Shared Decision-Making

**A PATHFINDER PROJECT FOR
NHS EAST MIDLANDS**

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Picker Institute Europe

Picker Institute Europe is a not-for-profit organisation that makes patients' views count in healthcare. We:

- build and use evidence to champion the best possible patient-centred care
- work with patients, professionals and policy makers to strive continuously for the highest standards of patient experience.

CONTENTS

Acknowledgements

Executive Summary

In March 2012, NHS East Midlands commissioned Picker Institute Europe to design and deliver a shared decision-making project. Funded by the Department of Health's Pathfinder allocation to the Strategic Health Authority, the work aimed to:

- build on and contribute to the evidence base for understanding and supporting shared decision-making;
- develop recommendations for advancing shared decision-making within local health services.

Key themes were identified and explored in-depth in a series of focus groups with young people, parents and carers, and through individual interviews, a discussion group and a hands-on workshop with health professionals. This report describes these themes and the recommendations derived from all elements of the project.

What is shared decision-making?

Understandings of what constitutes shared decision-making differed markedly. Participants variously saw shared decision-making as being part of, and relevant to:

- individual consultations with patients;
- care planning with patients, service users, carers and families;
- service coordination and the design of care pathways;
- multi-disciplinary and multi-agency working;
- service design and re-design;
- NHS system design and development.

Allied health professionals and others providing community-based services were more likely to take the 'broader' view of shared decision-making. General practitioners' views tended to focus more specifically on the individual consultation where, within the consultation model, the concepts of shared decision-making and informed consent overlap and, for some doctors, seem quite similar.

Participants in the focus groups and interviews shared a belief that not all patients would want to share in decisions or expect to be involved in decision-making about their health and healthcare. Health professional participants, some speaking from personal experience of, for example, end of life care, also agreed that there were particular circumstances where otherwise 'involved' patients might prefer to be less involved, and where some might not wish to share decision-making at all.

A major concern for health professionals was that shared decision-making might create a tension between patient expectations and NHS resource realities – would patients be asking for treatments that the NHS could not provide? A similar tension lay between the desire for clinicians to follow a 'gold standard' of good clinical practice and the need to take patients' lifestyle needs, values and preferences into account – which might mean embarking on a course of treatment (or non-treatment) that professionals would, objectively, perceive as a 'bad' decision.

A further complication lay in allocating responsibility for the outcomes of decisions that are being shared – who is ultimately accountable for a decision that may have less than optimal, or even adverse, health effects and outcomes?

Views of local service users

Young people attending the focus groups typically reported feeling excluded from discussions and decisions about their health, describing, for example, how some doctors spoke only to their parents during consultations. They also felt that doctors were too focused on the 'sex, drugs and rock and roll' aspects of teenage health; they would prefer clinicians to focus on discussing the health concerns for which they had sought medical advice. This has implications for the 'make every contact count' approach, whereby clinicians are encouraged to deliver brief policy-led interventions at every opportunity; there is a clear risk of unintended negative impacts on young people's experiences of healthcare where questions and offers of advice are not directly relevant to their reason for attending.

Parents of children and young people with paediatric diabetes were invited to participate in the project via an established group that has a good relationship with local services. Their expertise, experiences and views are not, therefore, necessarily entirely representative. In the focus group, the parents reported that care at diagnosis was excellent. Some described very positive experiences of shared decision-making, and all stressed the excellent care, support and service that specialist diabetes nurses provided for their children and for themselves. They also, however, emphasised that children's and parents' needs change significantly over time, and that available resources and support services do not necessarily mirror or keep up with these developments. Finally, all reported that peer support from other parents and families had been invaluable as they had navigated their children and teenagers through their condition and their care.

Parents and carers of children with disabilities and special needs were also invited to participate in the project via an established group. This focus group reported much less positive experiences. Their view was that, in the main, general practitioners were dismissive to their concerns about their children, to the extent of obstructing access to specialist paediatric services and the benefits of early intervention. They described 'a battle' to achieve a diagnosis in order to access a care pathway, only then to realise that the care pathway did not in fact exist. They did report better experiences when they were in contact with a community care coordinator who was able to talk them through, and

help them to access, available resources, services and support systems. Particular difficulties were noted for children who had no clear diagnosis, or who had developmental disabilities.

Shared Decision-Making in East Midlands

Participants' views regarding the *status-quo* of shared decision-making across NHS East Midlands highlight pockets of excellence, particularly in mental health and learning disabilities teams. The overall sense, however, was that shared decision-making is not pervasive. The Learning Disabilities Teams had particular concerns over the sustainability of their local education and training model, whereby (in addition to their own caseload) they facilitate shared decision-making with and by the many other health and social care professionals with whom their patients and service users interact.

Shared decision-making does appear to be taking hold where health professionals are working as multi-professional and multi-disciplinary teams. In understanding and valuing each team member's skills and expertise, professionals also become more aware of available services and better understand what they can offer. Further, including patients and carers in the decision-making process was seen as a lesser and less threatening cultural change where decisions were already being shared amongst professionals; patient and carer involvement tended to develop more organically. Newly qualified clinicians had more multi-disciplinary working experience within their training than those who trained some years ago, and they seemed to be more attuned to the potential for shared decision-making on a wider scale, for example in service re-design and commissioning. There was no consensus regarding whether or not current general practitioner consultation models provided for shared decision-making.

Impact of changes in the NHS

Changes happening and coming to the NHS were considered to have both positive and negative potential effects with regard to achieving 'shared decision-making as the norm'. The step-change in commissioning structures and models might facilitate some of the changes needed to implement shared decision-making more widely and more consistently. They might also allow local Clinical Commissioning Groups (CCGs) effectively to use and build on the East Midlands Primary Care Trusts' strong legacy of patient and public involvement. Patient and lay member representation on CCGs was also viewed positively; participants did however raise concerns about whether, as commissioners, clinicians would nonetheless base decisions on medical models, thereby placing less emphasis on 'softer' elements of care. The shift to Any Qualified Provider was regarded as potentially disruptive for shared decision-making and for information sharing between services. With the overriding need to deliver on financial and clinical targets, and given the existing and foreseeable resource constraints, services have little flexibility and innovation is severely constrained; this has implications for their capacity

to do and develop shared decision-making, particularly with patient and service user groups with intellectual and/or cognitive impairments.

Recommendations

Taking all the project elements together, five key priorities emerged for driving and developing shared decision-making in the East Midlands. These are:

- **Communicating and operationalising shared decision-making and the 'patient revolution'**

  o defining and communicating what shared decision-making is, and clearly setting out what it means (and does not mean), in practice, for health professionals, commissioners, patients and service users, carers and the public;
  o clarifying the East Midlands' strategic vision, communicating what is expected of staff and services, and providing unambiguous operational direction;
  o making and communicating the connections: helping staff to see and understand the relationships between shared decision-making, the 'patient revolution' and all other relevant extant documents and initiatives, rights and responsibility frameworks, policy drivers, outcomes and performance frameworks, metrics and so forth; in particular, to avoid presenting shared decision-making as 'something extra' that people need to do on top of everything else.

- **Securing senior- and very senior-level direction, leadership and support**

  o visible high-level interest, engagement and constructive operational oversight;
  o practical and tangible support to enable staff and services to deliver;
  o demanding and driving the necessary cultural shifts;
  o setting out clear expectations of what health service staff, including commissioners, should be doing to deliver shared decision-making and the relevant elements of the 'patient revolution', and describing how progress will be measured;
  o building the shared decision-making and 'patient revolution' ambitions into organisational and service-level values, systems and processes, performance incentives and reward and recognition schemes, and commissioning impact assessments;
  o identifying and addressing the resource implications of shared decision-making and the 'patient revolution' for front-line staff – especially the implications for the way staff and services use their time, and the need for

information, education and skills training to support staff in engaging patients (including harder to reach/seldom heard individuals, groups and communities) in service evaluation and re-design.

- **Developing multi-disciplinary and multi-agency models of working – including "IT systems that actually talk to each other"**

  Addressing the gaps and inconsistencies with regard to:

  o who knows about and is on board with shared decision-making as an approach to care, and who needs to be more/better informed and engaged among:
    o NHS staff and services, including CCGs;
    o other public sector service providers including social services;
    o emerging bodies and networks, including Health and Wellbeing Boards and HealthWatch.
    o voluntary sector organisations;
  o who is 'on' record-keeping and information-sharing frameworks and networks, who needs to be, and how otherwise professionals can access the information that they need and have the right to access;
  o which individuals (including patients, service users and carers) and which services and teams can and could see which sets and items of information.

- **Preparing and equipping patients and the public for shared decision-making**

  o raising awareness of shared decision-making and the 'patient revolution' outside the NHS, with:
    o patients and service users, including people living with long-term conditions;
    o carers and families;
    o the general public, including minority groups and communities;
  o identifying professionals' information needs for shared decision-making, i.e. determining which information materials and resources professionals most need in order to share decisions and to support patients, services users and carers in understanding conditions and sharing decisions about care and treatment;
  o establishing and/or signposting directories of reliable, up-to-date and quality assured information resources for professionals, patients, service users and carers, including information about local services and sources of support;
  o providing access to tools and toolkits and, especially, face-to-face development opportunities for staff to meet, network and share ideas and

good practice with regard to shared decision-making and the 'patient revolution'.

- **Showing that shared decision-making works**

    o communicating the 'theoretical' benefits of shared decision-making, according to the evidence-base – why it is important, why participate in it, why it is cost- and time-effective;
    o providing locally specific feedback to staff, patients and public about changes that have been made as a consequence of shared decision-making in clinical care and commissioning, and the effect that they have had on service quality and efficiency.

1. Introduction

1.1   NHS East Midlands

NHS East Midlands was formally established as a Strategic Health Authority (SHA) in July 2006, replacing the former Leicestershire, Northamptonshire and Rutland SHA and Trent SHA.

While the NHS undergoes structural changes, the SHAs remain guardians of the NHS until their abolition in April 2013. Their role is to relay and explain national policy, set direction and support and develop all NHS Trust bodies (Primary Care Trusts and NHS Trusts providing acute, mental health and ambulance services) within their area.

NHS East Midlands ensures that local health systems operate effectively and efficiently for a population of 4.3 million people, securing better services for patients and value for money from the £26bn spent on health and health care across the region. This includes making certain that national standards and priorities are met so that the population of the East Midlands is cared for in high quality, safe environments and that services are continuously improved and developed. Improving health and reducing inequalities remain high priorities.

The East Midlands has nine Primary Care Trusts (PCTs), which have been brought together into five Clusters. The PCT Clusters are the leaders of the local health communities, and are responsible for commissioning health and healthcare services for their local population. These organisations hold their community's share of the regional NHS budget of £6bn. They serve a range of rural, inner city and urban populations.

NHS East Midlands has a published vision for delivering better health and better care based on what patients, staff and the public have told them is important. They have identified seven promises which they believe everyone wants to see from their health service:

- safer services;
- a better patient experience;
- more clinically effective services;
- improved health and reduced inequalities;
- more accessible services;
- better value for money;
- real influence for patients and the public.

NHS Midlands and East Cluster 'patient revolution'

Pursuant to implementation of the Health and Social Care Act 2012, NHS East Midlands is now part of the NHS Midlands and East SHA Cluster, along with NHS West Midlands and NHS East of England.

The Midlands and East Cluster board and the PCT Cluster chief executives have agreed five 'ambitions' to make a difference to patients during 2012/13. These are to:

- eliminate avoidable grade 2, 3 and 4 pressure ulcers;
- significantly improve quality and safety in primary care;
- create a revolution in patient and customer experience;
- make every contact count using every opportunity to deliver brief advice to improve health and wellbeing;
- ensure radically strengthened partnerships between the NHS and local government.

