



Southend Estuary Clinical Commissioning Group

in partnership with

InHealth
ASSOCIATES

Big change: Small steps

What does a patient-engaged organisation
look like and how do we get there?

July 2011

Big change: Small steps

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1. Introduction

This project was commissioned by NHS East of England in order to deepen its understanding of what a patient-engaged organisation looks like and how it might be delivered. The focus of the project lay principally with primary care and with the emerging clinical commissioning organisations.

In our proposal, we committed to involving clinicians, GP practices, Southend Estuary Clinical Commissioning Group (formerly Fortis GPCC) and users/carers in addressing the following questions (among others):¹

1. How best can we build support for shared decision-making (SDM) and information giving in routine NHS care?
2. How can commissioning maximise patients' involvement in their own health and care (with SDM and information giving as outcomes) and how might this best be reflected in commissioning specifications?
3. How can we build an understanding of SDM as part of the same paradigm as personal health planning, supported self care and the wider personalisation agenda - to support spread and implementation across the region?

2. Our Proposal

We proposed several elements to the study:

- Clarification of the concepts involved
- In-depth telephone interviews with key stakeholders
- Desk/internet research
- Production of a simple website to draw information together²
- Action Learning Sets
- Recommendations to the Southend Estuary CCG Board

All of these elements of the study have now been completed. Given the numbers of people who put themselves forward for the action learning sets, we chose to run one Set rather than the two parallel sets that were included in the original proposal.

It is important to state that this report has been co-produced. Many of its ideas and insights came from those who have participated in the action learning sets. Their names are listed in the Acknowledgements section.

¹ For consistency, we have referred to Southend Estuary CCG throughout this report, although much of the work took place when the name Fortis GPCC was still being used.

² <http://web.me.com/grahambox/SECCG/Home.html>

3. Our method

We have presented the report as a synthesis of information derived from different sources. We believe that this will prove more useful than describing each of the components of the research independently. The different elements of the research are summarised below.

Clarification of the concepts involved

From the outset, it was clear that the scope of the project was extremely wide. We developed our understanding of the concepts involved through online research and then used this to provide written briefs for members of the action learning sets as a starting point for our discussions. They were then encouraged to focus on areas that were of particular relevance and interest to them. These briefs covered issues such as the nature of shared decision-making and its potential benefits, the patient-clinician relationship and the nature of informed choice.

In-depth telephone interviews

The work in the previous paragraph was almost exclusively concerned with national, and sometimes international, activities. We then conducted 14 in-depth telephone interviews with local stakeholders to find out about their experiences of the different elements of patient engagement, from the individual consultation at one extreme and through to collective engagement in organisational structures at the other. Those interviewed included GPs, a practice nurse, care managers, residential care providers, a carer's organisation, PCT staff, practice managers and commissioning managers. The report on the telephone interviews is included as an Appendix.

Desk/internet research

Relevant work was identified through internet searches and recommendations and we looked at a range of articles, reports and examples of good practice. The most useful documents were summarised and posted onto the project website. These are also brought together in the useful resources section towards the end of this report. Extensive use was made of a comprehensive collection of essays edited by Adrian Edwards and Glyn Elwyn, published in 2009, entitled *Shared Decision-Making in Health Care: Achieving Evidence-based Choice*.

Production of a simple website

The website for Southend Estuary CCG is under development and so could not be used to share information about this project. To fill this gap, a simple site was established using Apple's iWeb software. This was employed to bring together useful resources in one place, including information about the progress of the project, reports and report summaries, and links to other relevant websites.

Action Learning Sets³

"Action Learning is an approach to the development of people in organisations which takes the task as the vehicle for learning. It is based on the premise that there is no learning without action and no sober and deliberate action without learning. The method has three main components: people who accept responsibility for taking action on a particular issue; problems, or the task that people set themselves; and a set of six or so colleagues who support and challenge each other to make progress on problems. Action Learning implies both self-development and organisation development."

A great deal of the learning took place through the action learning sets. These brought people together from different backgrounds to look at aspects of patient engagement that they found particularly interesting or important.

We had originally hoped to attract representatives from every practice and to run two learning sets in parallel. This was not possible but a good number of practices were involved and an interesting range of projects was identified.

The learning sets were particularly useful in allowing the facilitators to explore ideas and options. Learning set delegates were able to comment upon the proposed recommendations and offer their own. Their views have been built into the recommendations that are a key element in this report.

In particular, action learning set members have encouraged us to think about (among many other things) information provision, patients with dementia and their families, the use of new technologies to improve communication, support for carers and the grass roots structures of collective patient engagement. See the list of projects in the column on the right.

Projects identified by Action Learning Set delegates

Complete overhaul of practice website which does not provide as much information as patients would like

Identifying and addressing patient concerns about the sharing of information which is vital for the success of a specific Southend Estuary CCG project

Promote shared decision-making with the carers of people with dementia

Develop survey for patients about shared decision-making and their hospital experiences

Establish a supra-Patient Participation Group as an umbrella for all the PPGs in the Southend Estuary CCG area

Set up a practice-based focus group as a precursor to putting a PPG in place

Develop an email database for patients as a valuable step in improving communication

Find out about carers' experiences of shared decision-making

Talk to care managers about shared decision-making in a residential care setting

³ Quote below is from <http://rapidbi.com/created/actionlearningregrevens/>

4. About this report

As noted above, this report brings together findings from national research and good practice alongside what we found through our local work. We have chosen to highlight the recommendations at an early stage in this report since they are the central output of this piece of work. We are very conscious that they might seem daunting and that the scale of the changes might appear unworkable. For that reason, we emphasise that the issues need to be addressed step by step, in a measured and planned way.

Having summarised the recommendations, the next section of the report looks in some detail at shared decision-making. This is a core component of the patient-engaged organisation and, in some respects, it has been used as a model for the other elements of patient engagement that are identified throughout the report. So, we begin by defining shared decision-making before looking at its potential benefits.

This is followed by an analysis of the challenges and enablers to deliver more, and better, shared decision-making. This area proved particularly fruitful in that the research unearthed several messages that could be applied to other areas. The work of Edwards and Elwyn was valuable in presenting a schema that describes the micro and macro elements that are required for organisations to be able to deliver what they describe as the “informed patient choice environment”.

The final two main sections look at the competing priorities and the options that are available to Southend Estuary CCG. These return us to one of our key messages - that progress in this area requires a long-term strategic plan that establishes priorities, timescales and allocates resources. The report closes with a brief conclusion and acknowledgements, a summary of useful resources and an Appendix that describes the main findings from the telephone research.

