Supporting Shared Decision-Making

A PATHFINDER PROJECT FOR NHS NORTH WEST

JOAN WALSH AND DANIELLE SWAIN
PICKER INSTITUTE EUROPE
AUGUST 2011

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.

picker
Institute Europe
Making patients' views count

CONTENTS

Acknowledgements

Executive Summary

The Picker Institute worked with people in the North West between April and June 2011, exploring their views about shared decision-making and identifying the support systems and structures that would be required to achieve 'shared decision-making as the norm' in health and health care. This work was commissioned by NHS North West as one of the Department of Health-funded shared decision-making pathfinder projects.

A qualitative and developmental approach was used, with the content and design of each stage being informed by learning from the earlier phases of the project. The work consisted of:

- individual interviews with general practice staff;
- a series of eight focus groups with health care professionals, adult members of the public, general practice Patient Participation Group members, and young people;
- two larger multidisciplinary workshops with NHS staff.

The key components of shared decision-making identified by NHS staff in the focus groups were:

- patients and service users who have:
  - the information and literacy skills they need to understand the options available to them, and the implications of their choices;
  - the knowledge and confidence they need to participate in the decision-making process as much as they want to;
  - the skills and support they need to implement decisions successfully where these require (for example) adherence to treatment plans and/or lifestyle changes;
- health professionals who have the necessary communication and information-sharing skills, and who genuinely respect patients/services users' knowledge and expertise within decision-making processes;

- in particular, health professionals who are able and willing to share information and decisions regarding desired and achievable outcomes, and regarding the risks, benefits and likely outcomes of different treatment options;
- inter-relationships between health professionals and patients/service users that genuinely reflect the principles of collaboration and partnership working;
- identifying and including everyone with a legitimate interest in the decision(s) to be made and supporting their participation throughout an ongoing joint planning process;
- a local health service design and infrastructure that supports shared decision-making – in particular:
  - o appointment/time allocation systems that allow patients/service users the time to find, absorb and understand information at an appropriate point in the care process or pathway;
  - o systems for ensuring that information about decisions and the factors that shaped those decisions are appropriately and consistently shared between health professionals, between services and across health and social care boundaries.

While some participants had experienced shared decision-making in health care, focus group work with adult members of the public, PPG members and young people suggested that:

- the concept of 'involvement' in health and health care had little meaning;
- the term 'shared decision-making' had absolutely no meaning for most people;
- there is a considerable gap between 'usual practice' and shared decision-making 'as the norm' in health care, especially for young people.

Building on the focus group outputs, workshop participants identified ten work streams to support shared decision-making:

- making the case for shared decision-making;
- achieving senior-level buy-in and leadership;
- developing and implementing communication and engagement strategies;

- reviewing and revising the way that information is recorded, shared and communicated;
- embedding and resourcing shared decision-making within professional education, training and continuing professional development;
- improving the availability, accessibility and quality of information for patients, service users and the public;
- developing support systems and structures for patients, service users, carers and families;
- integrating shared decision-making into care plans and pathways;
- developing information resources and support for health professionals;
- incentivising shared decision-making 'as the norm'.

1   Introduction

1.1   Background

NHS North West

NHS North West was formed as one of the ten Strategic Health Authorities in 2006. The region covers 14000 square miles, 77 parliamentary constituencies and 46 local authorities. It is home to more than seven million people.

The SHA is responsible for ensuring appropriate health care for each of those people. It does this by providing strategic leadership and monitoring for a wide range of healthcare providers including:

- twenty four primary care trusts (PCTs), arranged as five PCT clusters (Cumbria, Lancashire, Merseyside, Cheshire and Manchester);
- twenty three acute trusts,
- eight mental health trusts,
- seven specialist trusts, including children's cancer and learning disability services
- North West Ambulance Service.

It has a responsibility for ensuring that more than twelve billion pounds of public money is spent wisely to achieve its aims.

Its four main functions are to:

- provide a strategic direction for the NHS in the North West;
- make sure that the NHS provides high-quality services that are value for money and meet the needs of local people;
- manage the performance of NHS PCTs workforce planning and education; commissioning on behalf of the NHS organisations in the region NHS North West is responsible for.

1.2 NHS North West pathfinder project aims and objectives

In November 2010, the Department of Health, through their Patient and Public Engagement and Experience Division, submitted a successful proposal for funding for a series of shared decision-making pathfinder projects, to be led by each of the ten Strategic Health Authorities (SHAs).

The work was intended to progress 'shared decision-making as the norm, as set out in the Government's July 2010 Equity and Excellence White Paper[1]. The Department indicated that the pathfinder projects might address any of the following;

- assessing how staff culture and behaviour can best be supported to be consistent with the White Paper vision of shared decision-making, information and choice;
- exploring the views of clinicians about shared decision-making and self-care and the impact it will have on their relationship with patients;
- building support for shared decision-making and information giving, through focused engagement and for example the appointment of clinical champions;
- exploring with clinicians how commissioning could maximise patient involvement in their own health and care, considering shared decision-making and information-giving as outcomes, and how these might be reflected in commissioning specifications.

NHS North West decided that its pathfinder project should focus on building support for shared decision-making and information giving. In March 2011, the SHA commissioned Picker Institute Europe to design and deliver an engagement process within the pathfinder project to achieve a greater understanding of:

- the key issues and challenges to be addressed in achieving 'no decision about me without me' as the norm across the NHS in the North West;
- what shared decision-making means 'in real life' and the implications for professional approaches and behaviours;

---

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

- the nature and scope of the changes required for building support for sharing decision-making, covering professional and patient roles in the decision-making process.

1.3   Approach

A qualitative and developmental approach was used for this project, with the content and design of each stage being informed by learning from the earlier phases of the work.

Stage 1: April 2011- Interviews with General Practice staff

During April 2011 a series of interviews with staff from a general practitioner service previously identified by NHS North West were carried out. These general practice interviews were informal and deliberately less-structured, aiming to uncover people's thoughts and ideas about shared decision-making rather than to test any particular model or approach. The issues raised and Information provided by all the interviewees shaped the development of the focus group topic guides and the design of workshop activities carried out in subsequent stages of the work.

Stage 2: May 2011- Focus groups with healthcare professionals, patients and the public

In May 2011 a series of eight focus groups (healthcare professionals, patients and the public) were held in the North West area to explore:

- professional, patient and public perceptions of shared decision-making;
- the gap between 'where we are now' and the ideal of 'shared decision-making as the norm', and the priorities for progress;
- the 'real life' barriers and challenges for professionals and patients with regard to shared decision-making and information;
- the factors and opportunities that facilitate good information provision and genuinely shared decision-making;
- the support needs of individual health professionals and service delivery teams who will be expected to achieve shared decision-making as the norm.

Focus Group Schedule

Group	Location	Date / Time	Participant characteristics	Number of participants
1	Preston	11th May 2011 Afternoon	Clinicians and allied health professionals recruited through NHS communication networks	11
2	Manchester	12th May 2011 Evening	Clinicians and allied health professionals recruited through NHS North West communication networks	7
3	Manchester	17th May 2011 Morning	Clinicians and allied health professionals recruited through NHS North West communication networks	3
4	Manchester	17th May 2011 Afternoon	Clinicians and allied health professionals recruited through NHS North West communication networks	3
5	Preston	18th May 2011 Morning	Clinicians and allied health professionals recruited through NHS North West communication networks	5
6	Manchester	24th May 2011 Afternoon	Members of the general public representing mixture of age, gender, ethnicity and socioeconomic status. Recruited via a specialist research recruitment agency based in the North West	8
7	Manchester	24th May 2011 Evening	Members of GP Patient Participation Groups (PPGs) based in the North West region. Recruited via the National Association of Patient Participation (NAPP).	5
8	Knowsley	25th May 2011 Evening	Young people aged 13- 21 years recruited via THinK (Teenage Health in Knowsley) and LINked-Up (The Knowsley Children and Young People's Local Involvement Network).	13

Each group lasted for approximately two hours. They were held at different times of the day and evening and in appropriate venues to accommodate a range of potential participants. Refreshments were provided. Participants were assured of confidentiality and encouraged to talk honestly from their own perspective.

Focus groups with clinicians (nurses and doctors) and allied health professionals, hereafter referred to as 'professional' focus groups, were held on premises belonging to or sourced by NHS North West. The adult public, PPG member and young people's groups were held in non-NHS venues.

Participants were given a general information sheet about the project and were asked to sign a consent form for digital recording. At the end of the groups, the young people, adult public and PPG member participants were offered a small cash incentive in lieu of their time and travel expenses.

All the focus groups were digitally recorded and transcribed verbatim. Participants' analyses, recommendations and emergent themes were taken forward into the agenda for the deliberative workshop events

Stage 3: June 2011 Workshops

Two open-invitation multidisciplinary (NHS staff) participatory workshops were held in June 2011.

Invitations to the workshops were issued via the NHS North West communications networks. Some, but not all, participants had previously attended a Stage 2 focus group or were part of the interviews held with General Practice staff in Stage 1.

Workshop schedule

Group	Location	Date / Time	Number of participants
1	Manchester	14th June 2011 Afternoon	22
2	Manchester	15th June 2011 Afternoon	39

The workshops lasted for approximately three and a half hours. Participants were assured of confidentiality, and encouraged to speak directly from their own perspective and experience.

The sessions began with scene-setting presentations to achieve a level playing field among participants, describing the context for the project, locally relevant data about patient involvement in decisions about care and treatment, and the findings from earlier

stages in the project. The workshops were highly participatory, with whole group discussions and smaller group work. Delegates were asked to focus on 'what needs to be done' and 'what would help people do it' for the NHS in the North West to work towards shared decision-making as the norm

October 2011 Learning Event

The results of this project will be presented as part of a NHS North West learning event on 4th October 2011.