Of these, the ambition of 'creating a patient and customer services revolution' is most directly relevant to shared decision-making. Within this ambition, the Midlands and East Cluster describes three distinct areas of work:

- creating a customer services culture, exploring how we use the experiences of our patients to improve services through programmes such as patient stories, mystery shoppers and much more;
- strengthening community and citizen participation, looking at how the patient and public voice is played into decisions about the shape of services, the quality of NHS services and ultimately, with partners, in holding the NHS to account;
- the area of clinical and patient experience includes empowering patients to be in control of their own care, including shared decision-making and the use of technology to personalise care.[1]

1.2 The shared decision-making Pathfinder projects

The Government's July 2010 white paper *Equity and Excellence: Liberating the NHS* describes a commitment to putting individual patients at the centre of making decisions about their own health; giving people more information, more choice and more control over how their care is delivered. In policy terms, the White Paper requires the NHS to improve patient involvement, support self care and work towards 'no decision about me without me' in the interest of better outcomes for patients and better use of NHS resources.

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[1] http://www.midlandsandeast.nhs.uk/OurAmbitions/Patientrevolution.aspx last accessed 16 August 2012

In November 2010 the Department of Health put forward a proposal, through its Patient and Public Engagement and Experience Division, for SHA-led Pathfinder projects to explore NHS staff perspectives with regard to shared decision-making and the information-giving that will be necessary to support patient involvement in decisions about health and health care.

The premise is that delivering the potential benefits of 'no decision about me without me' requires health professionals and services to engage with shared decision-making and adopt it as the normative approach to service delivery. This includes being prepared to provide more and better quality information and being willing and able to support patients (and their families/carers, where appropriate) in sharing decisions.

Achieving the necessary step-change in (for example) people's expectations, attitudes and behaviours means first engaging with key stakeholders to identify, explore and understand their perspectives on shared decision-making. In particular, it means discerning:

- what shared decision-making means – and what it doesn't;
- the basis for people's enthusiasm for/resistance to shared decision-making and the implications of these for embedding shared decision-making in day-to-day practice;
- how people find, provide and use information within shared decision-making, and how any barriers might be overcome.

1.3   NHS East Midlands shared decision-making Pathfinder project

The East Midlands SHA's focus for its work within the shared decision-making Pathfinder programme is '*building support for shared decision-making and information giving through focused engagement and for example, the appointment of clinical champions'*.

In order to build this support, the SHA issued an invitation to tender for an external organisation to design and deliver '*focused engagement through a series of focus groups with key stakeholders across the clinical, patient and public landscape in the East Midlands'*.

NHS East Midlands commissioned Picker Institute Europe to lead this engagement process. Our brief was to focus specifically on the barriers to shared decision-making, i.e. what might, in practice, prevent shared decision-making from happening.

1.4 Approach

NHS East Midlands' desired outcomes, as set out in the project design brief, were:

- for the SHA and for participants, a greater understanding of the key issues and challenges that will need to be addressed in working towards 'no decision about me without me'[2] as the norm;
- among participants, a better understanding of what shared decision-making means for them on a practical level and how this will impact their behaviour;
- an understanding of the support required to achieve shared decision-making by staff with patients.

As originally proposed, the project had four interlinked phases:

1. new analyses of existing patient experience data;
2. single-discipline professional, patient and public focus groups;
3. multi-disciplinary workshop with health professionals;
4. analyses and report.

During implementation, the 'professional' element of Phase 2 was amended to comprise:

- a series of 15 one-to-one, 30 - 40 minute telephone interviews with range of NHS staff in widely varying professional roles;
- one multi-disciplinary discussion group with health professionals.

The individual interviews were conducted throughout June 2012. Details of the Phase 1, 2 and 3 groups are set out in the table overleaf. Everyone who took part received an information sheet describing covering the background and aims of the project. The individual interviews, professional discussion group in Newark and all the focus groups with young people and parents were digitally recorded and transcribed for analysis. All interviewees gave verbal consent to recording, and the group and workshop participants all signed a consent form.

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[2] Department of Health. Equity and Excellence: Liberating the NHS. Crown Copyright; 2010.

Group	Location	Date and duration	No. of participants
Phase 1: multi-disciplinary professional discussion group	Newark, Nottinghamshire	13 June 2012 2 hours	13
Phase 2 – Derbyshire Young Inspectors (younger age group)	Mansfield, Nottinghamshire	19 June 2012 2 hours	9 plus two youth workers
Phase 2: Derbyshire Young Inspectors (older age group)	Collingham, Derbyshire	19 June 2012 2 hours	5 plus two youth workers and one parent
Phase 2: Diabetes Parents Group (parents of children and young people with diabetes)	Braunstone, Leicestershire	20 June 2012 2 hours	10
Phase 2: Leicester Parents Forum (parents of children and young people with disabilities)	Leicester, Leicestershire	21 June 2012 2 hours	10
Phase 3: multi-disciplinary professional workshop	Kegworth, Derbyshire	11 July 2012 4.5 hours	23

Participants were encouraged to speak openly, and to give their own personal perspectives on the issues discussed. They were also assured that all contributions would be treated as confidential i.e. that observations and quotes would not be attributed to individual participants. Participants in the young people and parent focus groups were offered a small cash incentive at the close of the session, in lieu of their time and travel expenses.

This report captures and integrates findings from all elements of the project.

2. Perceptions of shared decision-making: health professional interviews, discussion group and workshop

At the outset of the health professional interviews, discussion group and workshop, project participants were all asked what shared decision-making meant to them. This section describes health professionals' understandings of what shared decision-making is, and what its implications are for services and service providers, and for patients and service users.

2.1 Relating to services and service providers

Health professionals had varying understandings and perceptions of what constituted shared decision-making, covering:

- informed consent;
- shared decisions about care planning with patients, service users, carers and families;
- decisions reached by multi-professional and multi-disciplinary teams working together;
- engaging with patients at their level of intellectual capacity, cognitive ability and health literacy;
- entirely 'holistic' patient and person-centred thinking.

Some health professionals also included service design and re-design, system design, commissioning and wider programme planning as aspects of shared decision-making and a very few included public health.

General practice participants and clinicians were more likely to describe shared decision-making within the context of their circa 10 minute consultation – discussing treatment options one-to-one with a GP or practice nurse, or in building a rapport with a patient over time, for example to support concordance with treatment plans for long term conditions.

Allied health professionals, particularly therapists providing GP-based and/or home-based services, were more likely to discuss shared decision-making as relating to lifestyle decisions or 'person-centred' thinking. They typically described shared goal-setting and negotiating (and re-negotiating) implementation of those decisions in day-to-day living in order to achieve agreed milestones and outcomes. In this understanding, shared decision-making is more of an ongoing and iterative process than an event or episode.

Participants in the health professionals' discussion group pointed to the mental health service care planning process as a well-established area of good practice in shared decision-making, which professionals have been developing for over 20 years. Similarly, specialist learning disability services are agreed to be leaders in the field, despite (or, more likely, because of) the particular challenges they have in communicating with and involving the diverse patients, services users, carers and families with whom they work.

Tension between shared decision-making and available resources

In the health professionals' discussion group, the 'no decision about me without me' message resounded as a good short definition of shared decision-making. There were however considerable concerns about how this all-encompassing understanding of shared decision-making, properly and consistently done, might impact on NHS resources and services. This was raised in many different ways, most notably with regard to:

- the time available for information-giving, discussion and negotiation within clinical consultations;
- the need to create (more/better) opportunities for patients to understand, discuss and consider options within care pathways;
- the breadth of treatment options that would need to be genuinely available within the NHS envelope to support patient choice.

General practice interviewees, in particular, emphasised that the eight to ten minutes of a standard consultation does not (considering all the clinically required elements) provide enough time properly to discuss options, weigh the risks and benefits of each, and come to a shared decision - particularly for more complex medical issues. Some questioned whether, given current workloads and targets, it would be realistic to develop shared decision-making 'as the norm', i.e. to go beyond 'informed consent' to achieve genuinely shared decision-making in every general practice consultation. When asked to consider how shared decision-making might be executed within current consultation guidelines, GP interviewees typically suggested that face-to-face consultation time could be used to discuss the options and needs of a patient, with a patient's decision communicated subsequently to the doctor after a period of reflection, either in a follow up appointment or via an electronic or telephone feedback system.

Thinking more widely, participants identified a key tension between the understanding of shared decision-making set out in the national policy aim and the reality of local service delivery – that is, a tension between patient *expectations* from shared decision-making and the NHS resources and options available. Although generally positive about the principle of share decision-making, participants did express anxiety about delivering on shared decision-making and the NHS Midlands and East 'patient revolution' in the current and foreseeable future financial climate. Participants' anxiety was, essentially, that 'no decision about me without me' might raise patient and public expectations that local commissioners and service providers would simply not be able to meet.

"I think that the media and the government, lots of things, have encouraged people to expect an absolute gold standard service to be handed to them on a plate, but everything else is telling us as time goes on there aren't going to be the options and the choices ... we are going to be much more openly rationing healthcare and ... people might have to make choices about what will and won't be available."

There was widespread agreement whenever this was raised in the professional groups – it seemed to be a 'goes without saying' worry for most participants, regardless of their professional role.

Concerns focused, in particular, on the potential for shared decision-making and improved customer service to be misunderstood as unconfined consumerism. That is to say, that patients and the public might misunderstand shared decision-making and the 'patient revolution' to mean that they are free to choose any treatment or service, and to access that within their chosen timeframe, regardless of whether it is provided by the NHS and regardless of local service pressures, policies and/or resource constraints.

Essentially, there was a sense that in encouraging patients to be more involved in the decisions made about their health and healthcare, we may be setting the system up for failure unless transparency about resource realities and managing expectations are explicitly acknowledged as necessary elements of shared decision-making for NHS organisations.

Precursors for shared decision-making

Many elements were identified as necessary for encouraging the culture of shared decision-making and the 'patient revolution' for NHS East Midlands. Clear and consistent communication, whether in policy or directives to staff, or in communication with the public on their 'patient rights' was seen as an essential first step to fostering shared decision-making.

Information sharing about 'patient rights', or communication materials for patients explaining that they should expect to share decisions, would help to shift the culture towards the goal of shared decision-making as the norm.

One interviewee described a particular challenge in shared decision-making as the 'burden on general practitioners' at the point of referral, which increases greatly within the context of shared decision-making and is crucial to the efficient use of resources.

Several recommendations were made on how this burden could be reduced. Information sharing and IT solutions for sharing electronic health records amongst *all* NHS providers would facilitate better sharing, and easier understanding along any patient's individual care/decision pathway. Multi-disciplinary teams were seen as both leading the way for shared decision-making and also as good practice for coordinated and efficient care. Better sharing of information and multidisciplinary teams were both seen as a solution to

the professional 'silo's that still define some healthcare settings. It also builds a culture where each health professional's expertise and role is recognised and consulted.

2.2 Relating to patients and service users

Among professionals, discussions relating to patients, service users and carers typically focused on:

- changing the professional-patient relationship and the power dynamic within consultations to foster and support shared decision-making;
- communicating, and communicating differently, with patients about their rights as set out, for example, in the NHS Constitution - what they should expect from healthcare professionals and services;
- supporting patients, service users and carers to ask the questions they could and should be asking to best access the 'right' care.

There was consensus that not every patient wishes to share decision-making within the clinical consultation. Rather, professionals see a spectrum, ranging from patients who would prefer or frankly expect doctors to make decisions on their behalf, to patients who expect to be equal and fully informed partners in making decisions with all health professionals. The general feeling was that elderly patients were more likely to ascribe to a 'doctor knows best' attitude, and younger patients and teenagers – while often more informed and wanting to be more involved – may in practice lack the confidence to share decisions, or even to question decisions, about their health and healthcare.