5. About *InHealth Associates*

This project was led by *InHealth Associates* (<http://www.inhealthassociates.co.uk/>) who are also working in partnership with Southend Estuary CCG on a separate project to support the development of their organisational model of patient and public engagement. *InHealth Associates* are a network of independent experts who have come together out of a shared belief in putting patients, users and carers at the heart of care. They offer advice, support and guidance for organisations and individuals on a range of issues, including:

Involvement: Supporting NHS and third sector organisations to ensure that engagement informs decision-making and leads to improvements for patients

Insight: Providing advice and guidance to organisations who wish to make better use of patient experience data or customer intelligence.

Innovation: Working to promote and mainstream social innovation.

6. Summary of recommendations

Our report is titled ***Big change: Small steps*** to reflect both the scale of the task and the fact that it needs to be delivered incrementally. Among all of the recommendations below, the most significant is that patient engagement should be embedded in the organisational culture of Southend Estuary CCG and its constituent practices. As a new body, there is a real opportunity for the Clinical Commissioning Group to define itself, what it stands for and how it wishes to develop.

The opportunity is also a significant challenge - to turn words into actions that will improve the quality of care, deliver value for money and improve the patient experience. This will require consistent, high level support for the principles of patient engagement, together with an ongoing commitment from health care providers and commissioners to understand what it is like to be a user of local services, or a carer.

As well as covering specific aspects of growing patient engagement, the recommendations address this implementation challenge. They do so by suggesting consolidation techniques (such as annual surveys and open meetings) as well as by promoting greater local ownership of the approach (through developing the statement of the Picker Institute “always” events and encouraging the continuation of the action learning set model).

“SDM needs to be cultural, systemic, part of how we do it, fundamental to us, not a bolt-on. Seems to me that this is highly ambitious for clinicians, professionals and patients/carers/families and will be a slow burn, not an instant hit. Needs to be effectively communicated at the outset, messages reinforced and in time will become how it's done.” (Patient Participation Group member of Action Learning Set)

Cultural change is clearly not the only area to be addressed and a number of practical and policy changes will also need to be introduced. We recommend that they are incorporated in a strategy that identifies priorities, timescales, resources and implementation methods. By breaking down the big change into small steps, Southend Estuary CCG and local GP surgeries can gradually introduce and refine ways of working that other organisations and areas will want to emulate.

Strategic Recommendations

6.1 There are a number of necessary conditions for the delivery of patient-engaged organisations. These need to be systematically addressed and implemented. Our preferred model is that proposed by Elwyn and Edwards who describe the key determinants as:

- Organisational culture
- Organisational policies
- Consultation routines
- Data systems and sharing
- Inter-professional communications
- Continuing professional development
- Decision support technologies⁴

⁴ Edwards, A and Elwyn, G (2009) Shared Decision-Making in Health Care p404

6.2 Southend Estuary CCG should design, with its patient/public population and other stakeholders, a detailed annual survey to assess progress with respect to delivering patient engaged organisations. This would be a high profile activity, ideally linked to financial incentives for practices, with the findings reported to an annual open meeting where the performance of individual practices and other providers is shared in a transparent way. Among other things, it would capture patients' own views on the extent of shared decision-making that they experience.

6.3 The development of these pre-conditions and the design and delivery of the survey should be key components of a patient engagement strategy to be developed by Southend Estuary CCG. We recognise that there is a real risk of attempting to 'boil the ocean', addressing too many issues simultaneously (particularly at a time when the CCG remains a "shadow" organisation). So we recommend that the strategy is carefully timetabled and prioritised, and supported by the strongest possible business case in each element.

6.4 This strategy, which needs to cover all levels of activity, will need to determine how, and when, it addresses key aspects of delivering a patient engaged organisation, such as:

- Increasing shared decision-making in the clinical encounter
- Information provision and information therapy
- Making more effective use of care planning processes
- Delivering individual budgets (in the right circumstances)
- Building more, and more meaningful, choice for patients
- Growing the uptake of self-care courses
- Improving support for carers
- Working in partnership with others

6.5 The strategy should also take a view on how patient engagement can be built into each future area of pathway redesign. Southend Estuary CCG can learn from initiatives such as the Year of Care to inform its future service redesign activities.

More detailed recommendations

6.6 These more detailed recommendations will also need to be built into the overarching strategy. They are dealt with in a separate section here since their discrete nature should make them easier to implement.

- Patients and the wider public should be fully involved both in writing/producing information (with strong clinical input) and in identifying the sources of information that have greatest value and relevance for lay people.
- Patient leaders and champions need to be systematically supported and developed as a critical part of building the capacity of patient engaged organisations (alongside continuing professional development - see recommendation 1 above)
- Greater effort is required to ensure (a) that patients and carers understand fully the choices that are available to them and (b) that the community served by Southend Estuary CCG has a clear and deep understanding of the challenges and opportunities for commissioning organisations, and what it is possible for them to

"If patients produce it,
they will use it."
(PCT Non-exec Director)

deliver. This emphasises the close relationships between patient engagement and effective communication.

- Given its importance, it makes sense to build patient engagement into the Quality, Innovation, Productivity and Prevention (QIPP) plans through (a) involving the community in identifying QIPP projects (b) encouraging patient-led QIPP projects⁵ and (c) full involvement of patients and the public in pathway redesign activities. This is consistent with recommendations made by *InHealth Associates* about the wider governance structures for Southend Estuary CCG.
- A specific piece of work should be undertaken to ensure that Southend Estuary CCG is aware of the engagement opportunities presented by new technologies and these should then be incorporated within the engagement strategy.
- Existing tools and support for shared decision-making need to be collated and shared (largely through existing communication channels), including the Expert Patient Programme, carers' champions in each practice and a directory of voluntary sector support organisations.
- As a commissioning organisation, Southend Estuary CCG should require all providers to undertake and publicise the findings from systematic research to understand what it is like to be a user (or a carer) of their services.
- In addition, we encourage the CCG, its component practices and the wider community to reflect together and define 'always' events. These are aspects of care that are invariably delivered. This process is a powerful one to define the consistent standards of high quality care that all patients and their carers can expect. Effective delivery will require commitment from partner organisations in the local authority and in other health care settings.⁶

The 2008/9 Annual Report from Picker Europe included a powerful summary of its research findings into what really matters to patients. The Report states that when patients' views really count...

...we can expect universal patient-centred care
...patients will determine the direction of health care
...patients will be fully informed and involved in decisions
...their care will include certain 'always' events
...healthcare organisations will continually seek patient views
...there will be demanding standards for patient engagement
...patients' experience of care will continuously improve
...patients will determine how services are provided

⁵ The Health Communities Collaboratives offer a suitable model, for example - <http://www.unlimitedpotential.org.uk/the-difference-we-make>

⁶ See foot of page at <http://web.me.com/grahambox/SECCG/Resources.html>

7. Shared Decision-Making (SDM)

There is a long tradition of trusting our doctors. Hippocrates observed that “some patients, though conscious that their condition is perilous, recover their health simply through their contentment with the goodness of their physician.” This model, of dominant doctors and passive patients, is typically described as *paternalistic*. It can be contrasted with the *consumerist* approach that emphasises patients’ rights and doctors’ obligations. Lying between these, and often seen as the preferred account, is *mutuality* where decision-making is shared. But this is not without its difficulties as we will see.