2 What does shared decision-making mean?

2.1 NHS staff understandings and interpretations of shared decision-making

During the general practice interviews and at the beginning of all the 'professional' focus groups, project participants were asked what shared decision-making meant to them.

2.1.1 General practice staff interviews

There were mixed understandings of shared decision-making among the general practice interviewees, both about its purpose and value, and the extent to which decisions are or can be genuinely shared. There were different views among the staff regarding the extent to which patients expect or want to be involved in decision-making, and also about which patients are more or less likely to want to share decisions.

Understandings ranged from regarding shared decision-making as synonymous with 'choose and book', to patients making informed decisions between treatment options, to the longer term negotiation and ongoing re-negotiation and implementation of management plans, including lifestyle, disease prevention and health promotion decisions. General practice interviewees mainly focused on decision-making regarding treatment options within the one-to-one consultation between an individual patient and the GP or practice nurse.

There was consensus that shared decision-making is not appropriate in absolutely every circumstance or consultation, for example where patients are very worried or anxious, in acute situations where it is clearly in the patient's best interests for the clinician to determine what happens next, and/or where there is otherwise a clear professional duty and/or medico-legal imperative for the clinician to make the decision. Time/workload was also cited as a reason for shared decision-making sometimes 'going out of the window', especially where patients present with a very simple problem.

The duration and quality of the relationship between clinician and patient was described as important in shared decision-making - as one of the doctors said, '*starting from the beginning is very hard*'. Doctors' confidence was also mentioned as a potentially important factor, i.e. that the confidence of older/more experienced doctors perhaps facilitated shared decision-making in contrast to younger/less experienced GPs being '*hung up on doing clinical medicine*'. In discussion, this was balanced by a consensus that younger doctors are much more likely to have received communication skills training than doctors who qualified some time ago.

Involvement in decisions

Some of the general practice interviewees firmly believed that patients appreciate shared decision-making. Others were generally less sure, or less confident that shared decision-making was welcomed by all patients. One interviewee, for example, said 'there's still a cohort that wants the doctor to make all the decisions'. Other interviewees also said that some patients prefer the doctor to make decisions, directly asking what the doctor thinks they should do and/or asking what the doctor would do in their circumstances.

One interviewee, whose view was that every patient can share decision-making to some degree, emphasised that patients' willingness and ability to participate depended on a wide range of factors, including previous experiences of the healthcare system, where they are in life, social class, etc. This interviewee also questioned whether the people who most want to share decision-making are the people who would most benefit from it (i.e. whether the people who would arguably most benefit from shared decision-making, e.g. the most disadvantaged, with more and more complex medical problems, would be least likely to share decisions about health and healthcare). Another interviewee also raised this issue, and specifically identified a risk of shared decision-making increasing, rather than reducing, health inequalities by further excluding already disadvantaged people/patients.

Supporting shared decision-making

None of the clinicians had any knowledge of decision support aids, or experience in using them.

With regard to information for patients, the key theme to emerge was the need for more targeted/personalised information that both empowers the patient and saves the doctor time. One interviewee cited a particular need for targeted information about the benefits of weight loss for people with diabetes.

Most interviewees discussed shared decision-making in the context of the clinician-patient (i.e. individual-individual) consultation. One did however discuss the complexities of family involvement in decision-making (the particular example given being familial involvement in decisions about whether or not to pursue diagnostic investigations towards the end of a patient's life). This interviewee also pointed to the potential for shared decision-making to create/exacerbate tensions between primary and secondary care services.

2.1.2 Nurse, allied health professional and doctor focus groups

In these sessions, shared decision-making was often discussed as an approach to health care, relating to broader concepts like patient-centred care:

"I think the term is something I struggle a bit with because we wouldn't talk in terms of the shared decision-making, we would talk in terms of being shared agreements and that we've come to an agreement with them on this about we're going to move forward rather than we've made a decision because that kind of feels like an end point whereas it's an ongoing process."

"So you put your cards on the table, you say, this is what I'm good at, I think you're good at this or I know that you know what you want or I know that you know how to run your life or what's important or what's a priority. And then, with the cards on the table, you can then come up with the best plan, either within the budget that's available, the equipment that's available, the time that's available, whatever it is and you share that."

The purpose of shared decision-making

Throughout the nurse and allied health professional focus groups, negotiating the '*common goal*', i.e. the desired outcome of health care and how best to achieve it, emerged as the primary purpose and/or effect of shared decision-making. This included

discussions about patients and health care providers perhaps wanting to achieve something entirely different. It also means working to agree outcomes with patients who do not want what the health professional has to offer or wants to provide:

"There can be quite a bit of conflict between what you as a physio want to feel that you want to treat and what you can make better but what the impact is on the patient, they may not want what you can offer them. So, you know, we're all about, you know, episode planning and things like that and talking to the patient about what they want to achieve more rather than what we feel as therapists."

2.2   Public, PPG members' and young people's understandings

Whereas 'professional' focus groups participants were asked explicitly about their understandings of shared decision-making, the adult public focus group participants were asked rather to describe their understandings and experiences of being 'involved in' health and decisions about health and health care.

The concept of 'being involved' in health and health care really had very little resonance with participants in the public, PPG and young people's focus groups. When later introduced by facilitators, the term 'shared decision-making' had no meaning at all for adult members of the public.

The facilitators did try, from a number of different angles, to determine whether people were being involved and were sharing decisions, to a greater or lesser extent, without using those concepts or that terminology, but this was not typically the case. Essentially, when asked to talk about their experiences of being involved in decisions about health care, these focus group participants were more likely to describe their experiences of not being involved.

The total number of public, PPG member young people focus group participants in the project was of course very small, and it is not possible to know how representative their understandings and experiences were of the NHS North West population.

2.3 The relationship between shared decision-making and informed consent

Focus group participants had different ideas about the relationship between shared decision-making and informed consent, but there was general agreement that they are related but different concepts:

"To me [shared decision-making] *insinuates that there has to be some kind of discussion and agreement that it's a… that the share part of it is not just "I'm going to share this with you as in tell you"*

"… there's some situations where you provide information and patients are informed but they don't actually make the decision so maybe it should be no decision about me without me understanding why that decision is being made."

"Informed consent sits inside shared decision-making, it is part of shared decision-making but not the whole of it."

"Informed consent is a yes or no decision, whereas shared decision-making is 'Well there's this option, that option, that option. If you took that option, this could happen or that could happen. If you took that option…', so it's kind of a branching tree, and I guess at the end there's a decision to be made, but by going through that process you've got informed consent at the end of it."

"I think shared decision-making is the process, I think informed consent is an end product basically."

2.4 The participants in shared decision-making

In Stages 1 and 2 of the project there was, broadly speaking, a difference between the way that doctors described the participants in shared decision-making and how nurses and allied health professionals discussed them.

Doctors predominantly (though not always) focussed on one-to-one sharing of information and decision-making about treatment options within the consultation or sometimes within a longer term relationship with individual patients. Nurses and allied health professionals typically included a wider range of people as participants in shared decision-making, particularly carers and family members, covering a wider range of decisions.

Nurses and allied health professionals were also more likely than doctors to emphasise a need to share decisions, and information pertaining to those decisions, between:

- individual health professionals;
- primary care, community services and hospital services;
- health and social care services:[2]

"And is it about a shared decision, about different health professionals sharing the decisions with the patient rather than just one person..."

"Sharing amongst health care professionals as well."

'Population-level' shared decision-making also arose in the focus groups, referring to the involvement of patients, carers and the public as participants in decisions about health care commissioning:

"Well two things come to my mind, one is shared decision-making about care at the individual level and it's actually shared with the home, is it just the patients or the carers and families? And the second thing is decision-making at population level which is about you know understanding the priorities of the population and how do you make priorities and make decisions in terms of what health care services are to be commissioned."

"I think there's also something around from an individual basis with an individual clinician, patient relationship but that's, that can be very different to engaging between patient or public groups and services as a group. So on an individual basis it's fairly

---

[2] A workshop participant subsequently raised the need to ensure that specialist service providers such as prosthetic technicians are appropriately included in shared decision-making.

straightforward to have a conversation and come to a decision but it's less simple to engage in groups, whatever those groups might be to look at developing the decisions around how services develop...“

"But in a broader sense if there's going to be shared decision-making about what services are available to which people and that patients are going to be involved with that, they need to know, they need to know the economics and they need to know the financial side in order to make an informed decision...."

Facilitators asked the public focus group participants if local people should get involved in commissioning. Reponses were mixed but typically expressed concerns that, without the right expertise, local people could not contribute effectively to decisions:

(A) *"I don't think they can fully get involved because the key to all of it is the budget and because we've got no control and no right to say over how they spend their money then your actual involvement is minimal to say the least. I mean we're talking about the cost now, you know, this new system where the GP's would control budgets but even GP's don't want to do that and as an outsider there is no way that they'll listen to me talking about spending money on tablet A or tablet B because I'm not an expert, I don't know, you know the holistic picture. So for me there are certain areas where you leave it to the expert...“*

(Facilitator) *"Is it something you potentially want to be involved in or you just think you can't be involved in because they wouldn't listen to you?“*

(A) *"... to make that kind of decision you need to have an almost daily involvement to know what is the bigger picture, you can't just come in on the back end of something and look at something in isolation because you know, whilst we're listening to your situation there will be thousands and thousands of other people in the same situations, if not worse, who are all crying out for the same thing.“*

Another participant added later:

"... I think they should be involved at the stage of like in your local area like my doctors in [place name], *it's packed out completely, patients should be involved in sort of like saying 'we're going to open a new health centre here', or something like that and we're going, 'you're going to phone and you're going to get on the register, have your say*

about things like that'. You know and appointments, those sort of things because at the end of the day they're the people who are going to use these services. As far as drugs and money and all that, you can't be asked, you can't be expected to be..

