Report on
Shared Decision Making
and Self-Management Support
AQuA Collaborative Programme 2013/14
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Foreword

This report encompasses the second AQuA collaborative on Shared Decision Making (SDM). We explored the links between SDM and Self-Management Support (SMS) to develop a common training and implementation pack.

AQuA is the leading UK organisation on SDM implementation. We built this collaborative on the lessons learnt from our first programme in 2012/13. We believe there are three crucial elements to successful and sustainable implementation of SDM and SMS:

1. Provider support at Board level so the implementation and training of staff are part of standard operations with regular reporting to the board on the impact of SDM and SMS
2. Training and support for individual clinicians on SDM and consultation technique to challenge the common misconception that “we are doing this already”
3. Empowering patients through the use of resources such as Ask 3 Questions and agenda setting tools

One of the key outputs has been the importance of measurement, both using generic tools such as SURE and CollaboRATE as well as pathway and specific measures.

The Health and Social Care Act has put the onus on commissioners and providers to ensure SDM and SMS are a standard element of NHS care. In order for this to become reality, providers and commissioners need to be familiar with the barriers to implementation and the tools to change practice. We hope you will find the lessons in this report both interesting and instructive in meeting this challenge.

There is a wealth of evidence that patients who are active partners in their care have safer and more cost effective outcomes. This report highlights across a range of teams and conditions how we can radically improve care for our patients.

Andrew Foster, Chair of Programme Board
(Chief Executive Officer of Wrightington, Wigan and Leigh NHS Foundation Trust)
Executive summary

The overall driver behind the AQuA Shared Decision Making and Self-Management Support Collaborative programme was to achieve a 10% improvement in the number of patients actively engaged in their care and treatment. Although we did not meet this overall aim during the lifetime of this programme we have made notable strides towards it through implementation of Shared Decision Making (SDM) and Self-Management Support (SMS). In addition, we have identified many positive data trends and captured a wide range of lessons learnt to support future organisations and initiatives.

Achieving this major culture shift and overturning paternalistic ‘doctor knows best’ attitudes will take time. Research indicates that improvement programmes initially meet with scepticism but that staff will gravitate towards the new culture in the second year. In the third year, remaining staff will align with the new culture or leave the organisation. In light of this, we acknowledge that a 10% improvement in year one was ambitious.

In seeking to empower patients as active partners in care, the programme worked with 22 teams using a Breakthrough Series Collaborative model. AQuA and the clinical teams involved used measurement for improvement to collect data and identify improvements. We believe that there are several key drivers for success:

Engaged leadership and an open organisational culture are the only tenable foundations for SDM/SMS. Buy-in to the principles of SDM/SMS must be sought at clinical lead and executive level. The most successful teams were highly engaged, viewing this as a long-term investment in organisational culture.

A wide range of tools and techniques must be implemented to achieve active engagement with patients in varied clinical settings. Agenda setting, Ask 3 Questions and SDM/SMS training sessions were essential tools for all effective clinical teams.

To facilitate effective staff delivery the most successful teams took time out from service commitments to train and practice tools and techniques. Through this programme numerous staff have realised and highlighted the benefits of SDM/SMS on engagement with patients, carers and families. This testimony forms a compelling argument for the continuation of this approach.

Patients are right at the heart of this project: patient engagement is both the reason for this project and the way to achieve its aims. Throughout the programme we have seen increased patient empowerment with more questions about choices and options. Teams with the greatest clinical commitment and fastest uptake showed the strongest commitment to patient voice, using the Patient Ambassador programme or established patient forums.

The continuation of SDM/SMS is an imperative within healthcare with benefits in quality, outcomes, experience and cost. We use systematic processes to secure the sustainable use of SDM/SMS. Organisational advocates with executive support, clear alignment with organisational values and continuous monitoring of relevant data are mainstays of sustainability. We believe we must offer measures of sustainability to ensure that the Collaborative’s achievements contribute to a legacy of shared learning and accelerate the uptake of SDM and SMS in clinical practice.
Introduction and approach

SDM empowers patients to become active partners in their care. Healthcare professionals and patients work together to understand acceptable treatment options and determine the preferred course of care for that individual. It can be used in any situation where there is more than one reasonable course of action and where no single option is patently the best for all concerned. This situation is very common.

For patients with a chronic illness, self-management can be defined as decisions and behaviours engaged in that affect health and wellbeing. Through the care and encouragement of Self-Management Support (SMS), these patients and their families can:

• Understand their central role in managing their illness
• Make informed decisions about care
• Engage in healthy behaviours

We need to achieve a paradigm shift within the healthcare economy to realise the potential benefits of SDM and SMS. Many patients are not aware that they can actively shape their care, do not participate in decisions about their care and, often, do not understand the information they are given by healthcare professionals. This leaves the patient ill-prepared to undertake self-management or health behaviour change.

International research has shown that a collaborative relationship between healthcare professionals, patients and their families can enable patients to make good choices and sustain healthy behaviours. This partnership supports patients to build the necessary skills and confidence to lead the lives they wish.