What is shared decision-making?

Among the various definitions of SDM, we pick out two that are worth highlighting:

(a) “involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment, and reaching an agreement about which treatment to implement.”⁷

(b) “involving the patient in decision making to the extent that they desire.”⁸

What are informed choices?

The notion of informed choice is of fundamental importance. It involves choices based on relevant knowledge, consistent with the decision-maker’s values and then implemented. All three elements are worth highlighting ie the need for adequate information, the importance of the values that are held by the patient, and the need for choices to be implemented if they are to make a difference.

Telephone research: Messages about SDM

SDM needs to be built into pathway design

Information flows need to support SDM and make use of existing communication channels

Those working within practices tend to believe that SDM is the current mode of practice while patients and community groups have a mixed experience.

Direct patient feedback is needed to assess the prevalence/quality of SDM

Not every patient wants to be actively involved in SDM but we need to avoid stereotyping and assuming that certain groups are not comfortable with SDM (eg some older patients)

The diversity of some practice populations significantly complicates the implementation of SDM

The Expert Patient Programme is a good model from which to learn.

⁷ Charles, C et al (1997) Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango) *Social Science and Medicine* **44** 681-692

⁸ Edwards, A and Alwyn, G (2006) Inside the black box of shared decision-making *Health Expectations* **9** 307-320

The benefits of shared decision-making

Action Learning Set 1: Perspectives on Shared Decision-Making “Happy Bunnies”

Effective SDM is likely to deliver “happier bunnies” ie it will benefit professionals as well as patients through increased compliance, reduced waste, encouraging patients to share information with each other, and more information/support for carers

Information Technology remains a challenge but maternity and child health demonstrate that patients can hold and share their records without problems.

Widespread adoption of shared decision-making only makes sense if it can deliver significant benefits. The systematic review carried out by Crawford et al in 2002 provides support for SDM showing that “higher levels of involvement resulted in better quality of care, increased satisfaction (for both patients and medical staff), and improved self-esteem for patients.”⁹

Further research has looked at specific aspects of SDM. Decision aids, for example, have been shown to improve patients’ participation, increase knowledge of treatment options and probably outcomes, and improve correlation between patients’ values and subsequent treatment decisions. They also show promise in decreasing variations in practice and preventing the over-use or under-use of health care options.

Moreover, SDM now has considerable cultural support. The General Medical Council, for example, has shifted from a focus on “seeking consent” in a 1998 pamphlet to referring in 2008 to the importance of doctors “making decisions together” with patients. Edwards and Elwyn argue that shared decision-making rests on a deep foundation - namely, that it respects the person as a self-governing agent.

Action Learning Set 2: Shared decision-making in other settings

Action Learning Set 2 looked at the elements of a “good” shared decision in non-health settings.

Participants identified the need to value and respect both parties to a decision, recognising the expertise that each brings to the table.

There also has to be an understanding of where power lies, which decisions cannot be shared, and the constraints on sharing decisions (time, money etc).

Finally, the process requires good information to support choices, good listening skills, being able to ask questions, honest negotiation, ability to compromise and good persuasional and influencing skills.

“Given that our society places a high value on the ethical principles of veracity, self-determination and non-coercion, it is hardly surprising that the shared decision-making ethos has taken hold in health care.”¹⁰

⁹ Crawford, M et al (2002) Systematic review of involving patients in the planning and development of health care. *British Medical Journal* **325** 1263-1266

¹⁰ Edwards and Elwyn (2009) Shared Decision-Making in Health Care p401

However, the evidence on the *efficiency* of SDM is rather unclear. There are likely to be increased costs as clinicians spend more time on eliciting patients' preferences and discussing alternative diagnostic and therapeutic options. Cohen, for example, "found that the cost per consultation was £2.89 higher for those who practised shared decision-making."¹¹ Yet, there is also evidence of the benefits of shared decision-making eg in increased adherence to chosen medication, in decreased decision conflict, increases in knowledge. There are also indications that patients, when informed, are more cautious about discretionary invasive or risky procedures.

¹¹ See Cohen et al (2004) Resource effects of training general practitioners in risk communication skills and shared decision making competencies *J Eval Clin Practice* 10 **439-445**. Note that there are two strands of efficiency that need to be considered. *Technical efficiency* involves doing the things right. *Allocative efficiency* involves doing the right things. Health services may be technically efficient, even when they are not providing patients with what they most want ie when they are not allocatively efficient

8. Challenges

“Study after study demonstrates that professionals find it extremely difficult to really involve patients in decisions about their health care (Gravel et al, 2006), even to educate and involve patients with life-long conditions such as diabetes, asthma, or epilepsy, where the pay-back, in theory, could be greatest (O’Connor et al, 2003).” (Edwards and Elwyn, 2006, p402)

SDM is challenging for professionals since every patient has their own preferences about the level of involvement that they wish to have in decisions about their health care.¹² Given time pressures, it is understandable that assumptions are made that may prove incorrect. Equally, as we will see below, effective SDM needs to be properly supported by systems and culture. The role of the clinician would be made considerably easier with ready access to effectively presented and appropriately targeted health information, alongside a broader range of decision aids to enhance decision-making.

Patients, too, have an important role to play to secure the full benefits of shared decision-making. This can be developed through training programmes, such as the Expert Patient model, or similar initiatives. A proliferation of similar terms have been adopted to describe desirable qualities in patients, such as empowered, activated, autonomous, co-producing etc. The “idealized” patient passes through developmental phases: (a) coming to believe that their role is important (b) learning enough and developing enough confidence and knowledge to take action (c) actually taking action to improve their health and (d) staying as healthy as possible.¹³

Through the Action Learning Sets, the telephone interviews and our wider research, we have deepened our understanding of the challenges to implementing a patient engaged organisation. These are summarised below:

- Organisations cannot work effectively in isolation. Failures in joint working frequently lead to failures in meeting patients’ needs. There is also a need to move away from a focus on sharing decisions within individual consultations to considering more effective integration across teams. This needs to look at:
 - team premises
 - team size and composition
 - organisational support
 - team meetings
 - shared goals and objectives
 - information systems
 - audit processes

¹² It is likely that SDM can be more successful in situations of equipoise ie where the clinician does not have a clear preference as to which treatment option should be chosen.