3 The distance from here to shared decision-making 'as the norm'

Participants in the 'professional' focus groups were specifically encouraged to examine the difference between 'usual practice' and shared decision-making as the norm. In the adult public, PPG members and young people's focus groups, facilitators asked more generally about experiences of 'being involved' in health and health care and probed for experiences of shared decision-making (with and without using the term itself).

3.1 Adult public, PPG member and young people's perceptions

As described above (Section 2.2), the public, PPG and young people focus group work suggested that being 'involved' in decisions about health and health care generally had little meaning. For those with the knowledge, confidence and assertiveness skills, or who are '*lucky*' with their doctor, the distance between current practice and shared decision-making as the norm is perhaps not so far. For the remainder, and particularly for young people, there seems to be a very considerable gap between current practice and shared decision making 'as the norm'.

3.1.1 Adult public perceptions

The expression 'being involved in health' had little meaning *per se* for the adult public focus group participants. When asked if they had heard about policies to do with 'people being more involved', participants generally talked about public health initiatives and particularly adherence to 'healthy living' advice such as 'five a day':

"They do, they used to give a lot of fruit. I mean, the schools, when my kids was in junior school, they was giving out loads of fruit..."

"Yeah, it's healthy lifestyle isn't it....the healthy living lifestyle that was splashed all over Manchester."

"I'm not sure there's anything left for the government to cover in terms of telling people how to live healthily. I think we're all aware of that.... If you're missing that there's something wrong with you."

"But I don't think you can push anything more now to say 'You need to do this, this and this to be healthy', we all know what we've got to do to be healthy, everybody."

As above, shared decision-making was presented as 'being involved in decisions about health care'. The concept had absolutely no meaning or resonance for the public focus group participants.

"You kind of get told.
Yeah.
Yeah.
I think you get told."

Support for involvement

As the discussion evolved, it became clear that 'being involved in decisions about health care' was, for these participants, primarily about being assertive as a patient and being prepared to challenge doctors when not feeling listened to and/or when health problems were not responding to treatment. Information on the internet and support from other people were both described as empowering in this regard.

Having explained what the expression 'being involved in decisions about health care' meant (for the purposes of this project), the facilitators asked 'what really helps you be able to get involved in decisions that you might have to make?'. The focus group participants all spontaneously spoke about:

- feeling able to trust the other person, and
- having the confidence, knowledge and skills to stand up for oneself.

"It's trusting the person you're speaking to isn't it.... It's this trust again and listening to family and listening to people rather than dismissing it, you've got to be... the experience, you've got to be so firm with some people. .."

"Confidence in yourself, being able to speak for yourself."

"Well I wasn't originally like that, it was my friends who went to the doctors with <u>me</u>, a few years ago, and she said 'You're not saying the right things, you're not asserting yourself and we're not taking any more flannel, so I'm coming with you', which she did, and from that day on that changed my thoughts."

"I think the internet has definitely helped people understand their own symptoms more, and I think if you go in to see somebody quite assertive and not a nodding dog and they're God and they know everything, because they actually don't, they don't know."

"But do you think that assertiveness comes from second, third or fourth appointment because you still can't work out what's wrong with you, because at first you might think 'Well you're going to the doctor because they know better than you don't they'?"

"If I had something wrong with me and went to the doctors, first appointment, and the doctor said 'This is what's wrong with you', there's no way I would challenge him and say 'No it's not', whether I went on the internet or not, because that's why I'm going to the doctor, because he's qualified to tell me what's wrong with me. Now if I went the second time, a month later, and I was still suffering from it, then I would say 'Look, doctor, I mean, you've told me it's this, you've given these antibiotics or whatever, it's not cured it, I've still got this problem', then I would be more... [assertive]."

One very well-informed participant described her experience of a private consultation:

"And I went in to see him and he said to me 'Oh right, we'll give you [treatment]'. I said 'Oh no you won't', and he was quite... I said 'You're not giving me no [treatment], because it was the one thing my mother said to me, it was the worst thing she ever did starting on [treatment]'. I said 'No, I don't want [form of treatment]', I said 'I will take it slowly with pain relief until I get to the stage, and then we will look at something like [treatment]', and he's looking at me thinking 'Oh Christ, I've got one here'."

Picking up on one participant's comment about a younger doctor, which others clearly agreed with, participants were specifically asked about younger (i.e. more recently qualified) versus older doctors:

"(Facilitator) "Are younger doctors different do you think, different from older doctors in this respect?"

ALL: "Yes."

"Very much so, they're more open."

"They're more open, more approachable, more open to suggestions."

"More comfortable to talk to."

3.1.2 PPG member perceptions

As in the 'professional' focus groups, PPG members were asked about their understandings of shared decision-making. The expression did have some meaning for them, though it was variously understood:

"I was thinking more, when you're talking about individuals more, is it to do with choose and book? ... I've no personal experience of it but that to me is how I see individual personally shared decision-making but I don't know if that's right or not."

"I think in some practices it's almost a non-choice, if you've got a big practice with partners but also we've locums and you would like to choose the doctor you can have but if you do that you have to wait when that person is available but if you take "any doctor", in inverted comments, you might get an appointment tomorrow and I think that's, you know it's different from the small surgery, the small practice that you have and I think that is a frustration. I'm not blaming the practice, it's a very good practice ... Interesting sort of being involved in the decision-making but recently... my wife's got [medical condition] and she saw a consultant in our surgery and the consultant asked her, "do you want to see your report?" And my wife said yes, and so she had a report which was actually you know, sent to her and that was brilliant..."

One PPG member, however, very clearly described his experience of shared decision-making and how it differed from informed choice:

(A)   "One, the older one, tends to tell me what is wrong and what I need to do or, and occasionally gives me three options, you know you could do this or that or the other. The other one asks me what I think I should do, to do with the clinical treatment and my ailment though. ... Now the first one gave me a potion to deal with it said "rub that on

three times a day" or whatever and the other one said "what do you think you ought to do? Do you want to go this way or that way?" And that is a really different kind of approach because it is actually asking me to share the decision literally. ... I thought that must be what they mean by shared decision-making. ... She's a very young, quite young doctor and she's obviously into that and of course what she did was she really threw me by saying "and if you'd like to take this and read it" and she printed off that moment from the internet a page about the condition, two pages about the condition and gave it to me to help me with my decision."

(Facilitator) *"Can I just ask how you felt about the two different approaches and did you prefer one to the other?"*

(A) *"I only realised quite a bit afterwards that it had been different and I just thought "what was, there was something odd there and I couldn't really place it", and then I realised it was because basically I was being asked about what should be done rather than told about what should be done and secondly I was being given information to help me say yes or no, that or the other... I mean the first doctor is a wonderful doctor and she's very expert and I'm quite sure she's computer literate but for this doctor it was just automatic to say "you might want to read this". Whereas she wouldn't have thought of that, that's not my job to read information, we'll take her decision on it. That was just different."*

Another participant described various examples of people he knew being involved in or excluded from decision-making. Based on this personal experience, he concluded:

"So it's ... I think it's probably hit and miss, which is the problem isn't it?"

Two PPG focus group participants argued for a tailored approach to shared decision-making rather than a normative 'every patient, every time' requirement, depending on the balance between seeking expertise and exercising preferences:

"I always get a bit amused by everybody gets het up about it, particularly the NHS, when it comes to about decisions about yourself and your health and that, because let's face it in the real world if you sent for an electrician to do something in your house he'd be

suggesting what you need to have done. Now you might not believe him, you might think it's going to be expensive but you take the fact he's an electrician that's why you've called for him..."

"Because the doctors aren't daft, the doctors are just experienced knowledgeable professionals and experienced knowledgeable professionals as we all know, [NHS trust] is a lovely example, can go completely and totally wrong. So I think that what we want from patients and the public is to understand that that's the case so most of the time you're dead right, most of the time I'd be exactly on your wavelength saying the same thing, "you know best, don't ask me", but there are people who know as, well they know a lot about their own condition and they know a lot about how they're feeling and what they want done to themselves. I mean the cancer patient who decides not to have any more treatment, you know the doctor might say "well you need to have something", and they say "no", I know there are people who say "no, I'll stop thanks"."

3.1.3 Young people's perceptions

The young people in the focus group generally felt that doctors (usually meaning general practitioners or doctors working within other self-referral services) usually did not listen to them or take them seriously, let alone share decision-making.

"Terrible. They just want to get you out the room. No, they just say "go home, take paracetamol"."

"They don't understand or like relate to you, like they've been there before, they've got their degree and all that, they've never been in your position."

"You feel like they're just sat behind a desk, you don't feel like, it sounds dead stupid but you don't feel like they're human because they're just sat behind a desk staring at a screen, they go "mm, mm, mm, okay" and that's it."

Young people also felt that consultations were sometimes driven by the national policy agenda rather than by their own individual needs and concerns:

"... they don't interact with you. Or they ask other questions like "do you smoke, do you do this, do you do that?" Not bothered what you've gone for."

"We're always pregnant or we might have Chlamydia."

Nurses had a better reputation for focusing on young peoples' concerns, listening and involving:

(A) "*And* [doctors] *want to pinpoint what it is, they don't want to sit and listen to you like what you, like what you're feeling and what's up, they just want to give you tablets or like...*
(B) *They just want to diagnose you.*
(A) *Yeah, and then get you out. Whereas a nurse you can sit and tell her stuff and then she'll think about it and talk with you and work with you to find out what's up ... ...*
(C) *Just seem to have a bit more time for you.*"

"I think that's the difference between the doctor and the nurse because like the nurses, like sort of when I've been in the nurse like lately, I go like once a month, and the nurse like has been talking to me about like how I've grown up since like last year when I started seeing her, but then I saw me doctor in a conference and said "oh hi doctor" and she didn't know who I was. I was like "oh my god", and it's just shocking to know like the way doctors don't know you the way nurses want to build relationships with patients to like make them feel more comfortable and stuff like that."