The 2013/14 Shared Decision Making and Self-Management Support programme

Throughout 2012/13 our experience, research and analysis indicated that SDM and SMS had a powerful synergy. Based on the previous AQuA SDM programme, the 2013/14 programme was a unique opportunity to co-develop, co-design and co-deliver a ground-breaking combined SDM and SMS approach to increase a patient’s engagement with their own care.

This report sets out the approach, outcomes and learning according to the main drivers of the programme:

• Leadership & culture
• Tools & techniques
• Staff delivery
• Patient demand/engagement
• Sustainability

The primary programme aim was to achieve a ‘percentage improvement (10%) in patients feeling they are actively engaged in their care and treatment’. Based on our significant past experience, the programme applied tested improvement methodologies to foster collaborative working.

Team selection

Teams applied to participate and were assessed against defined criteria developed from our learning from previous programmes, including:

• Demonstrable interest in SDM/SMS
• Evidence of clinical and patient willingness and commitment to participate in the full programme

A total of 22 teams were selected.

Programme model

The programme improvement model used was the IHI Breakthrough Series Model\(^2\). We created a driver diagram (see Appendix 1*), which was used as a road-map for teams to structure their improvement. Post induction, each team was assigned a dedicated AQuA Facilitator to provide training and support. This facilitator became the key contact for support in resolving challenges, reviewing data and developing Plan, Do, Study, Act (PDSA) cycles.

Team training and facilitation was structured around three learning events interspersed with action periods and training workshops. The teams tested and developed tools and techniques to support their PDSAs.

Patient involvement

Effective SDM/SMS requires open information sharing between patients and healthcare professionals as they accept responsibility for joint decision-making. Teams used resources from our ‘2012/13 Ask 3 Questions campaign.’ The results of this previous campaign indicate that three simple patient questions can prompt a clinician to give a higher quality of information about options, benefits and harms\(^3\).

In partnership with Self-Management UK (SM-UK), AQuA provided a Patient Ambassador course to increase understanding of the patient agenda and ensure genuine service user input. Volunteer patients and carers were trained in the core competencies of SDM/SMS and in communication, influencing and delivery.

Programme measurement

Teams collected an initial measurement of baseline data prior to programme commencement. The programme used a scorecard of quantitative and qualitative measures to capture patient and health professional experiences, clinical outcomes and patient engagement data (Figure 1).

Scorecard of Measures

<table>
<thead>
<tr>
<th>Longitudinal survey -</th>
<th>“So What” -</th>
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<tr>
<td>Assesses readiness and engagement in implementation of SMS/SDM and existing support and resources at disposal. Taken at 3 points throughout the year</td>
<td>Assesses impact on system processes and clinical outcomes. Individually worked up with team using existing data e.g. HES, admissions, HbA1C, quality of life, referrals, compliments... Reviewed monthly</td>
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<th>CollaboRATE &amp; SURE -</th>
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<td>Patient reported measures for SDM/SMS. Taken at every participating clinic/patient interaction throughout the year.</td>
<td>Qualitative and anecdotal evidence including patient stories, video clips and quotes via PALs, EPP and team patient participants. Collated throughout the year</td>
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Figure 1: Scorecard of measures for SDM/SMS programme

\(^2\) IHI Innovation Series White Paper, 2003

\(^3\) 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
Leadership and culture

Aim: “Senior managerial and clinical leaders understand, practice and support SDM/SMS.” Strong leadership support and a culture that engenders the principles of SDM and SMS are primary drivers for both the uptake and continuation of improved patient engagement with care and treatment.

Process

Each team had a named programme lead, clinical lead, data lead and executive sponsor who were responsible for describing the experience of achieving clinical and cultural change with healthcare professionals and patients. They were asked to evidence clinical engagement and show how they would transcend organisational barriers to engage with healthcare professionals. The focus on engagement was both within the patient pathway and also outside of the participating organisation.

Measurement - longitudinal staff survey

A Longitudinal survey, based on the Co-creating Health Programme principles and readiness for change, and qualitative case studies, measured change in attitude and behaviour amongst healthcare professionals (Appendix 2). All team members completed an online survey of 19 questions at three points during the programme. A total of 782 scores were collected throughout the year across three data points: April (336), December (253) and March (193). The following questions and results best represent changes to leadership and culture:

A2 There is a commitment to involving patients in decisions about their care (Figure 2)

Baseline and follow up surveys, per team.

“There is commitment to involving patients in decisions about their care”

12 teams (55%) showed positive changes. Four showed no change and six teams showed a decline during the programme. One mitigating factor for those indicating a decline is that staff members potentially became more discerning as they learnt more about SDM/SMS and as a result expectations increased.

4The Health Foundation invested over £5million in a large-scale demonstration programme called Co-creating Health. This programme aimed to embed Self-Management Support within mainstream health services across the UK and equip individuals and clinicians to work in partnership to achieve better outcomes.
A3 There is an environment that is conducive to the development and sharing of ideas (Figure 3)

11 teams (50%) showed positive changes over the lifetime of the project. Two teams remained the same and nine teams (around 40%) indicated a negative trend.