Some pointed out that a patient's position on the 'involvement spectrum' is not necessarily fixed and may well be different in different circumstances – perhaps leaning more to clinician-led decisions when, for example, when people are very unwell, in pain and/or terminally ill.

Many health professionals questioned whether shared decision-making was always appropriate, possible or meaningful, giving specific examples where sharing decisions might conflict with their professional duty of care to the patient and to others. As a general rule, safety transcends shared decision-making: acute clinical situations and sectioning a patient under the Mental Health Act, for example, were cited as clear examples of inappropriate times to attempt to share the decision about options.

It was felt that getting the balance of decision-making right for each individual in end of life care was particularly important. The general view, among participants who discussed this issue, was that some people wish to be fully informed and involved in making decisions about continuing or discontinuing treatment, whereas others, given the implicit stress involved in making end of life decisions, may wish to be guided through the process without necessarily being given all available information. Participants felt that

the onus was on clinicians to communicate the possibility of sharing in decision-making, but that occasionally a patient's decision may be to decline, i.e. not have to make all the decisions related to their care. Accounting for this requires flexible and context-specific understandings and models of shared decision-making.

Responsibility for 'bad' decisions

Further tensions between shared decision-making, professionalism and usual clinical practice flow from national and local policies and guidelines. For health professionals – individually accountable for their decisions, and ultimately for justifying non-adherence to relevant guidance – it can be difficult and uncomfortable to support patients making what, in their view, is a 'bad' decision. This may apply particularly where there is a difference in values and beliefs, rather than a different interpretation of 'the facts'.

"Which is fine when you agree with those options that you're giving them but it's about actually actively listening and then being able as a professional to deal with differences in that person's values or beliefs because I think that's where as a health professional then we might struggle a bit."

If a patient chooses or requests a 'riskier' treatment (or non-treatment) course, a substantial concern about responsibility for the outcome of that decision arises:

- What is the relationship between shared decision-making, the duty of care, and individual professional accountability?
- If a decision is shared, to what extent is responsibility for the outcome of that decision also shared?
- In what circumstances and to what extent can patients be held entirely responsible – and the professional not-responsible - for the outcome of decisions about health and healthcare?
- At what point should a health professional intervene to change a 'bad' decision?

These largely unresolved questions made some health professionals wary about shared decision-making.

Interviewees also described a potential for tension between shared decision-making and the fact that health practitioners are trained and expected to deliver 'gold-standard' courses of treatment, where these have been developed. Professionals may understand that a patient does not want the treatment that they are offering/recommending - but it is still difficult not to persuade for proceeding in that direction.

3. Perceptions of shared decision-making: young people and parent focus groups

Focus groups were held with young inspectors, parents of children accessing diabetes services, and parents of disabled children and young people. The young inspectors are a group of volunteers aged 13 to 19, recruited as part of a county-wide 'You're Welcome'[3] programme, who are given training to observe and assess the waiting rooms and services of local health centres and other services. Their findings and recommendations are reported back to the centres they have visited.

All focus groups comprised atypical patients in that they had unusual levels or knowledge and insight, and/or a high frequency of interaction with NHS services.

3.1 Themes from young people

In general, the participants in both the young people (and parent) focus groups were unaware of the concept of shared decision-making, or that it is a priority area for NHS East Midlands. When facilitators elaborated the concept, however, some participants in the groups reported that they had experienced shared decision-making on occasion.

"I didn't know it was called shared decision-making"

As with the health professionals, shared decision-making was seen as most prevalent within services provided by allied health professionals, or by clinicians working within specialist or long-term care teams, particularly within rehabilitation programs.

The young inspectors' focus group had a unique perspective on the care that they received or observed in their role. Privacy and confidentiality for young people was of high importance, especially when they had been visiting the sexual health clinic. They felt that reception areas were not always as private as they could be. They also reported that reception staff members were not always respectful or as helpful as they could be.

Though they were unaware of the concept of shared decision-making, many of them spoke of the confidence that the young inspectors programme gave them to access services and to engage with health professionals differently. They preferred those health professionals who took the time to get to know them, and those who remembered them from previous visits.

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[3] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813

The young inspectors reported that often health professionals 'hid behind the computer' when they were in the consultation room, they didn't look at them and simply typed in the answers to their question while looking at the screen.

"Well some doctors that I've been to I feel like they're quite interested but then others, one I went to in the past, he was...on the computer and I think he only looked at me once about three seconds and he wasn't even looking at me when I'm talking or when he were talking to me."

Another challenge that the young inspectors reported in consultations was that GPs spoke to their parents most of the time, and sometimes exclusively, throughout a consultation. This didn't make them feel at ease, involved or respected.

Teenage health inspectors also felt as though GPs focussed on the 'sex, drugs and rock and roll' aspects of health and felt as though the care they received was prejudiced or judgemental as a result of their age. There is perhaps a conflict here between young people's preference for doctors to focus on and address the issue that they present with, and the NHS Midlands and East 'make every contact count' ambition to use every opportunity to deliver brief advice to improve health and wellbeing. For young people, unsolicited brief advice is likely to focus on sexual and reproductive health, smoking and drug/alcohol usage (i.e. to reflect national policy priorities) which will not necessary be relevant or welcome.

Young people's perceptions of health information

The young inspectors reported that they were very likely to go to the internet for health information, though they were quite well versed on which websites could or couldn't be trusted as a source of information. NHS Choices and NHS Direct were both used by the inspectors, but they weren't certain if their peers who were not inspectors would have knowledge of these sites. They also discussed how the web can be a quite scary place to find health information, but that it was a good first step in looking for information to be followed up by an appointment with a GP.

When asked what type of health information they would like, the young inspectors thought that interactive and personalised information was ideal. In terms of information at health centres, they thought it should be colourful, with large print and illustrations to attract attention. One young inspector had designed some posters for one of the health clinics that he inspected.

3.2 Themes from parents of children and young people living with diabetes

Parents of children and young people with paediatric diabetes were invited to participate in the project via an established group which has a good relationship with local services. Their experiences and views are not necessarily representative of – and may, in particular, be more positive than – those of local parents who do not access the information, advice and support that the forum provides.

The parents in this focus group had an extremely proactive understanding of shared decision-making as an approach, and of the role they and their children could and should play in making and implementing decisions. This was considered to be important both in supporting children and young people in managing their paediatric diabetes effectively, and in preparing them for adult life.

"I think something that we can do for our children is encourage them to be fairly assertive when they're talking to the medical professionals and actually ask questions and keep asking questions until they get an answer they can understand … We have to show them how to go on to make sure that they know how to get access to the healthcare that they're going to need because they're diabetic."

"Yes, if it concerns me, I want to be involved in the decision of what happens to me and I naturally assume that my child would feel the same way…on balance, most people would rather be in control of what's happening to them, physically, mentally and emotionally. That's really important; it's part of respecting your identity as an autonomous adult."

This group also felt that paediatric care demands shared decision-making in a way that adult care perhaps does not.

"The characteristic thing about paediatrics is, of course, it has to be shared decision-making to an extent because you've got the parent and the child, whereas in adult medicine, of course, you're making a shared decision with the adult, the patient."

The parents in this focus group universally reported very positive experiences in terms of information and support that they received when their children's diabetes was first diagnosed. It was felt that all health professionals, specialists and general practitioners, were very kind and considerate in how they delivered information at this emotionally fraught time. Parents described feeling overwhelmed by the amount of information they were receiving, and really appreciated that way that professionals were prepared to repeat information frequently. The service that they received from specialist diabetes nurses, at diagnosis and subsequently, was rated particularly highly.

The ongoing nature and complexity of childhood diabetes and its management makes shared decision-making an ongoing and complex process for parents, affected children and the professionals responsible for their care. Inspiring confidence in children and young people to make and implement decisions is clearly a key competence for parents and professionals alike. One element of care which characterises this is the decision to move from injection to insulin pump. This decision is at times medically necessary and at others is a preferential decision; therefore, it is one where specialists allow families to consider the decision together. One participant discussed the experience of her teenage son who decided that he would like to go back to injecting insulin, which is not a decision she would intuitively have supported. Their specialist, however, agreed with her son that the he was able to inject as long as he remembered to measure his blood sugar levels regularly. After two weeks of injections, her son decided that the pump really was more convenient and changed his treatment back again – and the specialist remained supportive of his decisions and of his ability to manage his own care effectively and safely.

"We are going to teach you to be your own doctors. You are going to be your own expert"

Though parents reported very positive experiences of the information and support they received at diagnosis and the period immediately following in stabilising their child's condition, they also reported that their needs (and children!) change over time in ways that health services cannot necessarily keep pace with. For parents whose child's condition was medically stabilised, ongoing information and support was more usually provided by other parents within the diabetes support group than by the health system. Peer-support was also seen as a very valuable source of psychological strength, practical advice and helpful tips from personal experience; as one mother wryly observed:

"[diabetes] is not a disability until you go to Alton Towers".

Parents also felt that access to GP care is often difficult, and they experienced feelings of guilt when 'playing the diabetes card' to secure timely appointments. Further, emphasising a child's diagnosis did not always guarantee timely or otherwise appropriate primary care appointments; parents had often ended up in A&E unnecessarily, or trying urgently to reach a diabetes specialist, for medical issues which might otherwise be minor but could cause complications with paediatric diabetes. Some specifically reported that their GPs seemed to have little knowledge of childhood diabetes and could not offer information, or treatment options.

"…when I asked about [my son's] toe… I said, "Would you just look at his toe", and I said "Because he's got his diabetes, is it more of an issue?" "Ooh, I don't know." "Do I ask you about this or my diabetic nurse?" "Ooh, I don't know" "Could you ask someone and maybe get back to me?" "Yes." And then nobody got back to me and I got a letter from the hospital for an appointment."

Support in schools was also seen as variable. Whereas some schools were considered 'clued up' to the needs of children with diabetes, others were less aware of children's needs, and families felt it was up to them to educate the school staff, using the education resources that are provided by Diabetes UK or the pharmaceutical companies. Their children also had a role to play in educating their peers and their teachers.

3.3 Themes from parents of children and young people with disabilities and special needs

Parents and carers were invited to participate in the project via an established independent group that provides information and support; their views are not necessarily representative of all parents and carers of children with disabilities and special needs.

In stark contrast to the positive experiences of the parents of children and young people with diabetes, the parents of young people with disabilities and special needs have had very negative and difficult experiences with access to healthcare and information about healthcare options. Many of the parents had received their child's diagnosis prenatally, so their 'battle' had begun even before their child was born because of the limited availability of pastoral care or counselling within antenatal or foetal care clinics.

"It's been a fight, a battle …"

"We live from crisis to crisis."

The perception of parents was that, in order to access any services, treatment or referral to specialists, parents were forced to fight against gate-keeping or a laissez-fair attitude of GPs. This was particularly prevalent for parents of children without a clear diagnosis, whose diagnosis does not fit into a defined care pathway, or with a diagnosis of developmental disabilities. Most parents in the focus group described having difficulty getting their GP to take their concerns about their child's development seriously, and were concerned that the benefits of early intervention were lost due to a 'wait and see' approach.

"You assume some system's going to kick in; you later find out that there is no system"

Once the hurdle of receiving a diagnosis or referral was overcome, parents had varying experiences of the health system. Again, for parents of children with no clear diagnosis, navigating the various appointments, treatments and health professionals they interacted with was difficult.

"… if you consider health, education, welfare as the staff, we're dealing with a very surly workforce when it comes to it, who think that they know exactly what they're supposed to be doing but they don't necessarily know what they're doing because you're managing [your child] and you know bits about the child and the system that the child is in."

