don't follow AQuA's leadership in implementation and measurement." Glyn Elwyn, BA MB BCh MSc FRCGP PhD. Visiting Professor and Senior Scientist, The Dartmouth Center for Health Care Delivery Science, Cochrane Institute for Primary Care and Public Health, Cardiff University UK

Encouraging patients, the voluntary sector, community and voluntary organisations to promote Shared Decision Making through the multi-media use of Ask 3 Questions has been a key theme which has been well received by patients, the voluntary sector and health professionals. This simple, evidence based approach to encouraging patients to ask questions in relation to their treatment and care options has really struck a chord with people and has already been used extensively by the MAGIC Programme, funded by The Health Foundation. The challenge faced was not only to transform the culture of Health Service but also among patients that use it so that they not only accept choices, but actively seek them.

What we planned to achieve

AQuA planned to develop resources to support the spread of Shared Decision Making throughout NHS organisations, voluntary organisations and individuals. Ask 3 Questions was the focus of these resources. Research shows that encouraging patients to ask three simple questions leads clinicians to provide higher quality information about options and their benefits and harms. The AQuA 'Ask 3 Questions' has been adapted with kind permission from the MAGIC programme, supported by the Health Foundation and is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85.
In addition, AQuA planned to identify and work with patient leaders to influence and support patients about how Shared Decision Making can empower patients to make choices that work for them. It also planned to work with Patient Opinion and other patient empowerment organisations, to start to develop a social movement to encourage patients and clinicians to embrace Shared Decision Making.

What we actually did

Ask 3 Questions

For its Ask 3 Questions campaign, AQuA developed a range of resources that have been displayed in patient areas, consultation rooms and other public places. The campaign also included leaflets for inclusion with appointment letters to encourage patients to ask three key questions when asked to make a choice about treatment. Further information is available at: www.advancingqualityalliance.nhs.uk/sdm/

The three questions are:
1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?
Cameras were given to patients to record their experiences using Ask 3 Questions. One patient, Jean filmed a consultation with her GP to show how effective Ask 3 Questions was in action and demonstrated that even without a decision aid in front of them; health professionals are able to provide information on the options available.

“I really liked the Ask 3 Question leaflet and although the questions did not feel natural at first, they were a good prompt for me to keep focussed on what I wanted to discuss with my GP. The result was that my normal ten minute consultation only took five minutes and I got all the answers that I wanted and we agreed on a plan.” Jean

Teams have reported that the simple message and usability of Ask 3 Questions resources has been one of its biggest draws for them and their patients. Having a resource that doesn’t need explaining, is in plain English and prompts the patient to think about framing their questions in a consultation format that leads from choices, through options to a decision is of great benefit to patients and health professionals.

A number of teams have also reviewed or produced new patient documentation to support Shared Decision Making. Mid Cheshire NHS Trust produced a new consent form for women undergoing the 20 week anomaly scan to ensure that all women received the same information related to the potential outcomes of the investigation. Wrightington, Wigan and Leigh NHS Foundation Trust, Maternity Team developed a Shared Decision Making handout for infant feeding to support new mothers make an informed choice about whether to bottle or breast feed. This tool was designed with new mothers in the delivery suite and has been well received. Recently the Trust was also accredited stage 3 Baby Friendly status by UNICEF.

Links into the Perinatal Institute, the Royal College of Obstetricians and Gynaecologists (RCOG) and the Royal College of Midwives (RCM) have meant that the Ask 3 Questions resources have been included and embedded into their patient documentation e.g. the green hand-held maternity notes, patient information leaflets, and links to Shared Decision Making resources on external websites.
Patient champions

Consultations have been held with patient focus groups, to better understand the role that patients can play and ensure resources that are developed are as beneficial for patients as possible. In addition, teams have taken Shared Decision Making to their patient participation groups both to get the patient perspective on their work but also to ask them to take the message out to other patient groups and raise awareness.

Pennine Acute Hospitals NHS Trust developed a virtual patient focus group by asking their antenatal women to sign-up if they wished to be involved in email feedback on the service and any future plans. Engagement went wider than they originally thought it would; with the usually hard to reach groups i.e. ethnic minorities, signing up and engaging via their smart phones.