B4 Staff know where to refer service users for advice and support in relation to self-management and shared decision making (Figure 4)

The vast majority (77%) showed positive changes in staff knowing where to refer service users for advice and support for SMS and SDM during the lifetime of the programme. Only two teams indicated a decrease. These improvements suggest an increased level of awareness as a result of the work and training undertaken within this programme.
Detail of results within a team

At the individual organisational level, two teams showed consistent improvements across all the question areas within the longitudinal survey:

**The Walton Centre NHS Foundation Trust (Figure 5)**

![Figure 5](image-url)

Figure 5

Particular improvement was observed in B3 (“Staff members have received training about supporting self-management and shared decision making”), B5 (“The whole team have an agreed approach to supporting service users”), and B7 (“Appointment and follow-up systems support self-management and shared decision making”). These strong results were founded on:

- A strong patient focus group, which was actively engaged in the improvement work
- An excellent Patient Ambassador who attended all training and worked closely with the team
- Several training sessions in SDM/SMS for staff members throughout the lifetime of the programme, some tailored to specific levels of staffing

**University Hospital of South Manchester NHS Foundation Trust (Figure 6)**

![Figure 6](image-url)

Figure 6

Particular improvement was observed in B3 (“Staff members have received training about supporting self-management and shared decision making”), B4 (“Staff know where to refer service users for advice and support in relation to self-management and shared decision making”), B6 (“Service users are provided with a named contact and information about availability of staff and opening hours”), and B8 (“Patients are supported to self-manage and get involved with decisions throughout the entire care pathway”). A number of attributes contributed to these results:

- Active meetings empowered staff to feedback and get involved
- Clear and de-lineated clinical and project manager leadership
- An agenda setting tool and brief decision aids were implemented for all staff to give clear direction
Tools and techniques

Aim: “Where appropriate, clinicians and patients are using SDM/SMS tools and techniques.”

Process

AQuA identified potential tools and techniques to support SDM/SMS in a wide range of care settings and clinical areas. These were selected according to the following criteria:

- The most significant impact on patients compared to the input time from healthcare professionals
- Simple implementation
- Simple to sustain

Training in SDM/SMS

Each team had at least one dedicated AQuA SDM/SMS training session on the implementation of the relevant tools and techniques. Participants had to actively engage with the training by discussing and developing actions to implement SDM/SMS in practice.

The aim of these sessions was for individuals to understand:

- The need for change in current practice
- The benefits of SDM and SMS
- How to manage the challenges to implementation
- Key opportunities for SDM and SMS conversations

There was also focus on understanding patient activation levels, active action planning as well as measurement for improvement and sustainability plans. More than 350 healthcare professionals were trained between April 2013 and March 2014 as part of the programme.

“The best thing about the SDM/SMS training was it helped me to understand why SDM is being used and how effective it is to be improving patient care and helping them in their consultation”
- Participant, University Hospital of South Manchester NHS Foundation Trust

Building on the training, teams utilised the following tools and techniques throughout the programme:

Ask 3 Questions

All teams were given access to the Ask 3 Questions (A3Q) patient resources, which were developed by AQuA in 2012/13 and adapted with kind permission from the MAGIC programme, supported by the Health Foundation.

By the end of the programme, 100% of teams had used A3Q materials by including them in appointment letters and waiting rooms.

Feedback from patients and healthcare professionals indicates that the A3Q campaign provided structure during consultations, actively engaged patients in the decision-making process and improved efficiency for healthcare professionals.

“The sheet of paper (A3Q) I was given helped me decide what questions to ask so that I understood the pros and cons of having a vasectomy and then I was happy to have it done on the same day.”
- Vasectomy patient, Wrightington, Wigan and Leigh NHS Foundation Trust
Agenda setting

Agenda setting using open questions, to explore what the patient wishes to cover in the consultation and their priorities, worked well with the A3Q material. A number of teams developed their own tools, some in collaboration with patient groups. These tools received positive feedback from both patients and healthcare professionals.

“Dennis is a 68 year old gentleman with COPD, who came for a pulmonary rehabilitation assessment. He had been sent the A3Q leaflet and a ‘My health plan’ form with his appointment letter. When he attended his appointment, he had highlighted 4/12 areas on the ‘My health plan’ that were important to him and that he wanted to discuss. As his clinician, I found this very useful as I could focus on these areas within the limited time of his appointment.

Dennis commenced his pulmonary rehabilitation sessions; he engaged well and continued to ask questions throughout the various educational sessions over the six weeks. He also went on to commence a follow-on exercise scheme at the local gym to maintain/increase his fitness levels. Knowing what was important to the patient helped me to focus my time with him more efficiently.”

- Healthcare professional, Respiratory Service, Pennine Care NHS Foundation Trust

Motivational Interviewing (MI)

Evidence suggests that simply giving patients advice is ineffective. The way we talk with patients about their health can significantly influence their personal motivation towards making health/treatment choices as well as behavioural change. MI offers a guiding/reflective style to engage with patients, clarify their strengths and aspirations, utilise their own motivations for change, and promote independent decision-making. We offered MI training in SDM/SMS through the programme. Feedback on MI training was overwhelmingly positive.