The parents felt as though they had to be 'project managers' for their child's care. Divisions between community and acute care, health and social care make the navigation more complex, particularly if the children attend mainstream schools. However, parents reported excellent service and support when they were in contact with a community care coordinator who was able to assist them with what services were available, what services they may need to access, and when and how to access those services. Once parents had reached a specialist paediatrician they felt as though more answers and clarity were available to them, and that the specialists reported information back to GPs, but they felt by this point the GP relationship was already broken.

The rigidity of both service models and of some reception staff exacerbated an already stressful system. For parents of children with Autism Spectrum Disorder, for example, a delayed general practice appointment further upsets an already difficult disruption to their daily routine.

Most parents reported that their best source of information and support were the parents they met through the various support groups which they attend and not from the health professionals, paediatricians, general practitioners or social workers who are working with their children.

"I think the strongest link is from other parents... and not professionals, I think that's probably what most people would say there, because it's how we get information."

One mother who has a child with Down syndrome had recently assisted in developing a care pathway for Down syndrome, starting in the maternity ward. Included in the programme is a 'pack' with all the information a parent may need, including services that should be available, various milestones and contact information for the parent participation and support groups that are available. The group felt that this was likely to be an isolated example of a structured, condition-specific information resource, and a huge step in the right direction.

Discussing the gap between expectations and experience, the group described a 'Great Ormond Street' effect. Seeing television programmes about the Great Ormond Street hospital's work, and its specialist staff, services, and resources, makes them feel as though they have 'lost the postcode lottery'. When they do achieve a referral and receive care at Great Ormond Street, the marked difference to what they experience 'at home', particularly in terms of information and coordination, contributes to their overall sense of frustration. Parents were also frustrated at media portrayal of Great Ormond Street as a unique centre of excellence; their view is that, to a great extent, this trust stands out because their experiences of local service provision have been poor.

"Great Ormond Street's just a hospital delivering what hospitals should do... We're actually in the point where we're perceiving that when a hospital's doing what it should be doing, it's good. It isn't. It's just okay, but it's great because we've broken through the years of crap what we had to get through to get there."

4. Shared decision-making in the East Midlands: professionals' assessment of the *status quo*

4.1 Shared decision-making in professional practice

As described in Section 2, there was considerable variation in individuals' and professional groups' understandings of shared decision-making. There was, for the most part, agreement on the goal of shared decision-making – essentially, to identify the best achievable outcome for the individual, taking their values and preferences into account, and to agree how to achieve it. Where understandings differed substantively, this largely reflected differences in professional roles and difference in relationships between service providers, patients and the wider public.

This project was not designed formally to assess where and to what extent shared decision-making is happening in clinical consultations across the NHS East Midlands. Interviewees were however asked for their views, and some of the focus group and workshop activities implicitly addressed this question.

We found that the way in health professionals understand shared decision-making not only underpins how they implement it in day-to-day practice; it also influences how they assess and compare others' performance and progress. This can be useful in encouraging people to learn from each other where professionals and services share a similar understanding, but it can create tensions and frustrations where they do not.

Tensions may also reflect the level of risk inherent in different professionals' services and client groups, i.e. the likelihood of them needing to respond quickly to an acute situation, to make a unilateral decision to protect a patient's or others' safety, or to very strongly recommend one course of action over other possible options.

Among the participants in the project, for example, clinicians providing acute mental health services, for example, are more likely to encounter these situations than allied health professionals providing community-based physical therapies. Consequently, they are also likely to have a different 'take' on shared decision-making and to prioritise it differently in different circumstances. Similarly, within time-limited and clinically complex consultations, patient safety will be 'top of mind' and the primary consideration.

"You know, effectively, we have eight minutes for consultation. That's a tall order for any significantly complicated clinical issue to explain to somebody options. It's possible but it's always going to be done on a curve so, on the same line, it isn't the most important thing. … If you do a beautiful consultation with a lovely shared-care management plan and the patient is fully engaged…and then, as a consequence, you miss something really important that would put the patient in danger, I think if dealing with finite resources

means that it's a good idea and it's a good, sort of, try to do it better. But it actually isn't the most important thing. The most important thing is patient safety."

There was consensus that patients and service users increasingly expect to be involved in decisions and that this upward trend will continue; while healthcare policy is not necessarily a key driver, the NHS will need to respond to changing expectations.

"I'm not sure that it's actually filtered through from the NHS end of things, so from the policy end of things, but actually it's probably been driven the other way because people, like I say with the internet and stuff, I think people expect to be more involved now. Now whether that's partly because they've heard it from an NHS policy point of view or whether it's just with, you know, the sort of the emphasis on customer focus and customer service and all that that is coming from the private sector I'm not sure, but I think there is a feeling that people should be more involved and I think, especially as the younger generation comes through, there's a lot less of the "doctor knows best" attitude."

This participant also noted that the NHS could usefully do more to deploy its communications expertise and resources to influence patient and public expectations of involvement, and to inspire people's confidence in sharing decisions including commissioning decisions.

"The communications role is … then making sure that the public are aware that they have that right and interestingly, we've been just doing some consultations around principles of decision-making and one of them is there's "no decision about without" meeting the principle and a number of the comments were "Well that's fine but you've got to make sure the clinicians know that as well", i.e. that they have to give people the opportunity, and I think that is where our role is - to make sure the public almost have the confidence to challenge I guess."

Similarly, one therapist discussed how increasing patients' expectations of being involved in decisions ahead of time could be helpful in setting the tone of the clinical interaction:

"Like, for example, the phrase called "no decision about me without me", if they were aware about these words before I went to them, then their frame of mind, their thinking, will be different. Like, they will think, "Okay, they are not going to impose anything on me, rather they are going to take my questions, my feedback and then they are going to suggest me something."

Taking participants' views together, practice has developed partly in response to the inter-related factors of:

- changing patient and service user expectations and access to information;
- developments in approaches to service delivery (in particular the Care Programme Approach in mental health);

- an increasing emphasis on communication skills and clinical placements in professional education and training.

Multi-disciplinary team (MDT), multi-agency working and care pathway approaches are also regarded as key drivers of shared decision-making. This applies particularly to professionals whose understanding of shared decision-making focuses on ensuring effective and co-ordinated health and social care in community settings.

"I genuinely think multi-disciplinary team working has such a huge impact and we do clinics with an orthopaedic consultant that'll have an orthotist, a physio and a consultant, and that does so much for giving the patient the options and also learning each others' professions. And I can't, I know there's obviously research of how important the MDT team is, but I can't highlight that enough."

One participant discussed opportunities for improving the cohesion and coordination of MDT working, particularly were care pathways cross organisational boundaries:

"… I think that we're still lacking in terms of having robust multidisciplinary teams and, actually, where we have multidisciplinary teams, they don't necessarily all work effectively either. I think there's still quite a lot of work to do along care pathways when you're crossing different care settings and geographical areas. Because I think what I find in some of the work I do is that although there are very robust systems in place and the patients are very well cared for and, on the whole, do understand what they're getting as part of that care pathway, I think the inefficiencies are around the number of the same practitioner that they see."

There were concerns about doctors' levels of engagement in MDT training and working, though some participants did report recent improvement:

"… we were talking about training at the time and actually getting [GPs] involved in some of the training that we actually do so they are a little bit more aware of some of the things that we do and some of the things that we've put in place, so some of the sort of like you manage your training and sort of going back to your kind of your evidence based practice a little bit and your best practice and putting things in and putting standards in and things like that, sometimes I feel that the GPs aren't always aware of, you know, we're creating this sort of, hopefully a centre of excellence, but I'm not always sure that they are aware of that and that they are involved in that for whatever reason."

"… the doctors tend to divorce themselves from the multi-disciplinary teams to a high degree, but they're still based in one place altogether and they come out occasionally and tell us. … But again with the pathway working, I think it's forcing the situation more and I can see some little chinks appear. I don't think it's an intentional strategy, I just think again that's the culture that's developed here, and as people say things, you know, I can say things now that they would have just not understood or expected even two years ago.

You know, things have moved on, things that I was fighting for two years ago are now 'Oh yeah, that's fine', you know?"

One participant noted that the rise of MDTs provides opportunities for younger (i.e. more recently qualified) doctors to receive support from other professionals and to share decision-making within the team. Another pointed out that increasing expectations of involvement in decision-making are not confined to patients:

"I think things are improving and I think challenging your seniors is always very difficult, but I think that because there are more multidisciplinary teams around, I think that the younger doctor gets that support from other healthcare professionals, social care professionals as well, so I think that the improvements can happen."

"I mean even in staff coming in, I'd say their expectations are very different as well, they don't expect just to be told what to do, and I think that's very positive, isn't it, but it is a different feel."

The key area of disagreement among project participants was in their perceptions of shared decision-making in general practice consultations. Most who expressed a view emphasised that it is not possible to make sweeping generalisations about a very diverse group of health professionals and that, all else being equal, some general practitioners will inevitably be 'better' than others at sharing decisions with patients. This might reflect, for example, their personal characteristics, their experience and maturity as a clinician, the nature and duration of their relationships with patients, and the time pressures that they work with.

With that caveat, there are essentially two camps: those who believe that general practitioners are, for the most part, doing sharing decision-making with patients, and those who believe that general practitioners are over-estimating the extent to which they are sharing decisions. That is to say, some believe that general practitioners are doing shared decision-making, and doing it consistently, while others (including some GPs) suspect that sometimes they only think they are doing it.

It seems likely that this again relates to individuals' different understandings of shared decision-making.

"... I think you learn to manage the patient situation once you qualify, but I also think general practice is very good at listening to and managing patient expectations, whereas hospitals are probably not so good at that."

" ... ... GPs, yes, I would say very much so in primary care. They do listen to the patient and they try to shape what the patient wants to do or wants in terms of the patient's action plan or treatment plan. I would say that is the style of the current... Not in 100% of the cases, you still will get GPs that don't perhaps listen to patients, but I think, by and large, GPs, because of the nature of the way that they work with people, and they do

work with families and they do get to know people over many, many years and they know the whole family, it probably lends itself because their interaction with that patient isn't going to be a single interaction or a single episode, they are going to keep seeing that patient and, you know, the patient makes a recovery because of this or the patient isn't improving because of that. You know, I think they do much more actively engage patients and their carers, and probably would be criticised by their peers if they didn't, I would say."

"I think sometimes they do, they sort of pay lip service to it, I mean most of the consultation models say something about it in terms of negotiating a plan or something similar, sometimes in terms of the amount of negotiation it's just a matter of 'is that OK?' and then not even giving the patient time to reply before you've carried on with the rest of the plan. So it's all, some of it is possibly paying lip service to it, but I think some people are very good at it and patients actually recognise that."

It is possible that these two positions arise from variations in professional understandings of shared decision-making and from differences in how shared decision-making, as a concept, translates into day-to-day professional practice in different care settings. As noted in Section 2, general practitioners typically understood shared decision-making to apply to decisions about care and treatment made with an individual patient during a (usually) one-to-one structured, circa ten minute, consultation. To professionals providing community-based services (including home- and residential care-based settings) whose understanding of shared decision-making typically covers making decisions with several other individuals and agencies, including carers and families (as well as with individual patients), the general practitioner understanding of shared decision-making may look, at best, more like 'informed' than 'shared' decision-making.

General practitioner referrals to hospital- or community-based therapy services perhaps illustrate the issue. A general practitioner and patient may together, taking the patient's expertise, circumstances, values and preferences fully into account, decide to refer to a therapist rather than for surgery. The therapist to whom the patient is referred finds that s/he has no understanding of what the therapist does or can offer, what they might be able to achieve, or what the limitations are.

"I feel sometimes we have to make it clear to them because I think I would say 50/50. Some people, they know, but 50% of the time I have to explain to them why I'm here, what I'm here for. So, it's still I think lack of awareness."