“Using Ask 3 Questions meant that my GP appointment was structured and I got much more information from my GP than I think I would have normally, which was very helpful. I have also used the questions since then for my appointments with the specialist and the nurse and it seems to be a better way of dealing with a consultation.” Adrian

Throughout the programme there have been a number of events and information sessions designed at raising awareness and in turn starting to enable the transformation of the culture among patients, for example by attending patient focus groups, patient education sessions, promoting the Ask 3 Questions resources through third sector organisations such as The Stroke Association, Citizens Advice Bureau, Age UK, MS Trust and others.

“Putting patients in control of their healthcare. Patients who are in control are less likely to jump straight to surgery in my experience. They feel more willing to try conservative approaches if they know they can do something else later.”

A joint conference “Your Health, Your Decision” – A conversation about Shared Decision Making for patients, Health Professionals and the voluntary sector was held in October 2012 by National Voices, The Expert Patient Programme Community Interest Company and AQuA. To trigger discussions, three films were shown of patients talking about their experience of using Ask 3 Questions with their own health professionals. The patients reported that Ask 3 Questions can be used easily and naturally. It provides a structure to the consultation where the patient is more in control, the consultation took less time and the patient got what they wanted.

Following the conference, a Shared Decision Making Resource Pack for voluntary organisations was developed and wide consultation undertaken. The pack is available for download at: www.advancingqualityalliance.nhs.uk/sdm/
Lessons learnt

Positive aspects

• Creating case studies of Shared Decision Making with patients to inspire staff to continue using this approach
• Hosting patient engagement events, presence at AGMs/Trust events to promote awareness
• Improvement not performance message – ‘this is the right thing to do for patients’
• Trusts promoted their work on their public facing website (Wrightington, Wigan & Leigh NHS FT, Salford Royal NHS FT)
• Handheld notes included Ask 3 Questions
• Expert WebExs were useful
• Expert Patient Programme now promotes Ask 3 Questions as part of their self management support courses

Points of learning

• Strong and visible senior executive essential to support culture change
• The teams struggled to recruit patient champions and many did not involve them in their Shared Decision Making. Patients should be recruited and involved from the beginning
• There was an initial delay in getting resources out to teams
• Information about involving patients was insufficient and not particularly helpful. Patients need something tangible “this is what you could do”

Top tips

• Link in with your Patient Advice and Liaison Service (PALS) and Local Involvement Networks (LINks) to see where patient resources can incorporate Ask 3 Questions
• University Hospitals Birmingham involved patients on their project steering group to ensure they were keeping the patient’s perspective at the fore
• Utilise patients’ skills beyond that of ‘being a patient’ – Salford Royal NHS FT have a videographer in their Kidney Patients Association and they are hoping to work with him to develop some training videos for their staff
• Wrightington, Wigan and Leigh NHS Foundation Trust launched ‘Ask 3 Questions’ in Orthopaedic Outpatients. All patients were given a leaflet, staff wore lanyards to promote ‘Ask 3 Questions’ and the team had a photo opportunity with Chief Executive Dr Andrew Foster, which was publicised
• Involve the PALS team, the Patient and Public Involvement (PPI) team and Health Watch – they may already have professional patients who are prepared to support your work
• Think outside the normal patient feedback ‘box’. Many people have mobile access which can give you immediate feedback. This can be beneficial if there are groups you struggle to engage with i.e. teenagers, busy professionals, ethnic minority groups
• You can use “Ask 3 Questions” anywhere – don’t limit it to clinical areas, but make it visible everywhere to get patients involved and raise awareness
Chapter 7 – education

“Involving patients in decisions about their treatment and care is not only ethically imperative, but is also of benefit to patients, clinicians and the NHS. Shared Decision Making can be enhanced by patient decision aids and other support materials, but we will never have sufficient of these for every treatment choice. Changing the attitudes and culture of the service is challenging, but we will never effectively implement Shared Decision Making without changing the way that clinicians interact with patients. This requires support for advanced skills training for clinicians at all stages of their career, as well as wider initiatives to change attitudes that put the patient at the centre of all decisions” Richard Thomson, Professor of Epidemiology and Public Health Institute of Health & Society, Newcastle University

Promoting the inclusion of Shared Decision Making within pre and post registration/undergraduate and post graduate education has been another key objective for AQuA this year. This has been the most challenging workstream for the AQuA programme.