Communication between different professionals and services to implement decisions and care pathways was also a concern for some of the young people in the focus group:

(A) "I went to see the orthopaedic doctor to talk about me right foot because I can't stand on it in me stand frame, and he said he was going to try and bring it forward with them, and I'm on it because it's down as an emergency because I can't stand in me standing frame. And I'm still waiting now so I think there's a lack of communication with the physios and with the orthopaedic doctor.
(Facilitator) *So ... you don't feel they necessarily communicate very well between themselves?*

(A) *Yeah. I understand they're very busy but when it's coming to get me shoes off and stuff and I'm like cramped up in pain because me foot's been in a bad position and you try, and I think it's just that they should bring it faster if you know what I mean?"*

(B) *"…they said "oh no, you're not having physio" and I went "but the doctor said two weeks ago that I was going in for physio and I need the physio". And then now to this day I still can't like kayaks, you can't get in kayaks properly because I can't bend me leg in a certain way, so like I spoke to me doctor and stuff about it and she said "well if you would have got the physio you would have been able to get into like the kayaks and stuff and have full flexibility and stuff" and I was thinking so why couldn't they just listen to me and let me explain that I'd been told two weeks earlier by another doctor that I was having physio when I needed it? Because he wouldn't, a doctor wouldn't say "you need physio" if I didn't need physio."*

(A) *"… I had the pain in it while I was out and I got an ambulance and stuff, and they were in the middle of rushing me into the ambulance thing and they were in the middle of rushing off and the lad went "we're going to [Hospital A] now", I said "I'm still under [Hospital B]", he said "no, I think you should go to [Hospital A]", I said "I'm still under [Hospital B]", he said "but you're 16 you need to go to [Hospital A]". I said "but I'm getting things done in [Hospital B]]", but he was sort of arguing with me … He was just trying to get me into [Hospital A] when I was trying to explain to him well I'm still in the certain hospital. … … Because children, just to let everyone know children with disabilities is still under [Hospital B] up until 18 or 19, and that's where all your case files are and everything so all the doctors know.*
[Youth worker] *And would that make you feel anxious [name] having to go to a new hospital, build new relationships?*
(A) *Yeah. Because I was in pain, I've got to try and argue with them as well."*

3.2 NHS staff perceptions

Taken as a whole, this project suggests that most health professionals also perceive a very significant gap between current practice and shared decision-making as the norm. Their views fit closely with the PPG member's '*hit and miss'* assessment - the overall

impression from the 'professional' groups is that some of the elements of shared decision-making are in place, in some areas and services, some of the time, and for some patients and service users.

The challenge, from this project's findings, seems to be to clarify exactly what is intended and expected, to identify where it is already happening to a greater extent, and to put systems in place to drive and support a much more consistent approach to shared decision-making as 'the way we do things'. 'Professional' focus group participants also emphasised that understandings and expectations of shared decision-making 'as the norm' need to respect patients' and service users' preferences and capacities, and must also allow professionals to exercise judgement. In working towards a common understanding of 'shared decision-making as the norm', NHS North West might best characterise it as the 'default' way of working, rather than the 'only' way.

"Your percentages of, is it 50/50 shared or is it 60/40, maybe you'd have to adjust that a little bit. So still shared but, you know, maybe the doctor or professional has more ownership in certain cases and I think it will have to be that way, not everybody's going to have a 50/50 decision."

"... patients like it because you give them time, we're doing this shared decision-making in these consultations but it causes various other problems. But at the same time sometimes when you're trying to make these shared decisions the patients don't want that, many of these patients just want you to give them something and go, and this is what they've been used to for quite a long time..."

"Long term conditions is an area where you've got much more time with people to get the right information to them and to take, like you say, somebody who's got MS and has had MS for 25 years is going to be very, very well informed and it's almost the difference between complete acute care, emergency care versus long term care and one is going to be much easier to make shared decisions with because you've got the time to be able to do that and one where you've got your situation where somebody comes through A&E where there's no time, you've got to make split decisions without... And that's where your professional knowledge, you are the best person to make that decision at that time, whereas your long term condition patients may be the best person to make those decisions."

General practice interviewees and 'professional' focus group participants otherwise generally agreed that that, even where shared decision-making is practicable; health professionals can and should exercise judgement about whether or not to pursue it:

"I think it's about appreciating the fact that sometimes shared decision-making isn't actually the right thing to do for some patients actually being told "this is what we're going to do at this moment in time and you're not going to play a part really" in that is actually the most appropriate thing just because they either can't handle the decisions that are being made, it becomes too complicated at a time of grief or whatever so actually it's a fact that shared decision isn't always the right... it's about choosing the right course of action for the right situation."

"I think the waters get a lot more muddied when you have people with very complex lives and multiple pathologies, very little education, sometimes no literacy skills, all of those things get a lot more complicated and that's where you would get worried, because to take that kind of approach would deluge somebody with very marginal literacy skills for instance to the point where they actually wouldn't know what to do with the information that they've got, so part of the job is actually empowering them to be able to understand the information that they have. It's more complex than you think in other words."

Overall, focus group participants felt that shared decision-making could legitimately include a patient or service user choosing for the health professional alone to make the decision:

"But that in itself is a shared decision, it's an agreement that you know, the bottom line is "I would like you to make the decision", you've come to that as an agreed option, you know it's not someone saying I'll make it or you make it..."

"... until you reach a point where if the person then says, what would you do, I tell you what, I've listened but I still don't know what to do, can you advise me? Then that is your duty because that's your expertise. And that is still, in my opinion, shared decision-making because what you've done is you've explained, you've helped people reach a point that they contribute to the best of their ability and then they've decided that you decide. So they have participated in the decision to take advice. So it can be a long process but it's not always. So that's my little spiel on, is it normal? Yes. Is it complex? Yes. I have

experienced, as patient, where I actually wanted someone to tell me... Because I was thinking, you're a consultant, you see thousands of this. I'm one person, I've read what I can, I've researched what I can but I don't know so can you just tell me!"

Not everyone agreed about this:

(A)*But wouldn't that be their decision to say "I don't want to make a decision I want you to make that decision".*
(B) *We would be very uncomfortable with that.*

The following quotes are included as exemplars of focus group discussions about the complexities and the need to tailor approaches to shared decision-making:

"Going back to the question is shared decision-making the norm, no - basically. I think there's huge variation. I think the first question, is shared decision-making at the same level, the same for every patient? No its not, it's different to how much each patient wants to participate in shared decision-making, and there's a kind of shared decision-making about shared decision-making before you can get to that point."

"So it is hugely variable from patient to patient, from doctor to doctor, probably from surgery to surgery with the same doctor, so it's a dynamic thing that changes all the time, and I think you're assessing all kinds of cues, all kinds of body language, using your communication skills to explore how much the patient wants to know at this stage. So there's a whole process around it, it's not just that 'This is the right level of shared decision-making', that doesn't exist, you've got to vary it, you've got to vary it to the patient level of education, your previous knowledge of the patient, all sorts of things, their condition, it's just hugely variable and hugely complex, so there's not one level of shared decision-making."

"I think you get an understanding of what a) the patient wants, and b) what is in their best interests. It's like any negotiation, it's a two-way discussion, or maybe three-way if you've got relatives, or even four-way if you've got a few other people thrown in, so it's a multiple, it's almost like an MDT isn't it, it's like a multidisciplinary team coming to a decision about what is in the best interests of that patient with regard to their current treatment, future treatment, care in general."

4 Risk and responsibility in shared decision-making

4.1 Communicating risk

Discussing issues of risk and responsibility inherent in shared decision-making, focus group participants emphasised the importance of health professionals being able to communicate uncertainties to patients and service users and to check understanding. This included being able and prepared to explain the '*grey areas'* and the '*conflict and compromise'* inherent in health care, where there is no obviously 'right' decision or choice for a given condition or a particular patient. In this context, shared decision-making might extend to a shared understanding of the evidence base (including the gaps in it) and of the '*balancing act*' that will be necessary in order to make a decision about how to proceed:

(A) *"And then you could end up having a compromise.*
(B) *There will be conflicts sometimes.*
(A) *Conflict and compromise on both sides where you might not get the best of either.*
(B) *No. And you will have misunderstandings. I don't think patients understand how grey medicine is; they think it's black and white."*

4.2 Sharing and shifting risk and responsibility

The implications of shared decision-making for the 'ownership' and management of risk and responsibility arose, in similar ways, in all the focus groups and in the workshops. By participating in shared decision-making, patients and service users are understood also to be sharing the risk inherent in any decisions. They are also understood to be sharing responsibility for the outcome(s) achieved (or not) as a consequence of decisions to accept, limit or refuse a form of treatment.

As described and discussed by participants, shared decision-making clearly includes a **sharing of** risk and responsibility. It potentially also includes a **shifting** of risk and

responsibility away from the health professional and towards the patient or service user. This was raised in various ways by participants in all the 'professional' focus groups and workshops.

"It's about shifting responsibility in a way as well as sharing responsibility."
"So sharing the risk as a consequence... of that decision, yeah."

Participants who commented were very clear that there are and should be limits on this 'shift' - shared decision-making is categorically '*not a get out clause'* that allows people inappropriately to delegate - or entirely to abdicate - their professional responsibilities.

"And so it isn't just joint decision-making, it's joint implementation, and we used to say you don't abdicate responsibility to patients, you delegate it to them if they want it."

Some participants were uncomfortable with the idea that sharing decisions necessarily also shifts responsibility. They questioned how this fits with well-established understandings of professional accountability and with the inequity of clinical knowledge and experience between a typical patient/service user and the health professional:

"I'm an expert in that but you're an expert in your life so I need to understand that. And that's been my script for getting on thirty years. So to answer that question, it's the norm. But the issue then of what it really means, just kind of collecting some of the things that have been said about, if it's done badly by anyone ... ... there's something about reneging on your responsibility."