¹³ “The idea of an expert patient is associated with an agenda of patient empowerment in which the use of information and attitudinal attributes are seen as a means of democratization...The challenge for this vision includes the need to capture a broad appeal to those most likely to benefit from adopting the values of being an expert patient. A further challenge is the equivocal evidence that these values will lead to the desired outcomes envisaged by policy makers.” See Rogers, A (2009) “Developing Expert Patients” in Edwards and Elwyn p98/9

- Progress in this broad area is likely to require the creation of an effective network between practices, Southend Estuary CCG and partner organisations. This will:
 - define the work
 - identify the talent
 - engineer exchanges
 - design the experience
 - assemble the technology
- It is clear that IT systems have an important role to play but they are not currently able to support integrated care. Patient concerns about how their data is handled will also have to be addressed.
- A training programme is required for doctors and other health care professionals that teaches procedures for eliciting the patient's knowledge base and reviewing evidence tools, in addition to the current focus on general communication skills.¹⁴
- Patients also need to be educated to interact more effectively with the health and social care system, developing skills such as those that currently feature in the Expert Patient Programme.
- Staff turnover can have a significant negative impact on the development of patient engaged organisations. Not only does it mean that new staff have to be inducted afresh, but it also means the loss of continuity that can be fundamentally important in building new, and different, relationships between users/carers and professionals.
- There is a need to eliminate misinformation and avoid information overload, alongside supporting the process of choice-making so that it is seen as an opportunity rather than an additional burden. In some cases, patients may simply lack the level of health literacy that is required.
- Finally, it is impossible to ignore the issue of sustainable funding. With so many initiatives launched as pilots but never quite reaching the mainstream, there is a real concern that the ongoing commitment to different ways of working (which often represent medium- to long-term investments) will be sacrificed to requirements that are deemed more immediate and more pressing.

¹⁴ Naturally, this process will be supported if shared decision-making has a more prominent place in medical training curricula.

9. Enablers

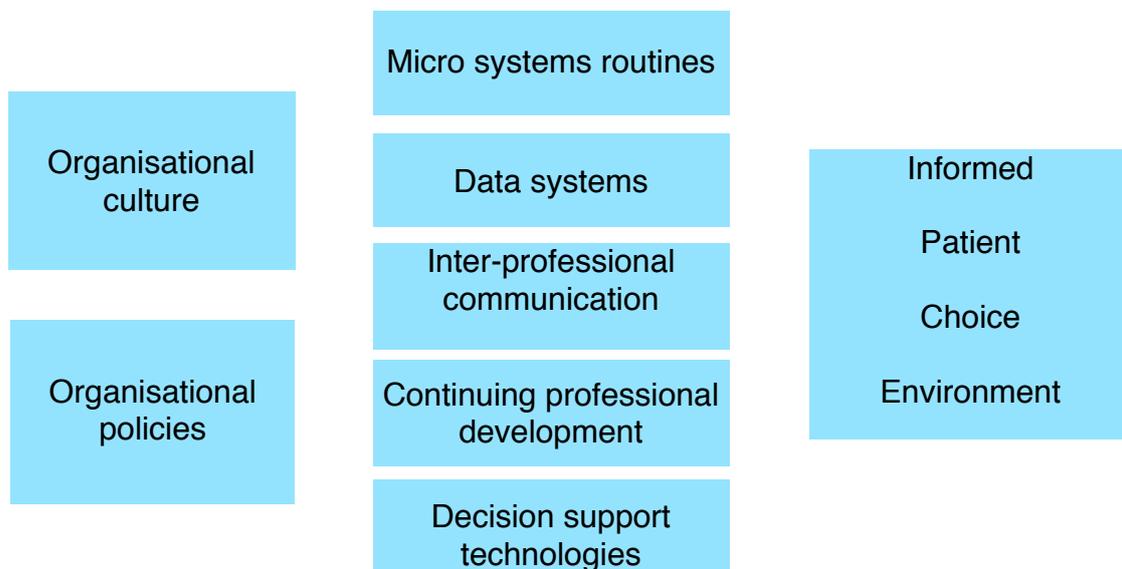
Enabling factors to delivering more patient centred organisations have been identified from different sources. In the first Action Learning Set, delegates identified the following:

- Positive and engaged people
- Effective decision-making processes that can deliver change
- Confidence from all parties in the use of shared data
- Effective communication skills
- Information that patients understand
- Clear menu of choices
- Open-mindedness on all sides

These are similar, but not identical to the key themes identified in the three case studies for the Diabetes Year of Care. In that setting, the key enablers were reported to include:

- High level support and a committed steering group
- Engagement, a shared vision and effective clinical champions
- Dedicated/effective project management
- Financial incentives
- Training

Finally, we can look at the structure identified by Edwards and Elwyn which helpfully identifies the key elements that need to be addressed by a successful patient engaged organisation.¹⁵



¹⁵ Edwards and Elwyn (2009) Sharing Decision-Making in Health Care p404

10. Focus

The scale of the challenge to become fully patient engaged could prompt disparate initiatives that are simply not effective. Change processes need to be carefully planned and paced. So, where should the priorities lie and how should they be identified? Again, we have addressed this issue from different angles.

First, we invited delegates to the action learning sets to identify their own priorities. These were based on the initial briefing documents and the discussions at the initial workshop. Naturally, they reflected the interests and expertise of participants. We feel that they brought a fresh perspective and we further hope that the action learning set model has allowed participants to feel a genuine sense of ownership of the challenges that they identified.

Second, we looked at specific issues that had been raised locally and nationally. With respect to the former, the Essex and Southend Local Involvement Network had produced an important report looking at information provision at the point of diagnosis for long-term conditions. One option would be to build upon that piece of work.

With respect to national initiatives, one could follow Donald Kemper who argues that information therapy should be given greater prominence. He maintains that it has been shown to reduce phone or in-person access to services, it can help to avoid medical errors, it can reduce costs and increase patient loyalty and it can bring kudos to those who deliver it.¹⁶

Action Learning Set 2: Reflections on priorities

Continue to work within the action learning set framework with the addition of dedicated support for ongoing tasks. This would constitute a more bottom up approach.

Find ways to make systematic connections between this project and the wider agenda - ensuring that the objectives are well understood, that they are supported by partner organisations and that effort is streamlined

Build these initiatives into the overarching engagement work that Southend Estuary CCG is undertaking, so that it is all clearly part of the same thing.

Tackle common barriers, such as time and resource constraints, head-on to avoid unrealistic expectations and ultimate disappointment for those whose efforts fail to bear fruit.