What we planned to achieve

Through linking with the deaneries, post graduate medical education and the schools of nursing and AHPs the programme aimed to start to influence how Shared Decision Making could be integrated into the curriculum as it has been in places such as Cardiff and Dartmouth.

The aim was to work with Royal Colleges, Professional bodies and associations to start to influence how Shared Decision Making can be integrated into the training and education for clinical professionals.

We also planned to co-develop resources with key stakeholders and patients to support the education and training of students and health professionals in Shared Decision Making.

What we actually did

The AQuA Team has liaised with the Council of Deans for Health, the Medical Schools Council, the GMC, the Academy of Royal Medical Colleges, the RCN and others to gauge what Shared Decision Making training activity is currently taking place within curricula across the Country, but also trying to promote how Shared Decision Making can be woven into current curricula without overburdening an already overcrowded curricula. In addition, AQuA has been working with Manchester Medical School specifically to see how Shared Decision Making can be integrated seamlessly into the undergraduate curriculum.

A baseline questionnaire using Survey Monkey was co-developed and issued with the Council of Deans for Health, which is a membership organisation covering 85 university providers of healthcare education, asking about the inclusion of Shared Decision Making within current curricula. This was circulated in July and again in September, but there was a disappointing response of only 6 institutions. The results were as follows to the key question about whether Shared Decision Making was included within their curricula:

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<th>Nursing</th>
<th>Midwifery</th>
<th>AHPs</th>
<th>Other</th>
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<tbody>
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<td>Pre-Registration</td>
<td>40%</td>
<td>60%</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Post-Registration</td>
<td>75%</td>
<td>75%</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>Support Workers</td>
<td>50%</td>
<td>50%</td>
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However, it was reported that it is usually called something else (user service involvement, client centred approach, patient centred care, family centred care, partnership working and advanced care planning).

“I introduce Shared Decision Making into a module entitled organisations and models of care which looks at how different systems of care affect the woman’s pathway through the antenatal, intrapartum and postpartum period” Kings College, London

‘It is integral in to a second year module for Physio students and forms the basis for their written assessments. The concept is explored within post reg Masters programme in Advanced Clinical Practice (Neurological Rehabilitation)’ Teesside University

“The School has a three year strategy for service user and carer involvement which was launched in 2011. This incorporates the facilitation of Shared Decision Making wherever possible” School of Nursing & Midwifery, University of Brighton

Although many of these areas would touch on aspects of Shared Decision Making, it was not clear how much was included. However, all the Universities that replied said that they would be open to hearing about additional resources when they were available.

AQuA also met with National Foundation Programme, Medical Education England, Medical Schools Council and General Medical Council to discuss the inclusion of Shared Decision Making in curricula.

However, one of the main challenges for making any changes in year was that the curriculum is not due for review until 2014/15. Nevertheless, with the kind assistance of the GMC, AQuA was able to compile a summary of all medical schools providing Shared Decision Making education as specified in ‘Tomorrows Doctors 2009’ curriculum. The three key outcomes are:

- Elicit patients’ questions, their understanding of their condition and treatment options and their views, concerns, values and preferences
- Assess a patient’s capacity to make a particular decision in accordance with legal requirements and GMC guidance (in Consent – patients and doctors making decisions together)
- Determine the extent to which patients want to be involved in decision-making about their care and treatment

Although specifics cannot be shared, all medical schools provided some form of Shared Decision Making training to comply with the above outcomes, but only 1 medical school referred to Shared Decision Making specifically.

A paper was also presented to the Academy of Royal Medical Colleges, by Dr Linda Patterson, Vice President of the Royal College of Physicians and the response was that the Academy of Royal Medical Colleges supported the principal of Shared Decision Making and that the documentation would be forwarded on to all the individual colleges with a recommendation that they consider the paper and in particular seek the views of their patient groups.
AQuA also provided training to tutors at Manchester Medical School as part of the inclusion of Shared Decision Making into parts of their PBL curriculum. As a result of the workshops, the participants advised that they would change their approach to medical student education as follows:

- Doctors of the future: need to know how material intention will change to involve patient in Long Term Conditions/Shared Decision Making
- Use it more in consultations with students present
- Will refer to websites use resources
- Three questions, websites, use option grids
- Would have liked more emphasis on teaching undergrads
- Share these decision and with students

AQuA has developed two E-Learning Modules in partnership with Dr Alison Lea, a GP Educationalist and E-Learning for Health. These are both freely accessible over the internet or via the E-Learning for Health Website for individuals and organisations who are looking for accreditation.