"Yeah, yeah, "it's your decision, I'll give you all the information, you make the decision" and that advisory, professional advisory role seems to be diminishing now because the decision is yours to make not mine as a clinician."

"But as a professional you've got a responsibility, you're still accountable for any information you give so if a patient should come back and say "well you didn't tell me that", you're still accountable aren't you?"

"I'm just picking up where people [were talking about] *responsibility and shifting the responsibility from the professionals to the individuals might be one other way of looking at shared decision-making but then there's always going to be pros and cons with the line, where the line is drawn between who is ultimately responsible for what."*

As participants in shared decision-making, the role of carers and family members in sharing risk and responsibility also arises.   One participant, for example, spoke about health care teams taking responsibility for difficult decisions in palliative care in order to avoid unfairly shifting responsibility to the patient's family:

"[In] *caring for patients who are palliative and who are going to die and making a decision* [as a team]*, for example that we're going to withdraw care or go onto the pathway and as a doctor I would think about that over and over again, thinking "could I have done something else, what if, what if" and that's something that I have to bear on my shoulders and it's not fair to put that on a family..."*

4.3   Working with 'real life' complexity

Among general practice interviewees, the clinicians were clear that genuinely shared decision-making becomes much harder to achieve and is arguably less appropriate when there are very complex decisions to be made and when the clinician does not already have a well-established relationship with the patient.

Similarly, there was consensus in the 'professional' focus groups and workshops, whenever the question arose, that the difficulty and complexity of shared decision-making reflects the difficulty and complexity of the clinical circumstances. The amount and complexity of information regarding the likelihood and severity of adverse events that is available for sharing with patients is also a factor. The following quote, for example, comes from a discussion about the extent to which it is practicable, useful or necessary to disclose absolutely all available information about the risks of treatment options in order to achieve shared decision-making:

(A) *"Can we just go back to your point which I think some of us perhaps feel a little uncomfortable with, would you be telling them that you're not telling them everything? Would they have that level of decision-making that you're able to say to them "this is very complicated and could be very scary and we don't want to scare you therefore are you comfortable with us giving you a level of information or are hiding it from them?*

(B) *I think so... I'm thinking about kind of extreme treatments and things like a* [treatment option] *and the level of complications involved in one of those are just huge and you might end up with the situation where someone develops something that they weren't told about at the start because it seemed very unlikely. Or just that you, it's an endless list of things and actually if a clinician sat there and reeled off literally everything that could possibly go wrong a) it would take an incredibly long time and b) you would walk out thinking "well I ain't having one of them". But they're so remote chances but actually I think the point that someone made after me was perhaps a better way of putting it in terms of the get out clause as well. And I've seen clinicians that have almost abdicated responsibility, I think in their eyes seen it as being a shared decision-making almost handing over too much and not wanting to actually make a decision.*

(A) *So it's a balance isn't it, balancing act?*

(B) *It is, yeah. But that's not always easy with life and death decisions."*

4.4   Are shared decisions always good decisions?

General practice interviewees and 'professional' focus group participants were clear that – even when shared decision-making was 'the right thing to do' - shared decisions could not always or necessarily be considered to be 'good' decisions from the clinical perspective.

There was, however, consensus that the role of the health professional is to support the competent patient's or service user's decisions, where this is consistent with professional standards and the duty of care[3].

"Is it about acknowledgments and people can make unwise decisions but it's their decision to make."

"Should have the respect, respecting whatever decision they make."

---

[3] One workshop participant subsequently observed that supporting a decision can include revisiting it periodically to see how things are going and offering opportunities to revise it accordingly.

"But at the end if the patient and their families do not agree with the decision that we made in the end we should act in the interests of the patient and not try and push what is professionally right but may not fit with the family or a patient. So it's a fine balance where you draw the line, I mean "these are the options, pick and choose whether you want the surgery or the medicine" and to say "actually this would work and the likelihood of you getting better there's this option, this, and the next option is this" and it's about clearly laying out the outcomes of the individual options and then making people more responsible for the decisions made about their health care."

4.5 'Advance' shared decision-making

The question of integrating 'advance' shared decision-making into clinical practice was not within the focus group topic guides, but arose spontaneously from the discussions. 'Advance' here means the same as in 'advance directive' and 'advance care planning', i.e. shared decision-making that is done with a patient or service user in anticipation of a time or circumstance when they are unable to make, share and/or communicate decisions or are not legally competent to participate in decision-making.

Participants who spoke on this issue agreed, on the whole, that advance shared decision-making was possible and practicable:

"...the person themselves isn't in a position to make decisions but they might have early on in their illness, if you'd done it early enough. So in fact, that's interesting because that commitment to shared decision-making starts to set the culture for, right, we know you'll reach a position where you won't be able to make a decision so what we're going to do is, whilst you're in space where you can make the decisions, let's do that work now so it's in place for later. And there's lots of examples in mental health like that. Like, you know, statements that people make about advanced treatment statements when they know they're likely to have a relapse so what you might want to do when you're in a position that you can choose..."

"And you can do it advanced care planning if you know somebody's in a deteriorating condition."

"But then that's also interesting because then you think about the not for resus decisions and you know, everyone's meant to have that conversation with patients well in advance, but it's a conversation with them that is incredibly difficult to have with someone [when] *it hasn't even crossed their mind that they're going to die and you're there saying "oh you know"."*

"But, yeah, in cancer, End of Life, you know, advanced directives, preferred priorities of care, that's all happening out there but it doesn't mean to say they're getting it right all the time and it's embedded in practice..."

4.6 Possible 'downsides' of shared decision-making

Interviewees and focus group participants were overwhelmingly positive about the concept and practice of shared decision-making. When specifically prompted to think about whether shared decision-making might have any adverse effects, and gave the following examples:

- "Pathologising"

One participant described a specific difficulty in sharing decisions with families as well as with young patients/clients:

"... we have issues in [service name] *about shared decision-making sometimes because of the expectations of parents who may be want to pathologise the son's or daughter's distress and actually it's not, it's lots of other things and we get constant re-referrals of families that are looking for answers and we can't medically give them."*

- Confusion

Another participant cited children's services and described the potential for confusion when parents, children and health care teams have clearly not all been fully involved in, or understood, a referral decision:

".... the implications of referring a child to a therapist is, it's kind of left hanging because that means you'll cure their child, well a significant number of the children we see we're never, ever going to cure them because they have a lifelong condition but we're there to help them manage their child's condition but... And the number of people so you can

have conflicting shared decisions, so a decision that might be made with one of our nursing team might absolutely contradict what one of the therapy team's and vice versa want to do. So you end up quite confused, the whole picture kind of quite confused…"

- Does not equal 'consumer choice'- managing expectations

Throughout the focus groups, participants emphasised a need remember that shared decision-making has to be implemented within existing NHS resources. Linked to this was a very real concern about keeping shared decision-making 'honest', at strategic level and within one-to-one interactions:

"It's the one-to-one communication skills just with that other individual who happens to be a healthcare professional, who happens to be a patient, it's the whole communication message and it's also about the openness and honesty about the communication. It still worries me that… I don't want to deliver a message that I can't deliver the promise on … if somebody's having shared decision about their care, that "actually I want this, this and this", well I can't offer that. I always feel that I'm not delivering, that you can't deliver, it's just not an open book. So it's having that integrity, the honesty and all that - on the wide level and on the individual level."

Some participants were concerned about raising expectations of an unlimited 'consumer choice' model of health care:

"You can't have a front without a back, can you? And it does mean different things, like the expectations of some of our patients, including the vocal ones, is very, very high so it's going to increase the expectations because the choices we've got to offer are still the choices we've got to offer."

(A) *"It isn't that you can have anything you want, it's that there's got to be a kind of boundary and within that boundary what is it that you would like to choose really. For example, it's not realistic for someone to demand a certain type of operation because their neighbour had it. They've got to be the right sort of thing for the right sort of person, whatever that situation is, could be surgery, for example, that you've got to choose the right operation for the person but you've also got to choose the right person for the operation and sometimes there are certain choices to be made, would you rather have this one, or there's this one, or this could have this risk or this this*

risk and... But in the end, someone's got to make that decision and the patient would decide within their little group of things that they can have but ultimately the consultant's going to be the one to say that that's right for you, yes, okay.

(B) *Can I just challenge though, that I personally don't think that shared decision-making is the same as a customer choice model, which is what I'm hearing a little bit, that here's a pile of options and you choose. That's not my understanding of shared decision-making ... that would be a commercial model of customer choice for me. What I understand is, let's have a conversation about what are the things you need to do, you want to do, the problems that you've got, here's my expertise, what is it that feels useful to you, let's sort out what we can do together and that, in a way, it sounds a bit tricksy, it's not side-stepping the, you know, is that available, the cost of that...*

(C) *Customer choice is another valuable thing. I see it as part of... It's in the same realm as what we're talking about but I personally don't think it's the same as shared decision-making, I think that's quite precise."*

One 'professional' focus group participant, speaking from personal experience, described how shared decision-making can be stymied when discussions are limited to the options available on the NHS:

"I was given "well you can have this, you can have that, you can have the other" but not like "and this the long term, just you could do this", and when I actually put it back to them, "well these are the options that I've [found by research]", "oh we don't provide that on the NHS", not like "well that's a really good idea, go ahead with that"."

The focus group discussions often returned to the importance of understanding, informing and managing patients' and families' expectations within shared decision-making. Although perhaps difficult, some focus group participants had found that the process of shared decision-making provides a useful opportunity for understanding and managing expectations about, for example, what is and is not available or possible. This, in turn, was thought to make for less confusion and better relationships between all the people sharing decisions:

"It's clearly documenting, avoiding getting into the children's scenario, where if you've got clear expectations at the start, that I can help you with this, I can't help you with the other and it's about agreement..."