Mental Capacity Act

The Mental Capacity Act (MCA) 2005:

- Applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves
- Designed to protect and restore power to vulnerable people
- Supports all aged 10 or over who have capacity, to plan for their future

All professionals have a duty to comply with the Code of Practice. It also provides support and guidance for informal carers.

The 5 Boroughs Partnership Intermediate Care Team determined that application of the MCA could facilitate SDM/SMS in clinical practice for their patient group. The team agreed that if the patient is considered capable and fully understands the risks of a decision, they have the right, under the MCA, to make their own decisions even if others see it as unsafe.

A pro-forma was devised, clearly identifying the choice of discharge environment, the therapist’s recommendations, whether the patient has chosen to accept or decline the recommendations, and if the patient has capacity to make decisions. This ensures that the whole team follows the law and provides reassurance that the patient has the right to make decisions others may consider risky. This form is shared with the GP and other services including district nursing.

Rollnick et al 2010
“The effect of SDM and the MCA is quantifiable. There has been a significant increase in patient satisfaction, all patients are being offered their choice of discharge location, and comparing six-month periods in 2013 and 2012 the average stay in the unit dropped from 38 days to 29 days, in November 2013 it fell to 24 days.”

- Healthcare professional, Intermediate Care Team, 5 Boroughs Partnership NHS Foundation Trust

Ready, Steady, Go

Dr Arvind Nagra, Southampton University Hospitals NHS Foundation Trust, designed the ‘Ready, Steady, Go’ transition programme to work in partnership with patients either transitioning from children’s services into adult services or returning to health services. It facilitates effective SMS and promotes SDM. This resource was introduced at the third learning event. Teams from Pennine Care NHS Foundation Trust, Bolton NHS Foundation Trust, 5 Boroughs Partnership NHS Foundation Trust, Salford Royal NHS Foundation Trust, Wrightington, Wigan and Leigh NHS Foundation Trust and University Hospital of South Manchester NHS Foundation Trust are introducing it and developing a network of users across AQuA’s North West footprint. Further information on this resource can be found online: http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

Decision Aids

Some teams (University Hospital of South Manchester, 5 Boroughs Partnership - Podiatry, 5 Boroughs Partnership - Weight Management) used existing decision aids or developed locally relevant aids, outlining the options, pros and cons to each patient. These were offered as preparatory reading in the waiting rooms and utilised in discussions during consultations.

Self-management guidance

Teams (Aintree - Renal, Wrightington, Wigan and Leigh - Sleep Apnoea, Manchester Mental Health, Blackpool and University Hospital of South Manchester) sought out and developed brief guides including written advice and group courses to help patients understand what they could do to manage their condition.
Staff delivery

Aim: “To build capacity among staff to effectively use SDM/SMS across all identified pathways.”

Translating knowledge and learning into practice

Tools, techniques, training and leadership were provided as pre-requisites for this programme. Teams then took individual responsibility for the use of SDM and SMS in practice. The use of SDM and SMS requires varying degrees of practice change in order to realise the full benefits. The uptake, continuation and outcomes of SDM and SMS varied considerably within and between teams. Feedback indicates that this was in part due to the different incentives, payment mechanisms and processes in place.

Teams showing improvement all instigated two core PDSA cycles:

- Introduction of the A3Q resources for patients, families and carers
- Attendance of selected staff at SDM/SMS AQuA facilitator led training

In addition to these core PDSAs, teams experiencing effective delivery of SDM/SMS implemented a wide range of relevant PDSA features.

5 Boroughs Partnership Intermediate Care Team:

- Implementation of new discharge planning process based on Mental Capacity Act (MCA) (2005)
- On admission baseline assessment of the patient’s short and long-term goals and chosen discharge destination
- Selected staff trained in motivational interviewing techniques

Staff feedback suggests a change in delivery culture: “In the past, we may have tried to persuade a patient to accept our recommendations, often resulting in a longer stay. As clinicians we are often uncomfortable with patients making decisions we perceive to be risky. The MCA is a challenge to professionals taught to work in a paternalistic way. The principles of SDM and the MCA have enabled us to accept that patients have the right to make their own choices.”

- Healthcare professional, Intermediate Care Team, 5 Boroughs Partnership NHS Foundation Trust

Respiratory (Sleep Apnoea) team at Wrightington, Wigan and Leigh NHS Foundation Trust:

- A Sleep Apnoea Patient Support Group, actively consulted and involved with improvements
- Selected staff trained in motivational interviewing techniques
- Patient Ambassador training
- Revision of patient information materials

“When we embarked on our journey, involving patients at the start was the key to ensuring we were meeting their needs. Seeing what issues the patients raised gave us the direction to improve their experience.”

- Dr Abdul Ashish, Respiratory Consultant, Wrightington, Wigan and Leigh NHS Foundation Trust

East Cheshire CCG and East Cheshire NHS Trust Cardiology Team:

The whole health economy in Eastern Cheshire was involved with a significant on-going project to improve SMS. They therefore looked at changes that would impact across their area.

- Development of a roadmap to embed SDM/SMS into their plan
- Staff trained in motivational interviewing techniques
- Actively engaging with patients throughout improvement process
- Patient Ambassador training
- SDM CQUIN incentive for providers
- Local area peer leads for SDM
Patient demand/engagement

Aim: “Patients feel empowered to ask about their choices and options in relation to their care.”