The Royal College of Midwives has already endorsed the resources and linked them to their learning portal. The resources can be accessed either through the E-Learning for Health website or through an open access route:

The Open Access Session allows anyone to access the information. This is freely available: http://www.e-lfh.org.uk/projects/shared-decision-making/open-access-sessions/

The E-Learning Session allows people to record their work for accreditation etc: http://www.e-lfh.org.uk/projects/shared-decision-making/access-the-e-learning/
AQuA has also developed a number of training videos demonstrating Shared Decision Making consultations – both good and poor consultations across a range of conditions:

- Bernie – Benign Prostatic Hyperplasia
- Jane – Place of birth
- Penny – Osteoarthritis of the hip
- Gabe – Dialysis options

Shared Decision Making films are available for free download at www.advancingqualityallinace.nhs.uk/sdm. The films are also available on USB sticks for use with patient groups please email aqua@srft.nhs.uk

Lessons learnt

Positive aspects

- The GMC and the Council of Deans for Health were helpful
- The Royal College of Physicians and the Royal College of Obstetricians and Gynaecologists were very supportive of the programme

Points of learning

- The academic timescales, particularly in relation to any changes in curricula were not synchronised with the needs of this programme
- Health educators work to different timescales and within different constraints to the NHS which created challenges for all parties, despite the goodwill to work together
Top tips

• A good way to promote Shared Decision Making is to explain how it pulls many different strands of the curriculum together, rather than an extra subject to shoe horn into a busy curriculum
• The films are an excellent quick way for Shared Decision Making to be added into a communications lecture
• Use the E-learning Resource as a way to meet some of the requirements within the Foundation Programme
Chapter 8 - next steps

How can we hope to find the right treatment for an individual patient without understanding what matters to them, their values and preferences and involving them in decisions about their care? To do this properly not only takes tools (such as patient decision aids), support (such as decision support or "health coaching") but it importantly requires a fundamental change to the traditional biomedical paternalistic traditional medical culture. This is the difficult task AQuA have been leading on for the National Shared Decision Making Programme 2012/13 and one in which we have skilfully taken hundreds of clinicians and patients on the journey from paternalism to active and supported patient and carer participation.

“I am delighted to hear that AQuA members will continue to be supported on the road to Shared Decision Making enlightenment!” Dr Steven Laitner, GP and Associate Medical Director, National Clinical Lead for Shared Decision Making (Quality and Productivity, Department of Health)

For AQuA, the end of this Programme does not represent the end of our work on Shared Decision Making or that of any of the teams within the Collaborative who are looking to spread Shared Decision Making into other departments, teams and pathways. In addition, AQuA will continue to work with a range of organisations and bodies to continue to promote Shared Decision Making. Support for the legacy of Shared Decision Making within the North West based organisations is continuing through AQuA facilitator involvement and a number of training opportunities to further embed the cultural change needed to sustain and spread the message of collaborative care between health professionals and their patients.

Motivational Interviewing workshops and Train the Trainer delivery by AQuA over the coming year are aimed at supporting organisations to really take the Shared Decision Making approach to as many teams and professionals as they can. The Ask 3 Questions campaign and resources are also providing a patient-led change in expectation of the clinician/ health professional led consultation, which is in itself prompting cultural change. Many organisations involved in the collaborative have also embedded the Ask 3 Questions format into their patient information leaflets, supporting an active, engaged patient receiving health care.

Looking forward to the coming year AQuA is planning to build on its learning to date for the foundations of its new programme for 2013/14. The plan is to work with 18 AQuA member organisations across 30 clinical pathways within the North West to look at how Shared Decision Making can be aligned with Self Management Support, in particular looking at supporting people living with a long term condition or multiple morbidities.