"If people are understanding and sharing then there should be less confusion and dissent."

"And the expectations that we're managing is seeing a child at three or four and being able to predict when that child is 20 of what the outlook is likely to be and we have the tools to do that. So it's a very long term managing of expectations and being honest with them."

- Managing the transition to adulthood

Focus group participants also discussed the difficulties of sustaining shared decision-making and protecting confidentiality as children progressed to adulthood and made the transition from paediatric to adult health services. This included the challenges of appropriately and progressively limiting the parental role in shared decision-making and of implementing shared decision-making within the context of shared care arrangements:

"...particularly [with regard to] people with learning disability, parents have had this responsibility of parental consent and they think that follows through into adulthood and they, then people automatically assume they have a right to make those decisions still on behalf of that person and that's a big issue ... we say "well we're not actually asking for your permission, we're consulting with you", but ultimately a best interest decision, I am the decision maker if I am delivering that. So in terms of shared care, where does that come in to making shared decisions because I am the decision maker."

"I think one of the interesting [issues] ... is the difference in the way that children's services function, particularly CAMHS and adult services so we look at what's [been provided] in children's services because that's where the support comes from but you move into adult mental health services and it's individualised which doesn't fit with what that person's experiencing because the main support is often from the family and it's overriding that individual confidentiality and the clinical needs of that person."

- Public health

Participants also discussed potential conflicts between the participants in shared decision-making and the implementation of public health measures in residential care facilities:

"... like the flu vac campaign, when you're going round to the care homes and you know, you're making that decision that that flu vac will protect them otherwise it would spread through the home and cause complications and then all of a sudden a family member who rarely visits the person says "I don't want them to have the flu vac", and what you're saying is "well it's in their best interest" ... ... it can get very fraught."

4.7   Health inequalities – access to health care and health status

Within discussions on the likely outcomes of shared decision-making as the norm, there was no consensus regarding any likely impact on health inequalities. Some participants felt that shared decision-making had the potential to increase health inequalities by further excluding already disadvantaged individuals and communities. Others disagreed or had no expectation either way. This chimed with the general practice interviews. Where the potential impact on health inequalities was not raised by participants, it was introduced via the question '*Do you think shared decision-making is going to impact on health inequalities one way or the other?*'

"I suspect shared decision-making will make inequalities in health worse, because the inverse care law is always in operation, you know, those that need it least get it most, those that need it most get it least. So we will probably be very good at shared decision-making with the one in four, middle-class, well educated patient who would kind of demand that from us and we give that to them, and be less good at the poorly educated patient who has difficulty understanding concepts like risk, for example, to really get into shared decision-making. So potentially we would do better for those that didn't really need it and do worse for those that really did, so I wonder whether it could actually make things, in terms of inequalities, worse, but we might be doing better for certain groups of patients."

"It certainly leapt out at me when you were saying about the GPs being concerned that the more vocal people might take more of the pie because they've been involved in the decision-making. Certainly I work with children [in a geographic area] *we have great difficulties because the well-educated, affluent parents are taking quite big chunks of the pie for their children and some of the others who aren't speaking up may have children with exactly the same problem and are getting a much smaller piece of the pie. And this is being reinforced weekly by legislation that gives the vocal parents a right in law to take large chunks of equipment, treatment time and medical time and that becomes enshrined in law the people get large chunks and the other people who have not asked aren't getting any. And you know, it could be that the shared decision-making is the same thing sort of amplified. There would be concerns on that."*

"I think that there's two things, I think yes, on an individual basis there's a risk that shared decision-making might favour, you know, a certain type of patient over another. But one would hope that, you know, if shared decision-making is made on a much more universal basis for commissioning, for supporting, education and information access to sort of more deprived groups within the population, that perhaps some of those inequalities might actually improve over time."

One participant argued that the possibility of some patients being excluded should not drive the overall approach to decision-making in health care:

"It's quite difficult to defend the opposite policy, we will not share decision-making because we think it may discriminate against people who can't make decisions. It doesn't stand up to much…"

5 Implementing shared decision-making in different care settings

5.1 Integrating shared decision-making into service delivery

From this project, achieving shared decision-making 'as the norm' will depend first on establishing the expectation that all health care professions and services will:

- share a common understanding of shared decision-making;
- integrate shared decision-making into the way that they work;
- be supported by fit-for-purpose information management and communication systems.

Participants spoke, in particular, about the need to ensure consistency for patients and service users when they move from one part of the NHS to another – for example, from primary to secondary care:

"There is a risk if the whole healthcare profession doesn't operate a common approach to that, because if one part of the system see shared decision-making as something - and so for example primary care sees it as choice but secondary care sees it more as something else - then there is potentially an opportunity for a conflict..."

The difficulties created when patients are referred between services with entirely different approaches to decision-making were described by another focus group participant:

"I find that sometimes patients get as far as my clinic and haven't even got the first idea why they're there... And I find that very frustrating because that means that someone a little bit further up the tree hasn't actually done their job to explain why they were bothering to send that particular person to me and what their options were otherwise. But once they're there and then it takes the first half an hour to actually unpick the reason for them being there, they then will actually say, well actually, I don't want to be

here. Or, well great, that's fine. You know, so we have to start the process sometimes a bit further down than you should have done."

5.2   How well-established is shared decision-making?

This project was not designed to provide a rigorous overview of the extent to which different parts of the NHS 'do' shared decision-making. Participants in the different groups did however seem to regard some services as being further ahead than others, for various reasons.

Most of the doctors who commented, including the general practitioners, felt that shared decision-making is already becoming integrated into medical practice:

"I don't know enough about the organisational stuff to be able to say how far advanced that is, and likewise I don't know that we are able to judge how much willingness there is on the patient to participate in this process. Having said that, our general feel is that we probably do some of it all of the time anyway within our own little microcosms of world."

Mental health services were typically cited as one of the services in which shared decision-making is relatively well-established:

"In mental health the tradition for many years now has been patient-centred care and patient-led decision-making actually. And I know it happens still, you know, at a greater or lesser quality but that is the norm so it doesn't feel new at all".

Some participants attributed this to the mental health service's explicit consideration of different care models and principles:

"I think crucial to the success of … more shared decision-making, you have to have a discussion about models and how that impacts. … I was thinking about, okay, I work in mental health, I've said… Claimed … that this is the norm. How did we do that? Why is that the case? And it's because we consistently have debates about which model, is it a rehabilitative model, is it a social model, is it a medical model, when's the right use? It's not a competition between the best, it's about the match of the right one at the right

time… …but unless you have that discussion, you can't… You can't agree the appropriate place for the right levels of shared decision-making, it then becomes dishonest."

"You know, look at what worked… Like how did we get in mental health to be more shared decision-making? One of the things was to embrace the belief that people will recover. So you start with that basis and then you work with, what does recovery mean? Well, it means getting on with your life. So what does that mean? Well, that means people describing what it is that they want to do with their life and in order to get there you can't make the decisions for them so it's kind of logic flow so I just had to come in with that."

Another cited regulatory requirements and evidence sources as key drivers:

"And how we do it is it's mandated. It's a requirement and it's supported by the documentation… We have electronic records. I saw a report just a couple of days ago that went through… We'd had a monitoring check that went through and it had comments about whether or not care records were evidence enough that there was decision-making by the service user. … it's so high level and so expected that it's actually a requirement, it's not an option. … You can't not do it because that's what you do. That's the job."

Cancer services and services for people with learning disabilities were also generally considered to be ahead of the field in adopting shared decision-making as an approach. In discussing how and why some services are further along than others, one participant highlighted the barriers created and perpetuated by 'professional silos':

"But what about professionals coming together? I think often we work in silos and we talk about things, and I'm not just praising [participant] in Disability Services but we often get told you've been doing it for years, we do person centred involvement, we've done it for years, it's our philosophy of how we work, it underpins everything we do. And we talk to people and we hear all this and we think we've been, I've been doing that for 20 odd years, that's nothing new, it's about communicating effectively with everybody who's

involved and not just that individual and I think sometimes, in partnership, in true partnership but you might not agree."

Community-based health professionals, in various ways, also discussed shared decision-making in terms of 'what we already do'. As they pointed out, the very nature of community-based service delivery, including the provider-client relationship and the environment in which care is delivered, perhaps lends itself to shared decision-making rather better than the acute hospital environment.

Nonetheless, as one participant observed, there is a difference between being generally '*more mindful*' of people's needs and consistently sharing decisions, and this has workload and resource implications. Further, the more conducive environment does not solve the problem of not being able to meet patients' expectations at the end of the decision-making process:

"You said about running the services from general practice, I'm primarily a community based service and, you know, I feel we're better, in a [better] environment, going a lot to people's homes, we have to be more mindful of their needs rather than [working in] an out-patient clinic or a hospital ward. Just because it's the dynamics of what you do. So I don't think it's that different but it is going to take a lot more work to come to a shared decision, it is going to take more time and if what can we offer at the end isn't what the patient, person, child expects, it's still going to leave it not quite right for them. So, it's difficult. I don't disagreee ... it's just I've gone, hmmm."

5.3   Expectations of shared decision-making in different care settings

While none of the focus group topic guides specifically included asking about people's expectations of shared decision-making in different care settings, the issue came up spontaneously in most of the groups' discussions. Overall, participants thought that there was a balance to be struck – recognising shared decision-making as a good thing, whilst also recognising that patients are seeking, and expect to be offered, professional expertise and advice.

5.3.1 Professional perceptions

Overall, health professionals who discussed expectations felt that, whereas patients might expect to be involved in decisions in primary and community care, they might not necessarily expect to share decisions in acute hospital settings. The physical environment and expectations of the traditional consultant-patient relationship were both considered influential:

"I think there is a difference between primary care and acute hospital as well because they go to hospital, they expect everything to be... You know, somebody's going to tell me that I'm going to need this and they don't... I don't know, people don't seem to want to make a decision as much or feel able to make a decision as they would in their own home when you come to see them."