Patients, carers and support workers are integral to SDM and SMS. The overwhelming majority of the average patient’s time (more than 5,000 hours) is spent outside of a clinical setting. Therefore, service users must engage with their healthcare professionals in the system and play an active role in their own care and wellbeing.

Figure 7: Life with a LTC as depicted by a patient; the green ‘life’ line is an opportunity for SMS and the vertical lines offer opportunities for SDM

Engaging with patients

We adopted a bespoke approach to increase patient engagement and develop patient demand. Clinical teams worked collaboratively with patients, patient forums and representatives to embed SDM/SMS in clinical practice. For example, teams:

- Addressed patient service user groups (Bolton NHS Foundation Trust – Respiratory)
- Invited patients to staff meetings (Pennine Care NHS Foundation Trust, Manchester Mental Health NHS Foundation Trust, 5 Boroughs Partnership NHS Foundation Trust, East Cheshire CCG)
- Formed bespoke patient forums for SDM/SMS (Wrightington, Wigan and Leigh NHS Foundation Trust – Respiratory, Bolton NHS Foundation Trust – Respiratory, Manchester Mental Health and Social Care Trust, NHS Eastern Cheshire CCG, The Walton Centre NHS Foundation Trust, 5 Boroughs Partnership NHS Foundation Trust – Intermediate Care)
- Accessed system structures such as Patient Advice and Liaison Services (PALS), support groups and networks (The Walton Centre NHS Foundation Trust, 5 Boroughs Partnership NHS Foundation Trust)

AQuA collected stories, case studies and quotes to capture changes to the patient experience from SDM/SMS. All teams were actively encouraged to collect these throughout the programme. Please see case studies at: http://www.advancingqualityalliance.nhs.uk/sdm/resources-2/case-studies/.

Patient feedback -

“I left our SDM meeting feeling we had the most productive discussion. I was listened to, treated with great compassion and the utmost respect, and left feeling the team had my best interests at heart. I do appreciate it.”

AQuA offered a tailored Patient Ambassador programme with two training sessions. 23 nominations were received for the November session and 33 nominations received for January. Six participants attended each session. The low attendance numbers were due to administration, co-ordination, child care responsibilities, medical appointments, wellness of nominees on a given date and the expectation of attending for two full days in a row.

“Having a patient perspective, with greater understanding of the condition and opportunities for feedback, is especially important in service improvement. Being a Patient Ambassador I can appreciate the genuine hard work going on behind the scenes.”

- Patient Ambassador, The Walton Centre NHS Foundation Trust

Sustainability

Aim: “Systematic processes are in place to support the on-going sustainable use of SDM throughout the organisation.”

Improvement initiatives often remain as localised pockets of excellence within their original boundaries. The main challenge for these programmes is to sustain and spread quality improvements in the medium and long-term. Sustainability of change and full use of resources are strategically important given the financial constraints of the current climate.

Assessing and supporting sustainability

We undertook an initial survey in June 2013 of all participants from the 2013/14 Collaborative and 2012/13 National Collaborative. This assessed participant commitment to embedding sustainable SDM/SMS in clinical practice and the best facilitation methods. The 20 respondents provided an indication of the appetite for sustainability and their opinion on the most effective approach to embedding SDM/SMS in clinical practice. Respondents highlighted a number of areas where support is required (Figure 8):

• 100% of respondents wanted to continue to embed SDM/SMS in clinical practice within their service
• 100% of respondents expressed a need for support to embed and sustain SDM/SMS
• There was a strong desire to embed SDM/SMS across all clinical areas, the whole organisation/pathway and recognition that SDM/SMS has whole-system relevance
• 85% of respondents believed they had organisational support for SDM/SMS

![Figure 8](image)
The 2013/14 Collaborative teams were encouraged to consider sustainability from the beginning of the programme. Facilitators encouraged teams to work through a simple pro-forma (Appendix 3*) enabling teams to identify objectives and ideas, actions, comments and date for completion including:

- Identify two further consultants to access the SDM training
- Include SDM as a standing item on team meeting agendas
- Identify patient champions/ambassadors for SDM
- Develop an SDM computer screen saver for trust/staff computers and place SDM banners and video in waiting areas
- Develop a press release and an article for newsletter/e-newsletter
- Supply of A3Q leaflets in clinics
- Include the PALS, Complaints and Litigation services in awareness raising for SDM and share SDM work with local CCGs and Healthwatch
- Include e-learning tool in new starter induction
- Include a paragraph in letters to GPs about use of SDM in specialist clinics
- Commit to 10 participants attending the SDM Train the Trainer

As we seek to ensure that SDM does not simply become a box-ticking exercise we believe that commissioning for quality and outcomes and a new standard clause within the NHS Standard Contract 2014/15 will accelerate the adoption of SDM/SMS:

Standard Clause 10 Personalised Care Planning and Shared Decision Making 10.1 *The Provider must employ Shared Decision-making in planning and reviewing the care or treatment which a Service User receives.*