Drawing from specific experiences to date, AQuA is going to work alongside a team of patient facilitators from the Expert Patient Programme CIC as well as PALS Teams from within the member organisations to help promote, support and embed the concept of Shared Decision Making with Self Management Support. This work will take the form of active collaboration with these individuals to provide a ‘real world’ view of what it’s like to live with a long term condition, the aim being to support the teams involved in the programme to develop and embed innovative ideas and solutions that work for both them and their patients.

In relation to measurement there was much to be learnt from the 2012/13 programme in regard to what worked and what did not. Reflection and study of how AQuA supported measurement within the teams in the Shared Decision Making Programme has prompted the decision to look at using a balanced scorecard approach to measurement for the 2013/14 programme.

This approach should offer more guidance to teams when deciding upon evaluating the efficacy and impact of their work. We are also looking to use a new measure specifically aimed at measuring both Shared Decision Making and Self Management Support, and will be working in collaboration with teams in the USA to do this. This new tool, called CollaboRATE, developed by Professor Glyn Elwyn and colleagues at Dartmouth College aims to research and refine a short three question tool for use within the healthcare setting.
We are particularly pleased that a number of Clinical Commissioning Groups have joined this coming year’s collaborative, and hope to look at developing commissioning support to implement Shared Decision Making and Self Management Support. The challenges to Clinical Commissioning Groups are various, complex, and continually evolving; and AQuA is pleased to be able to support these organisations in developing patient-centric approaches with North West teams.

AQuA will also be running a second cohort in the autumn of 2013 for teams or communities of teams who are interested in this area of development. Longer term, the ambition would be to develop an even more ambitious programme to join up the work of different teams across not only organisations (which is already commencing), but also across health and social care organisations within whole health communities.

As with the national programme of 2012/13, AQuA will share its journey and its learning from this forthcoming programme widely so that others can learn from our experiences.
Appendix A - SURE

SURE Tool

Can we have your help?

We are looking at how much information patients are given to make decisions. We would like to know how you feel about the decision we collectively made.

Can you please answer yes or no to the following 4 questions – by ticking the box in the table below? Please do not put your name on the form.

Thank you for helping us.

Clinician’s Name: _________________________________ Date________________

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<thead>
<tr>
<th></th>
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<tr>
<td>Sure of myself</td>
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<tr>
<td>Do you feel SURE about the best choice for you?</td>
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<tr>
<td>Understanding information</td>
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<tr>
<td>Do you know the benefits and risks of each option?</td>
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<tr>
<td>Risk – benefit ratio</td>
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<tr>
<td>Are you clear about which benefits and risks matter to you most?</td>
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<tr>
<td>Encouragement</td>
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<tr>
<td>Do you have enough support and advice to make a choice?</td>
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<td>TOTALS:</td>
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The SURE Test © O’Connor and Legare (2008)
Appendix B - SHARED

**Patient experiences of decision making form**

Date: ……………………………

You are making a decision about treatment or tests for:

…………………………………………………………………………………………

We are interested in your experiences of making a decision with the health professional you met today. In the questions below, the word *option* means the treatment or test choices you talked about for this healthcare treatment or test.

Your views will help us improve the care we give to patients making this decision.

- Please answer the 8 questions below. Tick the answer that best fits your experience, either agree strongly, agree, disagree or disagree strongly.
- Your answers are confidential. Do not put your name on this form.

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<th>How much do you agree with the following:</th>
<th>Agree Strongly</th>
<th>Agree</th>
<th>Disagree</th>
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</thead>
<tbody>
<tr>
<td>The health professional talked about other options from the one we chose.</td>
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<tr>
<td>I felt the health professional thought one option was better for me than another.</td>
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<tr>
<td>I felt it was OK to choose an option that was different from the health professional’s choice.</td>
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<tr>
<td>I felt the health professional gave me the support and advice I needed to make the best decision for me.</td>
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<tr>
<td>I was able to tell the health professional what was important to me about this decision.</td>
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<tr>
<td>I am clear about the benefits and risks of each option.</td>
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<tr>
<td>I am clear which benefits and risks matter most to me.</td>
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<tr>
<td>I am sure the option we chose is the best one for me.</td>
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</tbody>
</table>

Thank you for answering these questions

Please return this form to ……………………………………………………………………

Developed by Hillary Bekker, PHD, University of Leeds & AQuA