"If patients have come via other allied health professionals they often know a little bit more about what they're going to do because those people have spent time with the patient. If they come through the physio they've probably spent a lot of time with the patient and they've discussed at length what they're going to refer for. If they've come through their GP they just see the hospital not different departments, does that make sense? They said 'Oh we'll refer you to the hospital' and I think they get that, never sure what for. It also depends a little bit on the patients because we have such a vast array of

patients some people, you know, I don't know what the GP told them but it might or might not be what they said they said."

"Well, I go and see people in nursing homes and in their own homes so quite often I'll go to them, you know, can you tell why I'm here and quite often they'll go, no I can't. So I go, are you sure, what's happened to you? Sometimes they go well, this thing happened and I'll go, well that's probably it. But sometimes they'll go, no, I really don't know why you're here, in which case I have to do everything and find out sort of thing."

"Not always, no, because they often forget that they've actually been offered to get, that somebody has said to them 'Oh I'll make a referral through to the physiotherapist or to community therapy', and they don't know what community therapy means."

This can be variously interpreted to mean, for example, that the decision to refer for therapy was not a genuinely shared decision, that the decision was shared but that the patient could not recall their involvement, or that the decision to refer for therapy rather than surgery was shared *to the extent that it is useful and practicable, to all concerned, within the general practice consultation.*

Similarly, those whose vision of shared decision-making encompasses involvement in commissioning decisions about service investment and disinvestment, and/or decisions about public health, might consider the therapists' understanding of shared decision-making to be 'limited' in that it does not typically extend to beyond the patient's immediate circle of carers and family to the communities and general population served by the local or national NHS.

4.2 Capacity and consent: involving people who are living with mental illness or who have learning disabilities

Professionals leading and working in services for people with learning disabilities were well represented in the interviews, the discussion group and the workshop. People leading and working in mental health services were also represented, albeit to a lesser extent.

The issues and complexities of shared decision-making with patients and service users whose intellectual ability or cognition is impaired arguably deserves to be the subject of a separate and specifically designed project. We were unable, within the scope of this work, comprehensively to explore the breadth and depth of professionals' views and their expertise in involving these patients, services users, carers and families. The following highlights the key East Midlands *status quo* issues identified during the project.

Involving people with mental ill-health

In this project, and in previous work that the Picker Institute has undertaken, there is general agreement that that mental health services are generally 'ahead of the game' with regard to shared decision-making. Explanations vary; our sense is that a multiplicity of clinical and policy drivers have contributed. Above all, as one interviewee pointed out, it is well-established that mental health services very much depend on involvement to be effective:

"… I personally think a lot of this came from mental health because, in a mental health setting, you can't really get the patient to progress if they're not an active participant. So, they very much have to be involved in their care or, you know, they won't hit the milestones that you would like them to hit in terms of their treatment plan."

"Obviously, some people who are severely mentally ill and perhaps don't have the capacity, then that's where we get involved with their carers or family members or whatever, but generally if we think of people moving through various stages to recovery, you do have to work with what they want, what they think they can do, what they can cope with, and you have to assess their progress, you have to involve them in 'how are they?', 'how are they feeling?'. It's not something you can necessarily take a temperature and work out how they are, take their blood pressure. You know, it is very much dependent on how they're feeling and how they're coming across and what they want to do, and you have find various techniques to engage them, to get them to move beyond where they are."

Acute mental health service representatives in the discussion group described a systematic approach to involvement and communication in East Midlands services, from individual involvement in care and treatment plans to wider involvement in governance and commissioning.

"… we've got service user involvement in planning, commissioning and as a Foundation Trust we have a Council of Governors and we have service user Governors, you know, carer Governors, public, so I think in some ways we do have more involvement in terms of how our services develop as a trust and how we can influence the commissioners because we have a commissioner Governor as well."

"And I think the way that mental health services generally work under the Care Programme Approach is much more service user focused so they are the ones that decide who comes to their Community Psychiatric Nurse meetings, their review meetings and things. And you know similarly we're looking at clinical noting so that everything is on electronically so that different teams even within our Trust at the minute can't talk to each other always, but with clinical noting they will be able to, so it's about not creating more work. So yeah, I was sort of sitting here [thinking] 'dare I say that' but I think, you know, there are some good things …"

Involving people with learning disabilities

There was consensus that the East Midlands Community Learning Disability Teams are also ahead of the curve, with regard to sharing decisions - with patients, service users and carers, and also with other health and social care services. As in mental health services, the shift to more person-centred approaches began some years ago.

"Within learning disabilities there's an awful lot on person centred approaches, that's moved from person centred plans, sort of three or four years ago to much more person centred approaches and a lot more emphasis on people having say their own healthcare plans, that they carry with them.. ..."

"I think within our Community Learning Disability Teams we have very good examples of shared decision making, between professions, multidisciplinary teams and different agencies, I think at that level we work very well together."

However, cuts to specialist learning disability services in some areas risks a return to less collaborative approaches:

"I think that's typical of Community Learning Disability Teams in [area] and [area], I think some of the cuts that have happened in other areas ... have meant that they no longer have specialist learning disability teams so they've got much more generic teams and that's been a decision made by adult health and social care in other areas, and that has meant that in terms of health services they've gone back more into uni-professional teams rather than multi-disciplinary and multi-agency teams, so that by the nature of those decisions is going to make shared decisions and shared working more difficult."

Whilst all professional groups identified time constraints as a very significant challenge, those working with people with learning difficulties have extreme difficulties because, with their patients and services users, communication and involvement are much more difficult to achieve and takes much longer to do well. As with other patient and service user groups, but infinitely more so, the challenge is for professionals is to demonstrate to commissioners and other service providers that spending time involving people is time- and cost-effective in the long run.

"… I mean, time, I know it's silly, but we're under the same pressures as everybody else, time to do this well with somebody who's struggling to understand is really significant. Presenting the information in a way they understand is also time consuming, and expensive."

"Again, you don't want to make excuses because I'm sure we could be more efficient in other areas, but I think ... people come back to us all the time, and that's probably inevitable, but I think we could slow that process down a bit if we did things more thoroughly, you know?"

Learning disability service providers also face very particular challenges when their patients and service users transition from paediatric to adult services, which is also when carers' and parents' roles in decision-making change (or should change). For specialist services, this means supporting not only the individual making the transition, but also helping their carers and family to understand how and why their level of involvement and influence may change.

"We were talking about it yesterday, literally the day before they're 18 they have consent for them and the day after they can't, and it is a big shift, and obviously, if you've got a child with profound multiple learning disabilities and somebody comes along and says 'Well they can make decisions now', it's nonsensical to people, isn't it, and it's how we support people to understand that we're trying to help that person at least be engaged in the decisions."

Specialist learning disability service providers are not, of course, the only health professionals who work with people with learning disabilities. Specialist providers also have a role to play in providing training and resources for other professionals, to support them in communicating with and involving people with learning disabilities. We were not able, within the scope of this project, to assess independently how sustainable this is; our sense from the interviews and the discussion group is that the specialist learning disability services are under some considerable strain, and that the work that they do in supporting others' service provision is not generally well understood or recognised by, for example, commissioners.

4.3 Awareness and understanding of others' skills and services

There was consensus that health professionals and services in the East Midlands need substantially to improve their awareness and understanding of other professionals' skills and of what other services can offer patients and service users. The relevance to shared decision-making is, essentially, that patients will find it difficult to 'choose' and to access the most appropriate services unless other service providers can provide accurate and up to date information and, where relevant, make appropriate and timely referrals.

"…the only options an orthotists can give a patient are orthotic options, and the only options a physio can give a patient are physio options. Whereas the GP or the consultant can give the wider options and that's when it's difficult because they're not always going to be aware of all the options."

Project participants who raised this issue typically also acknowledged that there is a shared responsibility for ensuring that referrals are timely and appropriate, i.e. that services need to take responsibility for pro-actively disseminating information to other professionals, teams and services about what they offer, what they can (and cannot) help with and how patients can access them.

"You're raising all the questions we're discussing at the moment, but again I would say they don't know a lot because we're not very good at explaining it to people, and obviously, by the nature of our client group, it's harder, but we're very poor, I would say, at explaining it, and then we say to people 'Well we've got these rubbish referrals, they're no good', but we haven't really been that clear."

Despite moves towards multidisciplinary and multi-agency working, the continued existence of professional 'silos' arose spontaneously many times during the interviews, the discussion group and the workshop. In some areas and services, though not all, silos seem to be making a come-back. One participant offered the further concept of 'senior silos' whereby front-line service delivery teams are working well together but the system reverts to unhelpful silos 'upstream'.

"I think there is an expectation that the process should be rounded so that the right people are included in the discussions and I think what people get frustrated with is all this sort of working in silos so that you're constantly repeating similar things to people. And I think that's why people get almost bored with the system and can't be bothered, if they need to go and contact somebody about something and know that they have to repeat the same information again."

"I think it depends what area you work in as well … my friend works in a different area and she keeps telling me that it looks like it's going back to silos where she works and then other areas it's not, it's doing it in a different, and I think it is a bit of a postcode lottery as to where you work and what are you live in."

"I think that we've always said that actually at that clinical, at the clinical face we've worked well together as [service delivery teams], with the service users, with their carers, but it's the layers above that, so once you get into their line managers and the middle management and senior management and chief execs, that those are silos. And decisions that are made there that obviously impact on the coal face as it were, and that is affecting service delivery."

4.4 Shared decision-making about local health services

Commissioning

As set out in Section 1, most of the project participants were clinicians or allied health professionals. We did however specifically include some who whose role focused on commissioning, or on communications and engagement functions within commissioning organisations.

Overall, the view was that the NHS in the East Midlands is in a relatively strong position with regard to patient and public involvement in commissioning, and that the transition

from Primary Care Trusts to Clinical Commissioning Groups is providing good opportunities for building on the PCTs achievements to develop even stronger relationships with local communities and patient and service user groups.

Achieving authorisation is clearly focusing Clinical Commissioning Groups' collective minds on patient and public involvement; the key will obviously be to sustain this momentum and commitment post-authorisation, and to close the feedback loop to motivate and sustain patient involvement in future.

"I think we need to give them the confidence, we need to evidence where some changes have been made or a good example of what a shared decision-making looks like, so that if we prove that it's working, then... We can be quite bad at that, actually, evaluating in the NHS, I've found, so if we can prove that what we're proposing works, then I think that's quite a strong argument."

General practice-based Patient Participation Groups (PPGs) are emerging as the dominant model of involvement, with super-groups of merged PPGs also being established as (effectively) consultation panels for commissioning decisions. The concern is that PPGs and PPG super-groups will become 'the' means of achieving patient and public involvement and that the breadth and depth of insight delivered by the diverse approaches to patient and public involvement developed with Primary Care Trusts will be lost. On a positive note, some in the East Midlands are clearly aware of the risk and are working hard to ensure that established relationships with (for example) minority ethnic groups and communities are maintained and supported in the transition.

For now, the key concern is how to ensure that patients, service users, carers and members of the public who participate and express their views about local services are truly representative of local groups and communities, and that they are accurately and comprehensively representing the views of their 'constituents'.

"Interviewer: What's your view on the PPGs?
Interviewee: I think it's a bit variable, I think it depends whether you've got patients who are interested and interested in it for the right reasons, so they're interested in it not just for themselves or for some special interest group, but interested in just improving their lot for patients generally, and if you've got somebody who's got what I suppose you call a bee in their bonnet that may distort the discussion and I suppose the eventual decision, which might not be in the best interest of all of the patients in that population really."

"[we don't know] the knowledge that that person has or whether it's when somebody comes across as being a very personal one and actually therefore they're not representing that village that they come from, or that bigger community that they come from, they're very tunnel vision - but we as an organisation have ticked the box because we've got somebody on that group, so I think we must be more mindful of the quality of what we're doing and because of not going too far down that road before we have to come back again because the work we've done isn't to a very good standard.