The teams at 5 Boroughs Partnership NHS Foundation Trust, Bolton NHS Foundation Trust, Wrightington, Wigan and Leigh NHS Foundation Trust, Pennine Care NHS Foundation Trust, University Hospital of South Manchester NHS Foundation Trust and The Walton Centre NHS Foundation Trust have established robust plans to enable sustainability and spread of SDM/SMS across their organisations and wider health economies. AQuA has developed a Train the Trainer programme to provide a cohort of individuals in a range of clinical areas to train and embed SDM/SMS in clinical practice.
**Programme results**

The primary aim, a “percentage improvement (10%) in patients feeling they are actively engaged in their care and treatment,” was measured using the CollaboRATE\(^7\) and SURE\(^8\) score. The measurement of shared decision-making and decisional conflict undertaken as part of this Advancing Quality Alliance (AQuA) project was undertaken in partnership with Glyn Elwyn and Rachel Thompson from The Dartmouth Center for Health Care Delivery Science, Dartmouth College." A total of 4,718 responses were submitted. Of the responses, 4,466 have been included in the analysis for the collaborative programme (see Appendix 4* for details of the inclusion process).

**Results**

We used a ‘Measurement for Improvement’ approach\(^9\) to understand the baseline natural variation in the teams’ processes and look for special cause variation using run chart rules to identify impacts and improvements.

Teams were asked to collect six – eight weeks of baseline data prior to receiving a training workshop specific for their full team. At different time points during the programme teams implemented a variety of PDSAs. Teams attended further training e.g. motivational interviewing to support the primary programme aim.

Due to high levels of variability in the number of responses received each week, which teams submitted data each week and when teams received training, results from CollaboRATE and SURE responses are difficult to analyse. Results are plotted as the percentage of respondents answering positively in order to account for this variation to some extent, but caution should still be taken when interpreting the data. The charts below show aggregated data across all teams according to both the timescales of the project overall and the time before/after training for each team. These allow some understanding of the impact of learning events on the programme overall and the impact of training sessions on team progress. Appendix 5* shows the results produced by Dartmouth College, USA, for each team individually.


\(^9\)Solberg 1997
Figure 9, showing aggregated CollaboRATE scores for all teams across the course of the programme as a collaborative, suggests that in week 12 of the programme, there was an upwards shift; with more consistency of scores indicating special cause variation. The difference in the mean score before and after this shift was 12%. The reduced consistency in the last couple of weeks of the project may be because the number of responses submitted dropped significantly, so the percentages are influenced more heavily by individual responses. There does not appear to be any immediate impact from the Learning Events themselves.

Figure 10 shows aggregated CollaboRATE scores but this time plotted according to the date of data collection relative to their team specific training workshops. This shows a similar positive shift (mean moves from 67% to 74%) to more consistent scoring as in Figure 9, although as this does not occur until approximately 8 weeks after the training date it is unclear what the cause of this is. The teams were trying a number of different PDSA cycles at different times so it is difficult to ascertain which changes specifically brought about improvements. Interestingly, Figure 10 also shows a negative shift (to a mean of 70%) after about 30 weeks, perhaps due to teams starting to ‘wind down’ their work as the programme came to a close. We would expect this to affect the number of responses submitted but it is interesting that, as seen here, the level of SDM being demonstrated by teams also reduced.

Figures 11 and 12 show the aggregated SURE results, plotted both according to weeks since the start of the programme and weeks relative to team’s training date. We have seen in previous programmes that the SURE score is not always sensitive to change but it is disappointing that the SURE results do not appear to show any change and the target of a 10% improvement in these scores has not been achieved.
Selected results from ‘So What’ data

Teams developed and identified a range of ‘So What’ metrics to demonstrate relevant outcome changes including patient outcomes and economic benefits to the system. This data was collected as part of the balanced scorecard of measures and the results below are what were submitted to AQuA by teams to demonstrate their improvements in ‘So What’ measures. These suggest that adoption of SDM/SMS in clinical practice can have an influence on organisational business-critical measures.

The Diabetes team from Bolton NHS Foundation Trust collected DNA rates and admissions for diabetic ketoacidosis (DKA). An overall analysis of DKA admissions shows little change to date. The team has extended its work to analyse the time between re-admissions per patient to reveal changes in individual care and self-management. A number of PDSAs were implemented during the lifetime of the programme including:

- Staff training in motivational interviewing techniques
- Review of clinic appointments
- Use of text message reminders for appointments
- An introduction of the Ask 3 Questions resources
- Attendance of selected staff at SDM/SMS AQuA facilitator led training
Figure 13 indicates that there was a reduction in DNA rates during this time. This can be used as a proxy measure to indicate patient engagement levels. As several different changes related to reducing DNA rates were undertaken, direct links with SDM/SMS are unclear.

The respiratory team at the same trust meanwhile looked at:

- Staff training in motivational interviewing techniques
- Focus on use of personalised plans
- An introduction of the Ask 3 Questions resources
- Attendance of selected staff at SDM/SMS AQuA facilitator led training

The respiratory team’s ‘So What’ measures included occupied bed days (OBDs), non-elective admissions, and implementation of a physiotherapy plan.