"I think a lot of the time, if you go to see a consultant and I think we probably would be able to understand this ourselves. You're going to them, the clue's in the name, to consultant them, to ask them for their advice a lot of the time, and patients go along, sit in front of a consultant and expect them to come up with the answer for them. And that is an expectation, they don't want to be told, well what do you think then? They want to be told, well how can you make me better then, please do it for me."

5.3.2 Public perceptions

As discussed above (section 3.1), 'being involved in health care' had little meaning for adult public focus group participants. It was therefore not really possible for the facilitators directly to explore public expectations about shared decision-making in different care settings.

Taking relevant material from other discussions throughout that focus group, the overall impression was that (regardless of care setting) participants liked and appreciated being involved in discussions and decisions, and particularly appreciated feeling listened to and being asked for their opinion:

(A) *"When I went in he said 'Explain your symptoms', so I did, he told me what he thought, but before he actually told me what he thought he asked me what I thought, because I*

actually go on the internet, I had a problem with my eye, and I told him what I thought it was, he said 'Well that is on my list of things that it could be, but I don't actually think it is that'. Well that just sort of shows to me that he's actually taking a bit of an interest in what your situation is. He was a young guy, he was a young doctor, so yeah.

(Facilitator) *So he actually said to you 'What do you think'?*

(A) *Yeah, he said 'Before I tell you what I think the problem is, what do you think it is?' said 'Well I've been on the internet and I've had a look, and I've ranged from eye cancer to something as minor as … a bit of grit. So I picked one in the middle.*

(B) *You're lucky you get people like that."*

Otherwise, participants' contributions suggested that they had little experience of shared decision-making, as understood by 'professional' participants, in any care setting. Most participants had low expectations of involvement beyond feeling listened to or being copied into correspondence:

(A) *"It's nice when you get GPs that do, that are like that. I mean, with the first experience we had with my son, the GPs would listen, but the consultants and the hospital staff wouldn't listen, it was all through the… they wouldn't actually listen to you, because I was explaining that I'd done this research, went to see a physiotherapist, private, they dismissed it completely, completely dismissed it."*

(B, disagreeing) *"I always find that they communicate very, very well. You know, there's always letters and they always ask you 'Do you want a copy of the letter?'"*

6 Systems and support to facilitate shared decision-making: part I

Recommendations from the focus groups: 'what needs to be in place'

The 'professional' focus group participants were asked to describe 'what needs to be in place' for the NHS across the North West to work towards shared decision-making as the norm, and to generate key themes from their ideas. This section collates and integrates all the focus group outputs. These were taken forward into the 'what needs to be done' June workshop activities, so are also reflected in Section 7 of this report.

6.1   Overview

As described above (Section 2.1.2), in discussing understandings of shared decision-making, the 'professional' focus group participants went well beyond the point of decision-making within clinical consultations. Their discussions about 'what needs to be in place' to support shared decision-making also reflected this broader perspective.

Distilling all the 'needs to be in place' items documented by group participants and the associated discussions, the key 'pieces of the jigsaw' in shared decision-making are as follows:

- patients and service users who have the information, skills and confidence that they need to participate in the decision-making process as much as they want to, to understand the options available and their implications, and to implement decisions successfully where these require (for example) adherence to treatment plans and/or lifestyle changes;
- health professionals who have the necessary communication and information-sharing skills and who genuinely respect patients/services users' knowledge and expertise within decision-making processes;

- in particular, health professionals who are able and willing to share information and decisions regarding desired and achievable outcomes, and regarding the risks, benefits and likely outcomes of different treatment options;
- inter-relationships between health professionals and patients/service users that genuinely reflect the principles of collaboration and partnership working;
- identifying and including everyone with a legitimate interest in the decision(s) to be made and supporting their participation throughout an ongoing joint planning process;
- a local health service design and infrastructure that supports shared decision-making – in particular:
  - appointment/time allocation systems that allow patients/service users the time to find, absorb and understand information at an appropriate point in the care process or pathway;
  - systems for ensuring that information about decisions and the factors that shaped those decisions are appropriately and consistently shared between health professionals, between services and across health and social care boundaries.

6.2   Themes and elements

There were four over-arching 'needs to be in place' themes from the focus groups:

- information and communication;
- cultural shifts;
- system integrity;
- patient and public engagement.

6.2.1 Information and communication

As might be expected, 'information' and 'communication' emerged as the most important and all-encompassing themes from all the focus group discussions. Information and communication to support shared decision-making had very many dimensions and ran through all the other 'needs to be in place' elements (and subsequently through the workshop 'what needs to be done' items as described in Section 7).

Focus group participants identified three 'without which nothing' areas of information and communication: communicating with the NHS about shared decision-making; providing and signposting information and support for participants; and developing professionals' skills in shared decision-making.

- Communicating with the NHS about shared decision-making

There was consensus that there will need to be a clear and consistent 'message' about shared decision-making that is actively communicated to, and understood by, all NHS services and staff across the NHS North West area.

"Communication just sounds like, you know, we could have said that in the car on the way here. So it's something about positive message and commitment to a consistent message that gets communicated."

"I think there's something for me about strategic communication ... Are we allowing people to opt out at a strategic beginning? Or is the message, this is something that we are all going to do. And I think that's one of the big problems in White Papers, very often everybody has an interpretation of how they should be rolled out and it's poles apart."

The message must include a clear exposition of what shared decision-making means and does not mean in practice, and must set out:

- the rationale for working towards shared decision making as the norm;
- the intended/expect impacts on health and the outcomes of health care, and how these will be measured:
- providing and signposting information for patients – and supporting them to use it effectively.

"Just going back because I don't think we ever established what are we trying to establish with shared decision-making, what's our outcome, how will we know if shared decision-making is good? Does it improve clinical outcomes or is it just that people feel happier about the service so they might be dying sooner, they might not be getting into A&E and

being seen within 12 hours but they were quite happy while they were there, is that we're aiming for?"

There was also consensus that supporting shared decision-making will mean developing a systematic approach to collating and providing and/or signposting good quality information about:

- medical conditions, self-care and management, treatment options, outcomes and risks;
- relevant services and sources of support for all the participants in shared decision-making, including patients, service users, carers and families, and between health and social care services.

It will also mean helping patients to develop the communication skills and confidence that they will need fully to participate in shared decision-making:

Well like one of my colleagues ages and ages ago said with the cancer thing about everybody having advanced communication skills, it's like having a dance when you've got one person who's an absolutely fully trained ballroom dancer and the other person who's never danced before and is that... viable as, you know, the so called professional has got all these communication skills and the patient comes in feeling very sort of amateurish with their communications skills and to make it work properly, to make the dance perfect, that both people, both partners need to be on the same level.

- Developing professionals' shared decision-making skills

Participants were very clear that facilitating shared decision-making would require the NHS substantially to invest in developing health professionals' skills pre- and post-qualification, via education, training and continuing professional development (CPD), and by the example of influential colleagues. It was generally agreed that the provision of communication skills training with the medical undergraduate curriculum and in GP training has been a very positive development. There were however questions about access to communication skills training for other NHS staff, and about how people are supported to 'keep it going' post-qualification and throughout their career.

.

"We learn how to use our stethoscopes when we're medical students, we should learn how to include patients in the decision when we're medical students, it shouldn't need to be sustained because it should be self-sustaining."

"I think it's already there in terms of training, you know, there's so much communication for medical students, the GPs, Registrars, the core of the GP curriculum is the consultation, you know, it's all there already, perhaps its keeping it going after you've qualified and you've got the badge, and then integrating into other training programmes as well, I'm not sure how well surgeons are trained in communications for example."

The focus group participants' expectations and recommendations with regard to professional knowledge and skills reflected their multi-disciplinary and cross-boundary understandings and their concern that shared decision-making should be properly 'joined up'. For example:

"... it's being able to have those conversations and it's having the skills and knowledge to be able to talk, to be able to interact, to be able to know when to say and when not to say and whilst we always say we train the juniors in communication, we don't. And for me, it's ... about, you know, are we confident in our own ability, do we know what our services actually offer, do we know what we shouldn't be offering?"

6.2.2 Cultural shifts – patients, the public and professionals

Participants identified two types of cultural shift will be necessary in working towards shared decision-making as the norm, within the NHS and beyond:

1. A shift in the culture of NHS and in the behaviour of front-line staff, incentivised and driven by executive-level commitment.

"Your training isn't just theory in university, if you go out on a placement and the culture is not what you're trying to reinforce, actually you do exactly what you don't want to do

because culturally they pick up on "well I must do that because that must be the way it's done here"."

"It's come out in the actions of what you might expect a leader to do. So if we say that you want the right people recruited with the right attitudes, if you say you want high-level buy-in, if you say you want consistency in documentation, then actually those are the actions that a leading person will have to take..."

2. A shift in patient and public awareness of shared decision-making, their expectations of involvement in decisions about health and health care, and their willingness to become co-producers of their own health.

"It's not only the culture for the healthcare profession to change but also for the public to change, the patient user and to enable that to happen as well ... it's not just changing the NHS or social care of whatever, it's changing us all who are in partners in it."
"Tell the public what it's about. Or get the public's buy-in so it's a probably a better way of saying it, get the public to do that. We're all members of the public. We're all patients and it's getting that there..."

"... what I thought worked really well is in terms of the infection control campaign, the wash your hands campaign where they wore the badges and had posters up that said "challenge me, have I washed my hands". I think something like that would work really well, that we publicise it, a big awareness campaign and it's for the public to challenge us not for us to say "have I done this?" "

"... it's got to be in public education, in the educational curriculum and for the North-West of England, we've got to take up cudgels and arms and say "we are going to do this, we're all going to be co-producers of health."