Another issue, again by no means confined to the East Midlands, is getting patient representatives sufficiently up to speed with the NHS so that they can contribute effectively, without overloading and overwhelming them.

"... it has been a challenge with our Patient Reference Group, which has brought everyone together, because the NHS is quite complex and I don't think people realise how the different organisations work, Primary Care, Secondary Care, it's just a bit of a minefield really, and for patients to come as volunteers into this organisation, and we've felt like we need to give them things to read and the NHS constitution, you know, to give them a grasp of the NHS, but we had some comments to say that some people feel a little bit bombarded. But then we get the other side of the coin, that says, 'Oh, we want to know', you know, 'We want to see the board papers each January', and it's really, really hard to please everyone. But I suppose if you give them the opportunity to be involved in these decisions, then you're doing, it's better than not to include them, isn't it?"

One interviewee specifically raised the challenge of commissioning services in more rural counties, including the practical difficulties of achieving patient and public representation, and the risk of local authority decisions to cut public transport services adversely affecting the people's access to NHS services. This interviewee and a workshop participant also described the potential for local commissioning in such areas to create unacceptable variations in services.

"I think we seriously should be basing our decisions on the care provider around the public and population we've got. I'm not quite sure how achievable it is. I think, especially for somewhere as big and rural as [county], because we have lots of pockets of populations that have a need that the rest of the county doesn't ... ..."

" ... you know, in some cases things will need to be local, then again the danger is that you've got one locality that's shouting really hard about one thing, then they'll get a service that isn't, you know, that goes back to the postcode lottery whereas actually you want to get away from the postcode lottery."

One participant, whose role included supporting shadow Clinical Commissioning Groups, emphasised the important of clinical visibility in public involvement initiatives.

"The public do respond and respect the GP opinion, probably better than me ... who, you know, sets up the consultation, but they do need to see that clinician."

This participant also discussed the tensions when shared decision-making about local health services runs alongside other local democracy processes and interests.

"You know, it's basically dealing with the political side or the councillors that are up for re-election sometime. If they're independent, they're part of the discussion, but obviously, they're doing what they think is best for their constituencies, so they will sometimes be in an adversarial type of position."

Public health

Public health was very rarely mentioned during the project, and we did not ask specifically about it. Involvement work is however clearly going on, though not necessarily with the shared decision-making 'fold'.

"You know, they've been going out with the public health consultation around the county just lately, which is obviously part and parcel of shared decision-making, but not under that banner, if you like."

Service providers

For provider organisations and professionals, prioritising patient, service user and public involvement - among a host of high-level competing demands and non-negotiables - is a real challenge.

"We talk about focus groups, we talk about customer care forums, we talk about patient surveys, but that's just a one-hour talk once a year, so I think because there's so much of the mandatory stuff I don't think we sort of put something specifically on or around patient and public involvement and shared decision-making as such."

One participant suggested that patient involvement in service design is more achievable and most effective when there is a specific focus.

"Some of the more bespoke services, like the stroke service, they have regular focus groups with their patients to look at how they can improve their services, but it works because it's about a very specific service."

Many project participants spoke, in various contexts, of the need to keep focusing on East Midlands' patients despite recent and ongoing upheavals in the NHS. As one put it:

"We can't forget about the patients in all this bureaucracy that's happening at the moment, all the changes. We still need to focus on the patients."

4.5 Professional skills, education, training and Continuing Professional Development (CPD)

Professions other than general practice

With one notable exception (general practice, see overleaf), most clinicians' and allied health professional groups said that professional education and training (to qualification) had really not prepared them for the realities of shared decision-making 'in real life'. This particularly applied to more senior professionals, who all made a point of observing

that they originally qualified some years or decades ago, and to those now working with people with mental illness, cognitive impairment and/or learning disabilities.

The general view was that professional education and training had improved considerably since participants had qualified, with robust feedback loops having been established between senior practising professionals and education and training bodies, and a much greater emphasis on clinical placement (including placement in MDTs) during the pre-qualification period.

"Interviewer: So looking back, did your initial training prepare you for all of this?
Interviewee: No, no, absolutely not, and in fact, I still have in my head doing my training and going along with diet sheets that were specifically calculated out and you went along and you saw the patient and you did 'Hello, I'm [name] the Dietician and I've come to tell you about what you are going to need to do now' and that was how the conversation would have gone. And then you would have read from that diet sheet and then, of course, you had to remember you were being supervised, so, of course, if the patient then said 'I never have milk' or whatever, you'd say 'It says on my diet sheet, you have half a pint of milk a day and that's what you're to have.' And then they'd say 'But I don't have milk' and you'd say 'But the diet sheet says that's what you should be having' and that's how you were trained, so if you tried to say to the patient 'Well, actually, yes, I quite understand that, so perhaps you don't need to…' you wouldn't say that because your supervisor would then pull you up about that."

Interviewer: Do you think today's training equips your colleagues any better than your own did for this shared decision-making role?
Interviewee: Yes, I think it does, because I've been involved in doing things like, as an external reviewer for one of the universities, you become very familiar with the curriculum that they develop for the students. And I think, most certainly, because they build in much more about practical skills right at the beginning of training, so they do a lot of the mock-clinical skills work so that the students develop their broader range of skills that are going to be needed when they work with patients and carers."

"I trained 34 years ago and we didn't touch anything like this. But to be fair, we worked very closely with our [local training facility], and we do work closely with them, to say 'This is the new world and these are the sorts of skills people need', so hopefully we're shifting in that direction."

"Interviewer: Did your training prepare you, do you think, for sharing decisions with your patients and family members?
Interviewee: I feel it's an ongoing process, but when you read a book, I feel that you get the knowledge about the science, but this is something which is very practical and you get very little exposure. From my point of view, I felt that I had very little understanding about the subject until I came into practice.
Interviewer: Do you think that's the same for other people?

Interviewee: No, because nowadays I've seen like people, those who first come to me, they are getting more exposure about clinical set-ups. So, it is definitely good for them to have placements where they learn and they also look at the clinical reasoning skills and all other skills."

One more recently qualified therapist, whose view on shared decision-making included sharing decisions with other professionals, said that the training had been appropriate.

"We did quite a bit sort of working with occupational therapists and radiographers in university and on placement as well.... Yes, so I guess, you know, what we do now is what we did when we were training and I guess it probably hasn't changed that much because we would go to MDT meetings as a student and you would be expected to, if you were looking after the patient, you would be expected to speak at those meetings, you know, with maybe a consultant there, nurses, occupational therapists and they would, you know, take what you say as what you'd done so yes, I would say, we did."

Another, with a similar understanding of shared decision-making found a mismatch in the portrayal of professional roles.

"My university training was very different to reality I think, particularly in [therapy] it was very taught that we would do what doctors say and would be told what to do. Whereas in reality, you know, we work together and obviously take advice and we get referrals for particular things but actually the whole range of options available does depend very much on the individual, and the consultants or the doctors don't always, aren't always aware of that, obviously otherwise they would just do it themselves."

For therapists, the primary difficulty seems to gaining access to training and Continuing Professional Development opportunities to support them in shared decision-making (however they understand it) and to develop and disseminate best practice. This applies particularly to training in skills that are not necessarily recognised as being necessary competencies for professional practice.

Within the interviews, we asked health professionals to identify the skills required for shared decision-making – an exercise which some had already started to do in-house. We can safely conclude that shared decision-making, as practised by health professionals in the East Midlands, requires a very broad skill set that differs from, but obviously complements, 'traditional' clinical skills.

All interviewees of course identified communication skills as being key, but, however defined, it is clear that shared decision-making goes well beyond the basic communication skills of listening, explaining, reflecting back and so forth. There are, for example, a set of core management competencies that any practitioner will need in order to share decisions and to support others in implementing those decisions safely and effectively. These include leadership, change management, motivational and coaching

skills, which are only just now becoming recognised as core competencies for patient-centred care.

"... to be honest, I think it's only in the last year or so that we've actually sat down and thought about what these skills are really, because when you do your training needs analysis we're thinking 'Well, clinical skills and a bit of leadership perhaps', and I think it's only recently that... although in the past we've done things like motivation training and things, but it tends to be a bit ad hoc, do you know what I mean?"

A shift from medical models to social models of care (a relatively recent mainstream development) seems to be a key driver.

"To be fair there's not been a lot of recognition that our job is what I've just said it is ... So there's still quite what I would call a medical model of see lots of people and treat them, and it's broader, looking at a more social model, it's only just being accepted, I would say."

The difficulty is that practitioners, especially more junior practitioners, cannot necessarily access training or CPD to acquire and develop all these skills. Free training and development opportunities in, for example, leadership are highly valued (e.g. those provided by the NHS Institute of Innovation and Improvement); otherwise professionals most often find shared decision-making content with more clinically-oriented training and development opportunities.

Other than training and updates in the legal issues pertaining to capacity to give valid consent, formal training specifically to support professionals in involving people with learning disabilities in decisions seems particularly hard to come by. As noted above, some East Midlands service specialist service providers have worked to address this gap by providing training and support for people in other services, with the emphasis on informal training and 'on the job' learning opportunities:

" ... there's very rarely anything that's specific around learning disabilities but there are generic things around maybe clinical supervision or things, you know, some things about Mental Capacity Act and things like that."

"I think there are those sorts of courses around for communication skills and we've in fact done some training, our [therapists], we've provided some training across the trust ... communication skills for people who would work with learning disabilities but not from learning disability services, so we had people from mental health services or CAMHs services, I think even some PCT staff, so we did provide something like that. But people often don't, it doesn't come across as a priority amongst all the other training."

"... if I think about the kinds of things that we do as part of our continuing professional development, we have a requirement to do a module on capacity which is updated every so often, we've got a lot of stuff that really sort of goes through the whole of our service

which is about person-centred thinking and we have a whole load of different tools that we're encouraged to use where there are things where it's important to involve the person that kind of thing, and that's ongoing both in terms of training and in terms of professional development in being able to work with a colleague on using them, that kind of to be, the on the job learning as well as the formal teaching ...."

"So we have a range of training, but we don't focus so much on the formal training, we focus more on saying 'Look, here's a resource that might help you, here's somebody who could mentor you through this bit', because people can't... well, you know the problems around formal training, lack of generalisation and time to do it and all that sort of stuff."

General practice

The general practitioners whom we interviewed indicated that the emphasis on communication and consultation skills within general practice training had prepared them for shared decision-making, and notably in a way that other medical specialties' training does not:

"So I think if you're surgically-trained you have a different slant on things. I think, possibly, all graduates have a different slant and have to re-learn their consultation skills. So I think, you know, I think consultation training needs to be built into all the specialties as part of the requirements for them to gain accreditation in their specialty. ... the main focus, the focus of general practice training is around the consultation. Right, so before you can qualify as a GP, your final exam is actually a simulated surgery that actually looks at your behaviour and your ability to communicate with the patient in a consultation. You know, that's with actors, okay. And it is now compulsory for all GPs to pass that qualification. In other qualifications, in other specialties, the focus is around the disease setting and the disease management, rather than the consultation."

5. Impact of NHS changes: actual and potential

In the workshop, health professionals were asked to consider how recent and ongoing NHS changes would or could potentially impact on services' ability and capacity to deliver shared decision-making and the 'patient revolution'. Participants were asked to work in small groups to discuss what would help and what would hinder, and to report their findings back in plenary. This section provides a commentary on the major themes that emerged, and that are not discussed in Section 4, expressed as set out by participants' (i.e. without editorial).

5.1   Impact of NHS changes: how could they help implement shared decision-making and 'the patient revolution'?

The participants of the workshop saw opportunities in the impending organisational changes. They believed they could provide the significant 'step-change' needed in order to drive the cultural change necessary to embed shared decision-making as best practice in service delivery and commissioning.