Figure 14 shows a reduction in OBDs. Prior to the project, none of the patients seen by the physiotherapy clinic had personalised plans - by August 2013, 38 out of 39 physiotherapy patients with bronchiectasis had plans and 28 had been discharged with correspondence reflecting these plans. It is difficult to allocate a causal link for the introduction of SDM/SMS for these improvements; however it may be a contributing factor.

The University Hospital of South Manchester NHS Foundation Trust Pain Management Team looked at process measures and outcome measures. They reviewed their DNA and attendance rates for patients before and after the implementation of the programme: April 2012 - January 2013 against April 2013 - January 2014 for both new patients (Figure 15) and patients attending follow-up clinics (Figure16)
DNA rates for follow-up patients decreased following the implementation of the SDM/SMS programme. As no other improvement work was undertaken during this period, the improvement in DNA rates could be attributed to an increase in informed patients being activated to turn up to their appointments.

Wrightington, Wigan and Leigh NHS Foundation Trust’s Respiratory Service worked with patients to co-create a new clinic information leaflet and embed SDM/SMS in clinical practice. The team identified DNA rates as a ‘So What’ measure with an objective of reducing DNA rates by 8% during the programme. When comparing November 2012-March 2013 and April-September 2013 there was an overall improvement in DNA rates with some clinics reducing DNAs by more than 6%. During this period there was a 17% increase in attendance from follow-up patients. The increase in attendance suggests that more patients are engaged in their own care and are seeking to proactively manage their care, potentially due to the use of SDM/SMS.

“SDM helps us talk through the lifestyle issues facing sleep apnoea patients, how to use the apparatus as beneficially as possible and to discover what is most important to individuals. We are open about the associated health problems and the pros and cons of treatment. Patients respect that. Patients are leading the way. They are more aware of their healthcare choices and less likely to miss clinic appointments. Compliance with the agreed treatment is improving.”

- Dr Abdul Ashish, Respiratory Consultant, Wrightington, Wigan and Leigh NHS Foundation Trust
Aintree University Hospitals NHS Foundation Trust’s renal team focussed on patients with high phosphate binders. During dialysis the nurse specialist worked with these patients to provide education on phosphate control using SDM/SMS tools and techniques.

Following SDM/SMS training the team saw a reduction in the number of patients with high phosphate levels from 68 to 32 (Figure 17); taking into account that only 48 out of the 68 original patients were available for final programme analysis, this equates to a 33% reduction in patients who had high phosphate levels June-August 2013. A retrospective audit on the cohort of the remaining 48 patients six months after the intervention indicates that 95% of patients were able to maintain their phosphate levels since the SDM/SMS programme (Figure 18).

In collaboration with nursing colleagues and patients, 5 Boroughs Partnership NHS Foundation Trust’s Intermediate Care team, based at St Bartholomew’s Residential Care Home, looked at their discharge process. They aimed to increase patient involvement in choosing their discharge location and reduce Length of Stay (LOS). They measured LOS, re-admission within 30 to 90 days and quality of life through the Euroqual tool.

In collaboration with nursing colleagues and patients, 5 Boroughs Partnership NHS Foundation Trust’s Intermediate Care team, based at St Bartholomew’s Residential Care Home, looked at their discharge process. They aimed to increase patient involvement in choosing their discharge location and reduce Length of Stay (LOS). They measured LOS, re-admission within 30 to 90 days and quality of life through the Euroqual tool.
This team saw a steady decline in the average LOS from 36 to 24 days during the programme (Figure 19).

The Podiatry team from 5 Boroughs Partnership NHS Foundation Trust produced a decision grid for ingrowing toenail management to increase patient understanding of options and support decision-making. The grid was shared via email and in clinic. The team also looked at DNA rates. According to baseline data, the DNA rates were already very low - 1-2 DNAs per month. Therefore, the team decided to look at the total number of appointments.

The DNA remained stable despite the overall number of appointments increasing during the programme (Figure 20). This suggests an increase in demand with one possible factor being that patients engaged with SDM/SMS are more active in managing their care and attend surgery more regularly, however the data does not distinguish between new and existing patients.

The Liverpool Community Health team was late to join the programme but, due to strong commitment from their project lead and team members, they made excellent progress. Within this team a number of small services each identified relevant ‘So What’ measures to address areas of concern.

Aims:

- Liverpool Wheelchair Services (LWS) - reduce the number of reported problems in the first four weeks
- Manual Handling (MH) - increase the number of patients continuing to use equipment after three months and increase patient satisfaction
- All services - reduce the number of complaints

During the programme some significant improvements were seen.
During the SDM/SMS programme, the number of reported problems with equipment not fitting or meeting patient requirements reduced by 45% for LWS and 47% for MH (Figure 21). Complaints dropped by 54% in LWS (Figure 22). Following the programme, the team reduced equipment costs by 62% with no additional complaints measured or increase in adverse incidents (Figure 23). This suggests that patients were collaborating more effectively with their healthcare professional in determining necessary equipment, possibly facilitated by the use of SDM/SMS. Anecdotal feedback shows a reduction in the automatic allocation of equipment according to generic criteria and therefore a decrease in unnecessary equipment assignment.