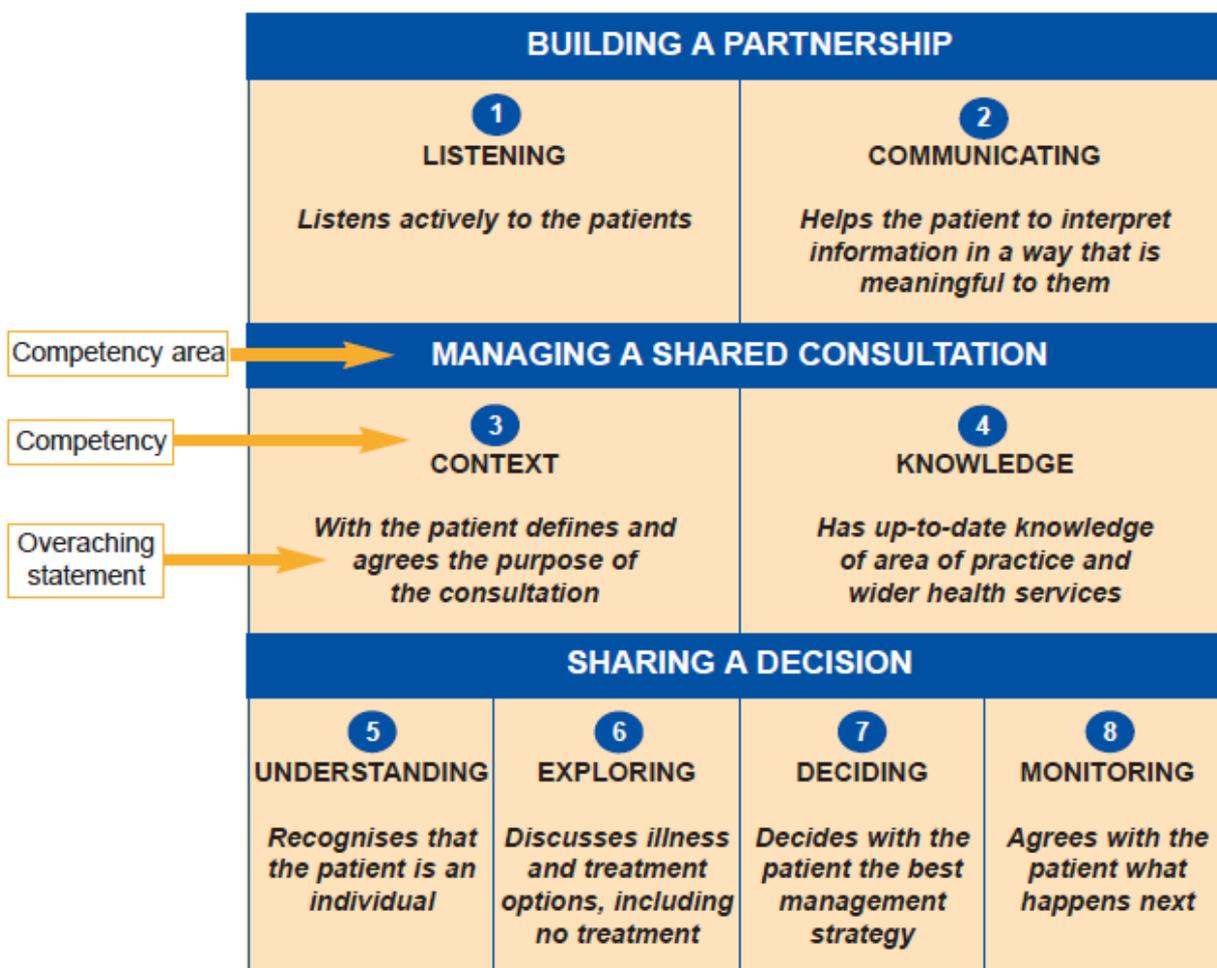
Learn from the action learning set activities to identify broad areas where skills building sessions might be most helpful eg how to develop a good PPG; designing questionnaires; patient information development and dissemination; project planning; building a team (i.e. to undertake a project); time management. These might be considered for the future as part of any project that builds on this one.

Identifying ways to attract clinical input into the engagement work, and to keep everyone informed, even those who are not actively involved. Clinical input is fundamental to meaningful progress in SDM.

¹⁶ <http://www.healthwise.org/Insights/leaders/dkemper.aspx>

Or one might look at the important work that has taken place looking at shared decision making with respect to [medications](#). This reported that 15% of all health expenditure relates to medication and notes that many problems can occur when medicines are poorly understood and when compliance is poor. These are both good reasons to prioritise this issue. Note that the competency framework reproduced below is valuable in all aspects of the clinical consultation and not just with respect to medication issues.

Figure 1: Competency framework for shared decision-making with patients: summary



A third approach based upon national initiatives would be to focus on decision aids. These cover a multitude of pathways and there is a growing bank of internet resources. Should a patient engaged organisation try to address/promote all of these or is a more targeted, measured response preferable (especially given that evidence in some areas is patchy)? A choice could be made to prioritise particular conditions, just as the Year of Care projects initially focused on diabetes (though some considered this a springboard to other long-term conditions).

The examination of each condition could focus on the broad range of issues that were covered in the tender document, such as the use of personal budgets, sharing decisions, use of care plans, information provision, support for self-care, multi-disciplinary team working and so on. This is similar to the approach described by in the Edwards and Elwyn book on Shared Decision-Making in Primary Care (2009) which devotes individual chapters to numerous different areas, namely:

- cardiovascular disease prevention and risk management
- multiple sclerosis
- inflammatory bowel disease
- mental health
- menorrhagia
- diabetes
- breast cancer decision-making
- aneurysms in the abdominal aorta
- prostate decision-making and PSA
- mammography screening
- colorectal cancer screening
- MMR vaccination
- clinical genetics

Finally, it is striking from our reading of the literature that the carer perspective is often overlooked in shared decision-making. Southend Estuary CCG and its practices could work with partner organisations to address this.

Whichever approach is taken, it will be important to build the strongest possible case for change, in order to motivate and support implementation. This could, in itself, constitute a selection criterion, leading to an initial focus on those interventions and practices for which the evidence is strongest.

Telephone research: When people talk about good practice of SDM, they mention:

- *My doctor shows me the screen of test results and we look at them together.*
- *We talk with patients about the right approach to smoking cessation, asthma devices, medications etc that works for them. In the end, compliance is better when they are involved.*
- *Patients involved in building the musculo-skeletal pathway helped us include information such as what to wear, when there is a physical exam and the need to include podiatry in the pathway because walking and back pain are related. Patients co-developed and conducted a survey to help make decisions about the pathway.*
- *Instead of deciding that patients need to be placed in residential care, GPs are now referring patients to access teams where there is more consultation with patients and families. Many of these patients are then able to stay home with some support, as they prefer.*

11. Structuring the options

Our recommendations are set out towards the beginning of this document. They have been developed from our review of the literature, from the telephone interviews that were carried out, from the three action learning sets and from our discussions with senior managers and clinicians at Southend Estuary CCG.

We are very conscious of the extreme financial pressures currently within the NHS and we hope that the recommendations will be seen as realistic and pragmatic. At the same time, we hope that the project will serve as a catalyst to greater engagement between Southend Estuary CCG, its practices and the users/carers for whom they provide care and support.