Participants also noted that the concept of shared decision-making is consistent with the (more) effective use of NHS resources. It fits very well with streamlining care pathways, and with rationalising referral systems to limit (for example) opportunities for clinicians to refer over-widely and inappropriately in seeking to cover all possible bases.

"We call it a scattergun approach, we were having GPs that were just basically going, "Oh my patient needs something so I'll refer there, there, there, there and there," and I mean it wouldn't be the first time that I'd turned up at a patient's house to find out that I'd been the second therapist to arrive that morning because somebody's come from somewhere else."

Further positives were seen in the requirement for CCG boards to include patient and nursing voices. Recruited properly, both could provide the necessary insight and 'checks and balances' to keep shared decision-making and patient-centred care firmly within the CCG board's remit and sphere of influence. CCG boards could be seen to provide the leadership needed to drive the 'patient revolution' throughout NHS East Midlands.

Within the NHS changes there were a number of reporting or accountability measures that workshop participants believed could help to ensure that, once implemented, shared decision-making remains embedded – not least the use of CQUIN goals that relate to shared decision-making.

Participants also identified opportunities to incorporate deliverables relating to shared decision-making in revalidation, professional development programs and individual appraisals. This was also regarded as a way to ensure its wider adoption.

Finally, the fact that GPs will be responsible for shaping the care pathways of individual patients means that they will become increasingly and more directly aware of and involved in patients' treatment outcomes. This should make for better links between primary, secondary and community care, which in turns will help to sustain shared decision-making and some elements of the 'patient revolution'.

5.2 Impact of NHS changes: how could they hinder the implementation of shared decision-making and 'the patient revolution'?

Workshop participants were worried that in navigating all of the reorganisation that is currently underway, there would not be time/capacity properly to plan and implement shared decision-making. Similarly, there was consensus that it would be difficult to achieve the cultural, policy and procedural changes that would facilitate and sustain the 'patient revolution', given the current stresses and strains on the system.

Defined targets (particularly financial targets) and performance indicators may not support - or even allow - the flexibility necessary to implement shared decision-making, despite any long-term health outcome and financial benefits known to be associated with patient-led care. In other words, the tension between quality and targets may be more pronounced in 'the new NHS' than it was in previous incarnations.

There was also a fear that, in having clinicians commission NHS services, 'medical models' would dominate and that 'soft' outcomes and patient needs may be overlooked. The view of the health professionals in the workshop was that general practitioners and other doctors are less likely than other professional groups to work well in multi-disciplinary teams. This, if reflected in CCGs' working and their approaches to commissioning, would result in a more difficult landscape for shared decision-making.

The other concern with the new commissioning model is that SHA- and Cluster-wide initiatives and drivers, such as the shared decision-making and the 'patient revolution', may be difficult to coordinate amongst the 22 CCG areas of NHS East Midlands. Moreover, the competing priorities of each of the 22 CCGs may make it difficult to undertake work toward integrated care pathways. Further fragmentation may arise from the competing commissioning requirements of the different CCGs, and the development of different local service constellations in response to (sometimes very) local need.

The 'any qualified provider' market in the 'new NHS' could also significantly hinder information sharing, integration of services, sharing of innovations or best practice and ultimately the success of the 'patient revolution'.

As resources become scarce, and contracts more competitive, providers will look not only to improve their service model according to CCG and patient needs; they will increasingly need to differentiate and isolate themselves from other providers.

"I do worry now whether we're going to get less information flow between different providers, because we're competitors, now that's never really happened before but even with my colleagues in [therapy services] in different areas, we're starting to get that actually we're not prepared to share that with you. And there's no way that two independent providers are going to show their cards to each other are they?"

A concern about this competition is that it could further increase health inequalities, particularly in the rural/urban divide of NHS East Midlands.

6. Delivering shared decision-making and the 'patient revolution' in the East Midlands: barriers and support needs

6.1 Identifying barriers and support needs

This section synthesises our findings about barriers and support needs from the individual interviews with professionals, the young people and parent focus groups, the professional discussion group and the professional workshop.

The young inspectors and parent participants were not directly asked about 'barriers to shared decision-making', not least because the term had very little meaning for them. Rather, their perspective is inferred from their responses to other questions and from their discussions about their families' experiences of care.

Professional interviewees were asked directly what they considered to be the biggest barriers to shared decision-making. Participants in the professional discussion group were asked to identify what health professionals, patients, service users and carers need for shared decision-making, and also what health services 'would look like' if shared decision-making 'as the norm' were achieved. This approach, effectively focusing on 'what needs to change', encouraged participants to consider and identify key barriers and also to think positively about 'what needs to be done'.

Building on the discussion group's work, participants in the professional workshop were asked to identify the support that health professionals and services would need in order to deliver shared decision-making and the 'patient revolution'. They were then asked to prioritise the various elements of support that they had identified by organising them on a timeline of 'now', 'within six to twelve months', and 'longer term'.

On the whole, there was very good agreement about what needs to be put in place and when. The most notable difference was with regard to patient and public communication, information and education initiatives, which most participants identified as a support need; some placed these in the 'now' category and others placed them in the 'six to twelve months' category, i.e. after the NHS had got its internal 'enablers' in place.

Rather than separately describing 'barriers', 'what needs to be done' and 'support needs', we have themed these together into five key priorities for delivering shared decision-making and the 'patient revolution' in the East Midlands.

6.2 Key priorities for delivery

The single biggest barrier to shared decision-making, identified by most who were asked or who expressed a view, was 'time'. Shared decision-making takes time, and it takes more time to do properly with some patients and services users than with others. Providers have less and less time, not more, that it not already accounted for – and so do many patients, service users and carers. Multi-professional and multi-agency working and decision-making takes time, which can conflict with the need to be responsive to patient and carer needs. Care pathways and provider systems do not necessarily include time or time-out opportunities to find, digest and reflect on information and options. Some important provider targets are time-bound. Involving patients, service users, carers and the public in commissioning and service-re-design takes time, and, to be meaningful, must be done at the right time. And so forth.

There is no doubt that 'time' is the river that runs through shared decision-making; we have however chosen not to identify it as a separate priority; rather 'time' and 'time-effectiveness' are implicit in each of the following.

6.2.1 Communicating and operationalising shared decision-making and the 'patient revolution'

The most commonly identified - and most urgently prioritised - support need with regards to shared decision-making and the 'patient revolution' was for direction and leadership from the top and centre of the NHS.

This means:

- defining and communicating what shared decision-making is, and clearly setting out what it means (and does not mean), in practice, for health professionals, commissioners, patients and service users, carers and the public;
- clarifying the East Midlands' strategic vision, communicating what is expected of staff and services, and providing unambiguous operational direction;
- making and communicating the connections: helping staff to see and understand the relationships between shared decision-making, the 'patient revolution' and all other relevant extant documents and initiatives, rights and responsibility frameworks, policy drivers, outcomes and performance frameworks, metrics and so forth; in particular, to avoid presenting shared decision-making as 'something extra' that people need to do on top of everything else.

In all professional interviews and group discussions, there was consensus that the aims and intents of shared decision-making and the 'patient revolution' were laudable and

would improve patient experience and health outcomes. However, a lack of clarity and transparency - about the reasons for sharing decision-making, the meaning of the 'patient revolution' beyond its three broad components, and the strategies for making progress with either − makes engagement and implementation nigh on impossible for front-line staff, particularly those who are more remote from the SHA and its strategic teams.

As evidenced in Section 2 of this report, NHS staff groups have different understandings of what shared decision-making comprises. There was however consensus that a crucial determinant of success would be leadership, guidance and genuine commitment from senior and central NHS leadership, in:

- defining what shared decision-making is;
- setting out what it looks like in practice;
- developing the strategy and timelines, and identifying the resources, for implementing change and supporting staff to achieve it 'as the norm'.

With regards to shared decision-making in clinical practice and along care pathways, health professionals specifically asked for 'robust policies', which were consistent across all NHS East Midlands organisations so that everyone was 'on the same page'. A codification of procedures and/or a shared decision-making charter would mean that:

- all professionals in NHS East Midlands would have the same 'core' understanding of expectations and indicators of involvement in decisions;
- patients, service users and carers should begin to experience a consistent and coherent approach to involvement within and across services and care settings.

This would not necessarily preclude the development of more detailed service- and context-specific models of shared decision-making, where these were considered appropriate.

Professional discussion group and workshop participants emphasised that shared decision-making should be regarded as an ongoing dialogue, not a single event, where decisions about care and treatment, and their implementation, are revisited appropriately. This fits very well with parent participants' discussions of how needs change over time, and the important of services responding accordingly and flexibly. Models of shared decision-making should therefore include creating opportunities for patients to review and revise decisions about whether or not to receive any treatment or any particular form of treatment, and to identify new needs for information and support.

6.2.2 Securing senior- and very senior-level direction, leadership and support

There was consensus that front-line NHS staff need executive, managerial and commissioning support in order to deliver on shared decision-making and 'patient revolution' ambitions. This includes ensuring that shared decision-making is embedded in the work and ethos of senior clinicians, trust executives and NHS boards, including CCG boards.

This means:

- visible high-level interest, engagement and constructive operational oversight;
- practical and tangible support to enable staff and services to deliver;
- demanding and driving the necessary cultural shifts;
- setting out clear expectations of what health service staff, including commissioners, should be doing to deliver shared decision-making and the relevant elements of the 'patient revolution', and describing how progress will be measured;
- building the shared decision-making and 'patient revolution' ambitions into organisational and service-level values, systems and processes, performance incentives and reward and recognition schemes, and commissioning impact assessments;
- identifying and addressing the resource implications of shared decision-making and the 'patient revolution' for front-line staff – especially the implications for the way staff and services use their time, and the need for information, education and skills training to support staff in engaging patients (including harder to reach/seldom heard individuals, groups and communities) in service evaluation and re-design.

Participants' emphasis on high-level leadership and support reflected their understanding that delivering shared decision-making and the 'patient revolution' will require considerable, wide-ranging and sustained changes in the culture of the NHS and its organisations. Most of the discussions about barriers and what is needed to facilitate and support shared decision-making came down, essentially, to cultural change - among professionals, patients and the public.

Some participants identified commissioning and commissioners as key drivers for cultural change.

"The biggest barrier? When people are threatened by it. … I remember when the internet first came out and the GPs were all up in arms because people were coming to them with things from the internet. You know, and I think they were actually perhaps quite threatened. For the first time, they had to treat people, you know, who actually thought they were on a footing where they … actually did know more about their condition and what to expect. So, I do think probably the biggest barrier would be around, you know, feeling comfortable, not feeling threatened by it. It is going to be a culture change. … I

think maybe another barrier is people knowing that they have the right to be empowered, you know, for people to know that they don't have to… So, perhaps it's around the culture … I'm not sure how we get this message across in terms of the public, that they can actually expect us to co-produce their action plans. I guess that's why we do need the CCGs now at this next stage to lead on that because, for the corporate body, it is probably now time for the CCGs to lead on that. Only they, as commissioners, can probably affect the next tier of change."

"I suppose the barriers … they're around the whole cultural understanding of what's required in learning disabilities, and to a degree, they're a bit controversial, the way we're commissioned, because the big battle I had to have last year was how costly [therapy services] are because we see so few people, because we're doing all this other work, so we cost on our price activity matrix more than a [specialist clinician], more than anybody, you know, the whole world, and that whole view then is distorted because they don't look at all the other work that has to be done really."

Participants also observed that resistance and 'keeping one's head down' are understandable and not unusual responses in the face of unprecedented organisational and structural change, or to yet another policy directive. Without high-level leadership, change is unlikely to happen. That aside, change on the necessary scale, as described above, cannot realistically be achieved 'bottom up', even by the most determined health professionals or service delivery teams. An individual GP or therapist, for example may be willing and able to share decisions within their consultation room. But without shared decision-making being embedded throughout their patients' care pathways, and in all the services and drivers that shape those pathways, patients are not consistently involved in sharing decisions about their health and healthcare.