“Patient experience improved and subsequent costs reduced as fewer reassessments are required and equipment is prescribed more appropriately”
- Liverpool Community Health staff member

Pennine Care NHS Foundation Trust’s Respiratory Team agreed the following ‘So What’ aims:

- Reduced A&E attendances
- Reduced outpatient (OP) appointments
- Reduced acute admissions and LOS

Marginal improvements were seen including a small reduction of five A&E attendances and a 45% reduction in outpatient attendance for chest medicine. These improvements could have been influenced by a number of factors but a proportion of these improvements could be attributed to the introduction of SDM/SMS and increasing self-management during this period. This proactive management could contribute to reduced A&E attendance and reduce the necessary number of outpatient appointments per patient. Longer term tracking of this data would be beneficial to show definitive changes.
Lessons learnt

Approach

• Use multi-stage application process - application forms, planning canvasses, Project Manager induction events and team interviews to select teams that were prepared to invest the time and energy embedding SDM/SMS
• Complete planning canvasses to avoid misunderstandings
• Use dedicated data submission links for each team to facilitate data submission
• Emphasise aim of measurement for improvement to maintain data submissions and allow teams to reflect accurately on results
• Complete patient questionnaires immediately post-consultation
• Networking and collaboration between teams increases over time
• Use dedicated facilitators to support teams in training, implementation and programme management - this model enabled busy clinical teams to change practice/culture in ‘real-time’
• Set realistic and meaningful ‘So What’ targets within each setting
• Invest time upfront to ensure greater understanding of ‘So What’ measures to allay concerns that the metrics were not ‘clean’ and could be influenced by many factors
• Factor declining attendance into programme design with shorter events (rather than whole days) in the latter stages of the programme – although event attendance declined over time almost all teams had continuous representation and completion rates of posters, presentations and case studies at these events from about 85% of participating teams suggests high engagement

Leadership and culture

• Identify strong clinical and high-profile advocates for SDM/SMS to promote improvement - embed regular team catch-ups with these advocates
• Identify senior sponsors who actively engage with team leads and support progress
• Teams must have common purpose and approach linked to organisational priorities
• Provide resources to support teams
• Facilitators must keep SDM/SMS on the agenda even during busy times
• Facilitators need to understand previous and current experience in improvement methodology and pace change accordingly

Techniques and approach

• Take time out from service commitments to train and practice learned communication styles and techniques when engaging with patients
• Use of the Mental Capacity Act (MCA) has had a considerable impact on approach to utilising SDM/SMS
• Motivational interviewing works well for healthcare professionals and patients
• Agenda setting and A3Q tools are essential to support SDM and SMS
• Include staff and patients in co-design of tools to ensure broad perspective
• Patient push for SDM and SMS facilitates wider adoption of tools and increases commitment to individual accountability
Staff delivery

- Use the A3Q resources and participate in the SDM/SMS AQuA facilitator-led training
- Ensure executive and organisational support for SDM/SMS
- Ensure patient/user involvement including Patient Ambassadors and patient group input
- Allow local peer leads to provide the 'case for change'
- Use agenda setting tools
- Develop and use brief decision aids
- Incentivise SDM/SMS through CQUIN payments

Patient demand/engagement

- Proactively encourage patient engagement from the outset
- Improve contact methods with (and persistence in contacting) potential Patient Ambassadors as part of the original programme
- Ensure clarity on the use of trained Patient Ambassadors within clinical teams
- Use a greater pool of patient nominations to increase overall participation in the programme
- Use existing, well-established forums as these patients are most keen to contribute

Sustainability

In organisations where SDM/SMS has been effectively sustained there are a set of common traits:

- Organisational SDM/SMS advocate with executive support
- Clear 'line-of-sight' between organisation values/aims and case for SDM/SMS
- Continuous measurement and review of data that 'means something' to the organisation
Legacy

SDM/SMS requires significant cultural change both on the part of the patient/carers and healthcare professionals. We recognise that effectively embedding SDM/SMS into the way we interact will take time, however there are significant benefits of such a culture change, as demonstrated by the ‘So What’ data. Healthcare professionals, patients and carers have cited the benefits of effective SDM/SMS. AQuA is proud to have worked with a committed group of patients, carers and healthcare professionals to embed SDM/SMS into clinical practice. As a result of this work, we have developed a range of tools for teams and organisations interested in delivering care using SDM/SMS.

Our next steps

In 2014/15 AQuA is delivering a new, specialist programme working with seven organisations and thirteen clinical teams to reduce hazards associated with transition of young people with long-term conditions into adult services through the AQuA SDM/ SMS programme. Teams will work as a collaborative and will be trained by AQuA in SDM and SMS techniques. Clinicians will problem-solve, use these techniques and work collaboratively to reduce common risks. This is an exciting new area of research, reviewing the impact of SDM and SMS on transition between services by enabling the right conversations to take place at the right times. This project is part of the Health Foundation's "Closing the Gap" programme. The Health Foundation is an independent charity working to improve the quality of healthcare in the UK.

AQuA will continue to offer training to members and non-members in SDM and SMS. Please contact: aqua@srft.nhs.uk for further information.

*Appendices can be found on the AQuA Portal or through the AQuA office.