Given the scale of the challenges to deliver a genuinely patient engaged organisation (many of which are identified above), it is important that effort and resources are targeted where they deliver most benefit. We recommend that this challenge is addressed within a patient-engaged organisation strategy for Southend Estuary CCG.

This strategy would commit to a vision whereby patient engagement runs through the organisation like a message through a stick of rock. It can be built into communication messages, woven into health promotion campaigns and strengthen bonds between organisations (especially the third sector). It should be rooted in, and driven by, the experiences of users and carers who rely upon health and social care services.

The next paragraphs contribute further reflections about the options that need to be considered by that strategy. They represent different ways in which the required activity might be organised or sub-divided. We do not believe that the options are mutually exclusive. Instead, they can be combined in multiple ways. We hope that they add depth and context to the recommendations and allow Southend Estuary CCG to develop its own priorities, using their in-depth knowledge of the local challenges and opportunities.

Option One: Investing in specific strands of patient engagement

The tender document for this project made clear its interest in a range of activities that can all be classified under the umbrella of a patient engaged organisation. These include:

- Shared decision-making in the clinical encounter
- Information provision and information therapy
- Effective use of care planning processes
- Delivery of individual budgets
- More, and more meaningful, choice for patients
- Uptake of self-care courses
- Support for carers and working with partners (which we have added)

Southend Estuary CCG and its practices could choose to focus on one or more of these and commit to delivering best practice in the chosen areas. For example, the focus in year one could be on promoting and increasing the uptake of self-care courses.

Option Two: Investing in specific clinical pathways

Rigorous delivery of patient-centred services is not easy. Change can be costly and it may not be realistic to address several care pathways at once. For example, the diabetes Year of Care pilot sites were each granted an initial start-up fund of £98,000 and additional resources were used to incentivise and support GP surgeries to change their working practices and consultation methods.

There are many different pathways that could be chosen (see section above on priorities) and it makes sense for Southend Estuary CCG GPCC and its practices to focus on building patient engagement into each of their future service redesign projects. Aspects such as medicines management cut across pathways but could also be prioritised.

Option Three: Systematic building of the necessary infrastructure

A third option is to work systematically through the organisational enablers that were identified by Edwards and Elwyn (see above). In their view, in order to provide an “informed patient choice environment” Southend Estuary CCG and practices need to deliver improvements to their:

- Organisational culture and policies
- Micro systems routines
- Data systems
- Inter-professional communication
- Continuing professional development
- Decision support technologies

Failure to address these headings in a systematic way may lead to sub-optimal delivery. In the Year of Care sites, for example, it was acknowledged that shortcomings in the IT systems meant that identified gaps and unmet needs from the care planning processes were not able to inform future commissioning decisions directly.

Option Four: Bottom-up approach

A fourth option would resist the temptation to design a detailed plan centrally. Instead, it would seek to motivate and support numerous task groups, each of which would be working to deliver change in their areas of interest and expertise. In similar fashion to the action learning set model, this would allow users, carers and professionals to come together to identify and deliver improvements. At the same time, they would clarify the blockages and the resources required to succeed.

Wherever possible, they would lead the process and Southend Estuary CCG would only step in as a problem solver and to provide financial and other forms of support where these are required. In essence, Southend Estuary CCG would give the community license to identify its own priorities and present solutions and ideas for the Board’s consideration. The Patient and Public Reference Group of the CCG would be well-placed to lead that process which, if successful, would move away from the default position of the community having to be reactive rather than proactive in improving health and health care.

12. Conclusions

Given the scale of the investment nationally in promoting patient engagement over the past decade, this has been a small-scale project. Nonetheless, we hope that it will provide valuable intelligence and insight to guide the development of Southend Estuary CCG as it moves towards becoming a statutory organisation. At the same time, we recognise that clinical commissioning remains at a very early stage of development and that it would be a mistake to expect too much, too early.

The timescale for completion of the project has inevitably meant that the engagement to date has not been as deep as one would like. Our ambition throughout has been to produce a report and a set of recommendations that will support sustainable and worthwhile changes. If we have succeeded, the credit should go primarily to the members of the action learning set who set themselves significant challenges to deliver real improvements from which we could all learn.

The rest of this report pulls together some of the notes and additional information that have been produced over the past three months. These include the report on the telephone research and some of the key research document summaries that were hosted on the project website.

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Telephone research: When people talk about poor practice of SDM, they mention:

- *Clinicians who assume that people who are older, have dementia, deteriorating conditions, etc are not interested or capable of sharing in the decisions about their diagnosis/treatment. This is compounded when people have been hospitalised or institutionalised and are consequently de-skilled. They need support to become more involved in SDM.*
- *GPs giving prescriptions to people without discussing the drug or side effects well. This results in people not taking the medication as prescribed.*
- *Inadequate information provided by surgeries about available support services, the Expert Patient Programme, financial assistance, etc which hampers people from making good decisions about how to manage their conditions.*
- *Patients receive written information about their condition from the surgeries and no one reviews or explains it. Patients do not feel they can participate in making good decisions if there is no one to answer their questions. Timing is also an issue as people often need these questions answered before their next visit.*
- *Clinicians who fail to involve carers, or to consider the carer perspective, in their decision-making*

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Michelle Hill	Group Manager	Southend on Sea Borough Council
Beryl Furr	Non Exec Director	NHS South East Essex

We are equally grateful to those who took part in the telephone interviews. These were undertaken on the basis of anonymity and so their names are not recorded here. Our thanks are sincere nonetheless.

14. Useful Resources

The following reports are included in the project website that can be found at <http://web.me.com/grahambox/SECCG/Home.html>

Report on the information given at the Point of Diagnosis of Long Term Conditions

[This study](#), carried out by Essex and Southend Local Involvement Network, looked at the information that was provided to people at the time that they were diagnosed with a long-term condition. It concluded that more information, and more signposting, are both crucial and that a database of national and local organisations for different types of condition should be readily accessible.

http://web.me.com/grahambox/SECCG/Resources_files/Point%20of%20diagnosis%20report.pdf

Shared decision-making in primary care: the neglected second half of the consultation

In [this article](#), Elwyn and colleagues identify shortcomings in processes of involving patients in the decision-making process with respect to the treatment and management of their condition. They indicate that future progress requires more time available within consultations, improved ways of communicating risk to patients, and an acquisition of new communication skills. (British Journal of General Practice (1999) 49, 477-482)

Implementing shared decision-making in the UK

This is a "[scoping paper](#)", prepared as part of a major study that is currently being undertaken by the Health Foundation. The publication looks at patient decision aids and initiatives from across the world. It also considers obstacles to shared decision-making and facilitators that make it more likely. Finally, it considers challenges for implementation.