"I mean it has to come from … one person in a team can have it, or a team can have it, but it has to be embedded as an organisation so that it is the norm in every service and it's naturally built in."

"And that's where some of the policies and things, a lot, you know, if it's the norm it will be naturally build in, I hate policies and procedures, you know, it's almost like dictating how you can do it but it's an in-built thing, ingrained so as much as it can be like a personality trait it almost should be like an organisational trait."

At operational level, health professionals looked to robust top-down direction that:

- seeks and uses staff, patient, service user and carer input in establishing and communicating best practice;
- creates spaces and opportunities for ongoing dialogue, engagement and buy-in from staff, patients and service users, carers and public.

The last point about engagement is important. In shifting the culture toward one that is open to change, health professionals emphasised that an engagement process would be

necessary to achieve buy-in for the desired cultural change and to ensure that any consequent changes in service delivery work for both patients and professionals. An explicit commitment to engaging patients and carers is also needed to allow NHS East Midlands staff and managers to:

- identify patients' needs with regard to information and peer support;
- understand how patients' information and support needs change throughout care pathways;
- understand carers' awareness of, and access to, available resources;
- better match information and other resources to patient and carer needs by, for example, developing information materials/resources, support systems and advocacy services.

This need to engage patients, service users, carers and the public in turn means building staff involvement and engagement skills, i.e. establishing external and multi-professional peer support skills training and support systems for staff. This includes communication and consultation skills, and support with gathering, 'making sense of' and effectively using patient feedback data

Requiring clinicians to relinquish the power and control that they currently hold in the patient-professional relationship was a particular form of cultural shift that participants said would be necessary. For individual health professionals and for NHS organisations, this means consistently regarding the patient as an active and equal partner in their healthcare.

In turn, this means that shared decision-making will need to become integrated in to NHS organisations' managerial procedures and processes, for example becoming part of staff objectives, appraisals and performance management systems. Fundamentally, it also means integrating the principle of shared decision-making into recruitment.

"I'm a nurse by background, so from a nursing point of view recruiting student nurses into courses, we have to recruit for attitudes and beliefs, not for education - I'm sorry, you know, I'm all for nurses having a degree, I've got a couple myself, but you know, if they haven't got the right attitude and the right values then all the training in the world will not make them a good nurse and I suspect that applies to other professionals as well…"

6.2.3 Developing multi-disciplinary and multi-agency models of working – including *"IT systems that actually talk to each other"*

Professional participants agreed that the NHS' default ways of working would need to change substantively in order to support shared decision-making and the 'patient revolution'. In particular, they said that the NHS will need to put much greater emphasis on:

- developing care models that put health professionals, patients and carers all in one room together;
- working effectively with all stakeholders including social care, the voluntary sector and LINks (and successor organisations/networks).

Again, this fits well with parent participants' experiences and their expectations of coherent and coordinated care.

Professional participants identified two key, and apparently highly inter-related, barriers to effective multi-disciplinary and multi-agency working:

- the traditional 'silo' mindset that persists in some areas, and is re-emerging in others;
- failures in intra- and inter- service communication and information-sharing.

Professional participants generally equated successful shared decision-making with effective information-sharing, and both of these with coherent, coordinated and patient-centred care. This understanding is strongly supported by the parent participants' frustrations at having to provide that same information over and over again to different professionals and services, and at obvious failures in communication and coordination.

There was however a clear consensus, from all project participants who commented, that record-keeping and information-sharing practices, systems and infrastructures in the East Midlands (and no doubt most other areas of the NHS) create a significant barrier to fulfilling shared decision-making and the 'patient revolution' ambition.

Illustrating how the two barriers are inter-related, one interviewee described how patient-held paper maternity records (introduced decades ago as an advance on hospital-held computer records) do not reflect today's IT possibilities and ambitions for joined-up care.

"So we have this kind of madness at the moment that the midwives give patients paper records ... some midwives will record something like [on computer records], sometimes they don't, depending on whether they're used to doing that or not, and actually, you could have totally computerised patients' midwifery records that could be seen at the hospital, in general practice and by the community midwife and, you know, you could get away from the fact that the patient hasn't brought their paper records with them today, so that nobody knows what's going on. And the GP doesn't know what's going on because

the midwife's not filling in the computerised record. So, you know, I think there's a lot of work to do to stop working silos and start joining all this stuff up."

In the group and workshop discussions, health professionals agreed that shared working and shared decision-making are much more easily fostered and sustained where there are easy opportunities for people to share information face-to-face.

Where people do not physically meet or share premises, robust primary, community and secondary care IT systems that 'actually talk to each other' are an absolute necessity for multi-disciplinary and multi-agency working, and ultimately for delivering shared decision-making (on any understanding of the term) and the 'patient revolution' .

Some participants could access the East Midlands Framework 1 system and this clearly has considerable potential. But there are access issues that undermine its effectiveness, for staff and patients.

"I think that it's just sometimes the set up in which you work makes joint decision making a lot more difficult. We're very lucky here, we work in a big health centre with lots of other professions based here and so it's much easier to make joint decisions. I mean Social Services aren't physically based here but we have a very close relationship with them and we can actually see their notes, we can see Framework I on our computers, they can't see our notes at the moment but that would make a big difference if we shared information, you know, across on our PCs."

"Yeah, because people have to trust you when you're making shared decisions, they have to, you know, to know sort of where you're coming from if you like. And so actually building those relationships is very important I think and we've just gone on to electronic documentation so all our notes are now on the computer. Our barrier at the moment is that we can't see the GP notes but we're hoping that some of that will, we will have access to some of that in the future and that will make a big difference."

In practical terms, the priority for NHS East Midlands might well be to work with services to address the gaps and inconsistencies with regard to:

- who knows about and is on board with shared decision-making as an approach to care, and who needs to be more/better informed and engaged among:
  - o NHS staff and services, including CCGs;
  - o other public sector service providers including social services;
  - o emerging bodies and networks, including Health and Wellbeing Boards and HealthWatch.
  - o voluntary sector organisations;

- who is 'on' record-keeping and information-sharing frameworks and networks, who needs to be, and how otherwise professionals can access the information that they need and have the right to access;

- which individuals (including patients, service users and carers) and which services and teams can and could see which sets and items of information.

Within information-sharing, electronic or otherwise, there are of course legitimate concerns about maintaining confidentiality and data protection.

One interviewee, however, was concerned that 'data protection' arguments might be used speciously to block legitimate and useful information sharing, and so undermine shared decision-making.

"I think part of the barriers and the resistance is around what they'll class as, you know, data protection and protecting the interests of their patients, and therefore not being happy to share information very readily."

Discussion group and workshop participants' view was that data protection and confidentiality concerns could and should be addressed by supporting staff with clear guidelines and protocols.

"... we had had complaints about breaches of confidentiality, people with good intentions, so it's about having support and people being very clear about what can we can share and what can't we share and that perspective. And about patients and carers and the family members and so on, that information should be and can be shared."

6.2.4 Preparing and equipping patients and the public for shared decision-making

Taking all the project participants' contributions together, a key barrier to delivering on shared decision-making and the 'patient revolution' is clearly that (across the NHS) the shared decision-making policy agenda has been almost entirely inward-looking. That is to say, it has focused almost exclusively on the health service rather than on the people who use health services. While, as described in Section 3, most professionals believe that there is an upward trend in patients wanting to be involved in decisions about health and healthcare, this is not really being driven or supported by NHS initiatives. Further, no-one knows who (if anyone) is responsible for communicating and engaging with patients, services users and carers to tell them what is going on, what changes they can expect to see locally, and what it means for them, their role and their relationships with health services and commissioners.

Participants emphasised that, for shared decision-making to make a real difference, patients and the public need to be equipped with the information, knowledge, skills and confidence to:

- share decisions with professionals about treatment options and about local service development;
- ask the right questions;
- challenge health professionals constructively and effectively.

For patients who do want to be involved in decisions regarding different treatment options and providers, the 'ideal' relationship of trust and rapport is necessary but not sufficient. Patients and professionals also need clear, standardised information on treatment options and relevant information about different providers in order to share decisions and make choices.

Some participants were concerned that patients should not (only) make choices based on providers' hotel services just because it is more easily accessible than on information about quality.

"Biggest barrier? I think it's about the right information presented in the right way. As a healthcare professional it worries me that people will make a decision as to what hospital they want to go to by whether they're likely to have their own room and what the menu looks like … but that sometimes is the easiest information to present to people when you're saying 'you know, you've got a choice, you've got a part in this decision-making', so I think it probably is the right information presented in the right way."

There was also general agreement that the NHS and other public services could and should do more to increase the confidence and ability of young people in sharing decisions with health professionals. Professional participants emphasised that includes working to enable and empower school-age children, with a view towards longer term cultural change in how patients and public view their relationships with health professionals and how they use health services. This is strongly supported by the focus group discussions with young people, and with the diabetes parents' observations about the importance of preparing children and young people for adult life, including preparing them for adult relationships with health professionals and services.

This is clearly a wide-ranging agenda, with very many potential elements. Taking all participants' contributions together, the immediate priorities for NHS East Midlands might be to focus on:

- raising awareness of shared decision-making and the 'patient revolution' outside the NHS, with:

  o patients and service users, including people living with long-term conditions;
  o carers and families;
  o the general public, including minority groups and communities;

- identifying professionals' information needs for shared decision-making, i.e. determining which information materials and resources professionals most need in order to share decisions and to support patients, services users and carers in understanding conditions and sharing decisions about care and treatment;
- establishing and/or signposting directories of reliable, up-to-date and quality assured information resources for professionals, patients, service users and carers, including information about local services and sources of support;
- providing access to tools and toolkits and, especially, face-to-face development opportunities for staff to meet, network and share ideas and good practice with regard to shared decision-making and the 'patient revolution'.

A recurring theme throughout the project was that shared decision-making, as an approach, is not a new concept. Some elements of it (however understood) are already well-established in some NHS services, particularly, as described above, in mental health and learning disability services. Consequently, there are also tried and tested tools and resources to support professionals as they in turn support others in making and implementing decisions; there no need to 'start from scratch' in deciding what good practice looks like. Participants cited Experience Based Design, The 15 Steps Challenge, the Health Foundation's Patient Skills modules and Co-creating Health as examples of tools that could and should be more widely disseminated and promoted.

6.2.5 Showing that shared decision-making works

Given the practical and cultural changes required, shared decision-making is unlikely to become self-sustaining until and unless people understand and experience tangible benefits.

'Showing that it works' emerged as a key theme in the professional discussion group and workshop, i.e. developing, communicating and contributing to the evidence base about the impact that shared decision-making can have on a range of 'soft' and 'hard' quality measures and indicators, including for example:

- patient, service user and carer experience of services;
- clinical effectiveness and safety;
- concordance with treatment;
- effective self-care and self-management of long-term conditions;
- health and well-being outcomes including PROMS and PREMS;
- use of NHS services and resources.

This means, with regard to service delivery and commissioning:

- o communicating the 'theoretical' benefits of shared decision-making, according to the evidence-base – why it is important, why participate in it, why it is cost- and time-effective;
- o providing locally specific feedback to staff, patients and public about changes that have been made as a consequence of shared decision-making in clinical care and commissioning, and the effect that they have had on service quality and efficiency.

Monitoring and evaluating the impact of shared decision-making and the 'patient revolution' in the East Midlands – and celebrating success - was important to staff. They were however clear that achieving shared decision-making requires a step-wise approach across the East Midlands – it should be regarded as the result or goal that is reached via a series of distinct building blocks, and not something that can be achieved like Superman 'in a single bound'. This means that indicators and evidence of progress and 'success' will also need to be developmental.

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