<http://www.health.org.uk/publications/implementing-shared-decision-making-in-the-uk/>

How engaged are people in their health care?

This is an important piece of [research](#) carried out at the end of 2005. Based on a national telephone survey, it found that four in ten people are not regularly taking action to manage and maintain their health. The study used a Patient Activation Measure to understand how engaged respondents were in their own health.

http://www.pickereurope.org/Filestore/PIE_reports/project_reports/Patient-Activation-Survey.pdf

Evaluating a training package for self care support

This [article](#) describes research with two GP surgeries in Oldham who received training on WISE (Whole Systems Informing Self Management Education). There are some important messages about the importance of teamwork, improving communication and raising the profile of self care support so that it is seen as an integral part of the work of the practice.

<http://www.implementationscience.com/content/pdf/1748-5908-5-7.pdf>

Commissioning services appropriately

The [Year of Care programme for diabetes](#) aimed to ensure that decision making between clinicians and patients becomes truly collaborative. They recognised that the services that patients value may not always be available and so they also produced a [guide](#) to commissioning support and care from non-traditional providers. One further resource is the [case study document](#) for the three Year of Care pilot sites.

<http://www.diabetes.org.uk/Professionals/Service-improvement/Year-of-Care/>

A competency framework for shared decision-making with patients

This [competency framework](#) recognises that prescribed medicine is the most common form of medical intervention and accounts for almost 15% of all health expenditure. It is therefore vital to ensure that people take their medicine as prescribed. The framework offers a clear structure to improve shared decision-making with patients, looking at listening, communicating, context, knowledge, understanding, exploring, deciding and monitoring.

http://web.me.com/grahambox/SECCG/Resources_files/shared%20decision%20making%20and%20medicines.pdf

When patients' views really count

The [2008/9 Annual Report](#) from Picker Europe included a powerful summary of their research findings into what really matters to patients. In their judgment, when patients' views really count...

- ...we can expect universal patient-centred care
- ...patients will determine the direction of health care
- ...patients will be fully informed and involved in decisions
- ...their care will include certain 'always' events
- ...healthcare organisations will continually seek patient views
- ...there will be demanding standards for patient engagement
- ...patients' experience of care will continuously improve
- ...patients will determine how services are provided

http://web.me.com/grahambox/SECCG/Resources_files/Annual_review_08-09_FINAL.pdf

Other useful websites

<http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/>

http://www.eoe.nhs.uk/page.php?page_id=542

http://www.healthtalkonline.org/Improving_health_care/shared_decision_making

www.npsf.org/askme3

www.informedhealthonline.org

<http://www.in-control.org.uk/what-we-do/staying-in-control-health.aspx>

Appendix: Report on Telephone Research

Southend Estuary CCG GPCC Shared Decision Making in Primary Care Background Interview Report

During April and May 2011, InHealth Associates conducted 14 telephone interviews to understand better how shared decision making (SDM) is currently experienced in primary care between clinicians and patients/carers and what could support the expansion of this practice. These interviews provided different perspectives and helped us identify issues that could be explored by the Learning Sets and other involved groups to support the spread of SDM and wider patient engagement.

Those interviewed included patients and patient reps/advocates, people involved in community based services and social work, surgery based GPs, nurses and practice managers, PCT staff and researchers. As there were few of them and anonymity was promised, their names are not included in the report and they were thanked directly by the researcher, Henie Lustgarten. Note that the report refers to Southend Estuary CCG although Fortis GPCC was the preferred name at the time of the interviews.

The discussions focused on:

- Experience of shared decision-making between clinicians and patients/carers over time
- Areas for improvement
- How commissioning could support this approach
- Ways forward

Highlights of findings and potential next steps follow.

- ***Some people define SDM more broadly, encompassing all clinical, social, and process issues***
- ***There is a mixed picture about how well SDM is practiced in GP surgeries***
- ***Some processes and tools require a SDM approach***
- ***The practice of SDM has changed over time***
- ***There are some key obstacles to SDM***
- ***Tools are available to support SDM***
- ***SDM may be supported through the commissioning function—in both what and how services are commissioned***
- ***Spreading SDM requires a strategy***

Some people define SDM more broadly, encompassing all clinical, social, and process issues

- For everyone, SDM means that patients and carers are given the opportunity to express their values and preferences and to participate in decisions about their care including the diagnosis, treatment, medications and referrals. This implies clear communication and understanding of the diagnosis, treatment plan, medications, etc among the clinicians, patients, carers, etc.

- Some also added a SDM aspect to the entire primary care visit experience. For example, the decision about whether a same day/emergency visit was required and whether information about the approximate waiting time in the surgery was shared are part of a SDM environment.
 - Patients and carers need a fuller clinical picture in order to participate in a meaningful decision. They also want the SDM approach used in other healthcare settings such as hospitals. There was a sense that SDM only works when clinical information and decisions are consistent and honoured across the health service.
 - The need to widen the clinical focus of the visit to encompass social and lifestyle issues is part of the SDM experience for some patients because clinical decisions cannot be made without this context.
 - Some included patient involvement in non direct care such as pathway design as part of the SDM process as 1-the actual pathway could have a SDM element and 2-the process of patients working with clinicians successfully fosters a partnership environment. Patient participation groups working on premises design also foster this partnership experience.
- ⇒ The Southend Estuary CCG practices need to work with their patients to agree the goals and spheres in which SDM is practiced. Depending on the response, information flows and activities need to be defined and addressed.

There is a mixed picture about how well SDM is practiced in GP surgeries

- Those working within the surgeries are confident that health care professionals (HCPs) use SDM as their preferred mode of practice. Patients and community groups have more mixed experiences as some find this true and others find that clinicians do not share adequate information and do not work together with them to agree diagnoses, treatment, ongoing support or changes to conditions.
- ⇒ Direct patient feedback is needed to assess the prevalence and quality of SDM.

SDM may not be suitable for every patient

- Some patients, especially those who are frail, have dementia, and/or have other conditions that hamper cognitive ability may not be willing or able to participate in this process. However, many may participate when HCPs are skilled at working with these populations. There is also a question of whether expectations by HCPs that older patients are not comfortable with SDM is a self-fulfilling prophecy.
- ⇒ Part of the process needs to include assessing the patient's readiness to engage in SDM and ongoing support to reach the optimum level for each person.

SDM may be uncomfortable for some HCPs

- Different people had a sense that some older GPs are uncomfortable using SDM.
 - Some interviewees sense that the 'line' of decision-making for clinical issues eg what medications to take, best treatment etc cannot be truly shared with patients who are not medically trained.
 - There is a perception that some GPs are not comfortable with SDM because it diminishes their role and power.
- ⇒ Incorporate SDM training in Time to Learn and peer review for GPs.
- ⇒ Link communication skills and SDM to good clinical skills; diagnoses and treatment require accurate patient information and understanding.

Some processes and tools require a SDM approach

- Personal Health Plans, Special Care reviews, Choose and Book, etc are examples of practices that empower patients to be fully involved in decision-making.
- ⇒ Incorporate SDM as part of this spectrum of services.

The practice of SDM has changed over time

- Most agree that 'nothing about me without me' and a shift to patient as consumer are strong government messages, although some patients are not experiencing it in practice. The NHS Constitution and voluntary sector/charity websites were specifically mentioned as helpful to SDM.
 - HCP training has fostered the skills and expectations required by SDM.
 - Most agree that positive experience with SDM for patients and HCPs over time has changed individual practice. This is true for individual GP-patient consultations as well as public and patient engagement (PPE) in general.
 - Scandals in general and in the NHS (Alder Hey, etc) have added to the culture of questioning HCPs and demanding SDM.
- ⇒ SDM needs to be supported in the context of the health service and society in general. It is not a fad.

There are some key obstacles to SDM

- The changing population requires new language skills and cultural awareness by GP surgeries to practice SDM effectively. Some practices may not be skilled at working with people from other countries, single parents or newly deprived communities.
 - Some HCPs assume that SDM is a good idea but unworkable because it takes extra time and is not compensated.
 - Some assume that single handed practices are less prone to use this approach.
 - Past negative experiences by patients and HCPs hamper uptake.
 - Some feel that SDM has been a tickbox exercise.
 - It is difficult to gauge whether SDM is used. Sometimes patients say they were not consulted about care when they were.
- ➔ These all need to be addressed by the strategy and commissioning as discussed below.

Tools are available to support SDM

- Long term care (LTC) patient registers help to identify patients who will benefit most from SDM. Practices could also be using their carers' register to identify patients who are carers and those who are 'cared for'. Accommodating both perspectives will improve the quality of shared decision-making.
- Expert Patient Programme (EPP) and voluntary sector support groups help patients to become more empowered to demand and participate in SDM. Carers' champions at each practice should help carers.
- Self help materials that are designed to support the SDM process are provided to patients in surgeries, but many patients and advocates do not find them helpful to this process.
- Intelligence from the Southend Association of Voluntary Services (SAVS), Well Being Forum, 3rd sector, LINKs, Patient Participation Groups (PPGs) etc can be used to support SDM. Do not lose the PCT's experience in this area and reinvent the wheel.

- ⇒ Link patients to local/national support services with current information/signposting.
- ⇒ Use existing communications opportunities such as surveys, TVs in waiting rooms, etc to support SDM.

SDM may be supported through the commissioning function—in both what and how services are commissioned

- Commissioning was viewed as key to supporting SDM through payments and requirements. Others view SDM as a cultural change that will take more than resources to achieve.
- Commissioning can include services and signposts for patients to be empowered to use SDM at various levels.
- Commissioners may require literature that is more personalised to patients.
- Some saw roles for patients and the 3rd sector in various stages of the commissioning process.
- There were caveats about how patients should be involved in financial decisions.
- ⇒ Commissioners may require that HCPs take SDM courses and refreshers. This includes training in multi-cultural communication.
- ⇒ Use the PPGs to help explore how patients should be involved in commissioning.
- ⇒ Commissioning may expand SDM by requiring more specialists and consultants to be proficient in SDM. Referral patterns may be influenced by this proficiency.
- ⇒ Commission pathways that require SDM and incorporate periodic reviews to ensure it is being used.
- ⇒ Commission a shared resource centre.
- ⇒ Commission feedback by patients about how well SDM is used.
- ⇒ Use the Quality and Outcomes Framework (QOF), Locally Enhanced Service agreements (LES) and other mechanisms to provide incentives to use SDM.
- ⇒ Commission ongoing information gathering of evidence of SDM outcomes, including costs and benefits.

Spreading SDM requires a strategy

- People with long term conditions who come to the practice on an ongoing basis are most suited to the SDM approach because the rapport with HCPs that is necessary for SDM is not attainable in one or very occasional visits. Staff who work with those patients, eg diabetes or asthma nurses, may be applying this approach most often. Spread may start there.
- There is a strong sense that SDM requires more consultation time and costly training. Evidence that links SDM to improved patient and HCP experience, reduced costs and referrals, and improved health outcomes is needed to persuade people to invest in this practice.
- There is little appetite for additional SDM websites and special programs.
- ⇒ HCP training includes communication and SDM skills. Those without these skills need training and others may need periodic refreshers. HCPs and patients can be involved in training for, and spreading, these skills.
- ⇒ Incorporate SDM messages, activities, evidence and skills building into existing websites, EMIS programmes, consultation processes,
- ⇒ Weave SDM into health promotion campaigns.
- ⇒ Anticipate the health care needs of the population in this time of austerity and the changes in the 3rd sector and explain how SDM may be more important.

- ⇒ Southend Estuary CCG can knit various strands of work together and link with empowering organisations and initiatives such as the 360 Health Promotion Team
- ⇒ The positive reputation of Southend Estuary CCG in the community will help them take a leadership role for SDM.

When people talk about good practice of SDM, they mention

- My doctor shows me the screen of test results and we look at them together.
- We talk with patients about the right approach to smoking cessation, asthma devices, medications etc that works for them. In the end, compliance is better when they are involved.
- Patients involved in building the musculo-skeletal pathway helped us include information they need such as what clothes to wear, when there is a physical exam and the need to include podiatry in the pathway because walking and back pain are related. Patients co-developed and conducted a survey to help make decisions about the pathway.
- Instead of deciding that patients need to be placed in residential care, GPs are now referring patients to access teams where there is more consultation with patients and families. Many of these patients are then able to stay home with some support, as they prefer.
- HCPs are now dealing with patients who come with more information from the internet and other sources. They are empowered and SDM is practiced. This builds trust, a sense of shared responsibility and confidence. Sometimes this is a problem because the internet has some poor sources of information as well.

When people talk about poor practice of SDM, they mention

- Clinicians who assume that people who are older, have dementia, deteriorating conditions, etc are not interested or capable of sharing in the decisions about their diagnosis treatment. This is compounded when people have been hospitalised or institutionalised and are consequently de-skilled. They need support to become more involved in SDM.
- GPs giving prescriptions to people without discussing the drug or side effects well. This results in people not taking the medication as prescribed.
- Inadequate information provided by surgeries about available support services, the Expert Patient Programme, financial assistance, etc which hampers people from making good decisions about how to manage their conditions.
- Patients receive written information about their condition from the surgeries and no one reviews or explains it. Patients do not feel they can participate in making good decisions if there is no one to answer their questions. Timing is also an issue as people often need these questions answered before their next visit.
- Clinicians who fail to involve carers, or to consider the carer perspective, in their decision-making