6.2.3 System integrity

There was consensus among focus group participants that working towards shared decision-making as the norm will require the NHS to work towards "system integrity". This included reviewing and developing the NHS' documentation and care models and

pathways so that they encourage, communicate and otherwise support shared decision-making and facilitate implementation of decisions that are made. Participants also emphasised the importance of ensuring, via recruitment procedures and management processes, that the NHS workforce reflects the policy-level commitment to shared decision-making:

"For instance, there's no point having documentation that is old style, if you're trying to adopt a new way of communication. There's no point in a White Paper saying one thing if it's allowed to be interpreted poles apart. There's no point having a commitment to it if you employ people who themselves are not committed to it..."

"I'm still obsessed with IT and information. I think we've been waiting for electronic records for so long and we just need to just do it and I think we are still limited like that."

"Systems and processes and documents, pro-formas, you know so that it can be standardised as much as possible to make sure it happens ... otherwise if you leave it to an individual, completely individual approach, how do you monitor it, how do you know whether it's happened?"

"It kind of feels as if we've trying to develop systems and processes, we've done that, we've done the education, we've done the systems, we've done the what resources we have, the bit that's missing for me is how we engage to make sure that the systems that we've developed, the processes we have, are what is going to work for not just us and not what we assume is going to work for other people but really is the right system and the right process."

With regard to system integrity, focus group participants emphasised that shared decision-making can and should be progressed by recognising and sharing good practice where it is already established. In particular, they would expect the NHS to avoid 'reinventing wheels' by identifying supportive systems and processes that have already been integrated into local services and are working well.

6.2.4 Patient and public engagement

While this project focused on support systems and processes for NHS staff, it is obvious that shared decision-making cannot be achieved and sustained unilaterally by the NHS. 'Professional' focus group participants consistently emphasised that patients and the public will have to understand and play their part too, and that developing patient and public engagement will need to be a strategic and operational priority in working towards shared decision-making as the norm.

Focus group recommendations regarding patient and public information, support and 'cultural shifts' are set out in earlier sections of this report. This section focuses on the general practice PPG member focus group discussions about their experiences of being involved in decisions and about the limits to their influence. While again accepting that the group participants were not necessarily typical or representative, the findings do raise some important questions about the statutory sector's preparedness to share more substantive decisions with patients and (especially) the public. If this project's findings are substantiated by other evidence, supporting shared decision-making could include building on local learning from the PPG experience, from the PPG and general practice perspective.

PPG members, as the best-placed and most experienced 'lay' focus group participants, were asked to give examples of the sort of decisions that they had been involved in, or things they felt they had had influence over. One PPG member described working with a local hospital to push for and develop a much-needed information resource for patients, and had also worked on a directory of local services. One had been involved in referring an NHS trust decision to the local Overview and Scrutiny Committee:

"… we took a decision that one of the trusts had made and argued that it was a substantial variation and that they hadn't consulted properly and we took that to the overview and scrutiny committee and initially they weren't very interested but they eventually agreed that that was a substantial variation and they put their weight against the trust to do something about that … "

Another referred to a PPG providing a useful information conduit between doctors and patients:

"... we would get feedback from other patients, we would get the doctor saying "well this is what we're encountering" and ... we were like treated as like a consultation to feed back to the other patients but also taking things to the doctors."

Otherwise, the overall impression was that PPGs were an under-used, and sometimes inappropriately used, resource. This seemed, primarily to reflect:

- a lack of clarity about the role and purpose of PPGs;
- concerns about the 'legitimacy' and boundaries of PPG involvement.

Participants described, in particular, unhelpful tensions arising from different understandings of the PPGs remit and sphere of interest. Some doctors, for example, were concerned about PPGs trespassing into clinical decisions:

"... our group has been going since they first mooted the idea ... there's a mutual, I don't know if trust is the word, but respect [between] *the doctors and ourselves, and if we started to impinge on the clinical side of it we'd lose their respect and I think the process would break down."*

These tensions can be expected to apply more generally to patient and public engagement in decisions about local health services.   As clinically-led commissioning rolls out, this project suggests that it will be extremely important to establish and communicate, from the outset, which sort of decisions patients and the public can share and which they cannot. This will include determining where the boundary between 'clinical' and 'non-clinical' lies in sharing decisions about the future of health services with local populations and communities.

The following PPG member quotes are included to illustrate the above observations:

"... the only thing I can say in all honesty about what we do ... our waiting areas and all that, the furniture was diabolical ... within six weeks the painters were in..."

"Don't get any decision-making as such, the nearest I think ... was that there was some [proposal] *to move* [a staff member] *and give her a much wider area so she'd spend more time travelling than she would visiting people which I thought was ridiculous. ... I was*

asked to go along to give my views to a Board which I did ... I don't suppose it was a result of what I said but they deferred it at least for a year. That's the only thing that I've been involved with."

... we've just moved into our new practice and our bit of moving was to go and pick up the litter from the old practice ... there was a lot of litter and so we were the litter collectors, that was our job. Now [another PPG member] *organised that and* [is] *in the process of organising - with great difficulty - someone to cut the grass... But then I don't really want to do that, I don't want to take over the doctors but I don't want to take over the janitor's job either, you know.*

"... the bottom line is for me, is for the health professionals to accept and understand we have a contribution to make, we're not trying to outdo them, we're not trying to tell them how to do their jobs but we have opinions, we're there representing the community because other people are not in a position to speak for themselves ... we keep saying ... we expect the health professionals to give dignity and respect in the surgeries and in hospitals and when we sit round and talk to them in whatever capacity we should get the dignity and respect."

7 Systems and support to facilitate shared decision-making: part II

Recommendations from the workshops: 'what needs to be done'

Building on the focus group work on 'what needs to be in place', participants attending the 14 and 15 June workshops were asked to focus on 'what needs to be done' and 'what would help people do it' for the NHS in the North West to work towards shared decision-making as the norm.

7.1 Overview

Workshop participants identified ten work streams to support shared decision-making:

- making the case for shared decision-making;
- achieving senior-level buy-in and leadership;
- developing and implementing communication and engagement strategies;
- reviewing and revising the way that information is recorded, shared and communicated;
- embedding and resourcing shared decision-making within professional education, training and continuing professional development;
- improving the availability, accessibility and quality of information for patients, service users and the public;
- developing support systems and structures for patients, service users, carers and families;
- integrating shared decision-making into care plans and pathways;
- developing information resources and support for health professionals;
- incentivising shared decision-making 'as the norm'.

7.2   Making the case for shared decision-making as the norm

One very clear message from workshop participants was the implementation of shared decision-making as the norm should be driven locally rather than waiting for national drivers. Local NHS leaders will need to develop and disseminate a persuasive rationale for adopting shared decision-making as the norm across the NHS in the North West, which:

- Identifies local executive-level NHS champions with responsibility for raising awareness of shared decision-making, cascading information to NHS North West organisations, and otherwise leading implementation;
- explains how NHS services in the North West should interpret 'shared decision-making as the norm' (what it means, and what it does not mean) in a way that can readily be understood by all potential participants in decision-making processes;
- provides exemplars of shared decision-making 'in real life'
- set out the evidence base regarding:
  - o the cost and cost-effectiveness of shared decision-making, including (for example) evidence regarding use of clinical time and impact on consultation frequency
  - o the impact of shared decision-making on choice of treatment options and the outcomes of health care
  - o the impact of shared decision-making on patients' experiences of care
  - o 'what works' in supporting patients and service users to be involved, as much as they want to be, in decisions about their care and treatment

- describe how the impact of shared decision-making as the norm will be measured and monitored;
- in particular, describe how shared decision-making should be integrated into existing initiatives and operational workstreams.

At national level, workshop participants suggested that the Department of Health's Long Term Conditions QIPP team could usefully:

- collate documents and other material about shared decision-making for inclusion on the relevant NHS networks web page;
- collate exemplars of shared decision-making in practice and hold a webex to raise awareness.

7.3   Achieving senior-level buy-in and leadership

Senior level buy-in and leadership was identified as a key driver of shared decision-making. This meant, in particular, achieving '*buy-in at the top'*, visible leadership by the chief executives of local NHS organisations, and 'leading by example' by consultant-level clinicians.

"Chief Execs to make shared decision-making the centre of organisation."

Workshop participants also said that shared decision-making should be built into:

- NHS organisations' statements of values
- NHS managers' expectations of transparency and honesty, and implementation of the values and principles expressed in the NHS Constitution
- staff recruitment, appraisal processes and performance-management processes
- clinical governance systems and online resources for clinical governance networks provided by (for example) the Royal Colleges and Deaneries

Workshop participants also said that local NHS decision-making forums could be reviewed to "*make them more transparent and aspire to include shared decision-making*". This would involve working with the new Primary Care Trust Cluster Board and the relevant Local Authorities "*to revise process and communication*".

Supporting shared decision-making was also understood to require greater flexibility with regard resource allocation, better planning processes and systems, and "*less defensive*" approaches to NHS management

7.4 Developing and implementing communication and engagement strategies

"NHS NW need to have a publicity drive - patient demand will drive change."

The workshop participants emphasised that communication and engagement strategies and shared decision-making campaigns will be needed to raise awareness and understanding of shared decision-making (and its implications) among all potential participants. These included:

- patients, service users and carers
- the general public
- health care organisation and professionals
- social care organisations and professionals
- voluntary sector organisations
- private sector organisations

Engaging with public health, and with the near-future local authority responsibility for public health, was also considered important:

"[We] need to influence local authorities to engage with patients since they will be responsible for public health. Joint event/workshops - need to develop joint performance matrix for secondary prevention and lifestyle intervention."

"We need to engage public in debate about lifestyles, social values, justice and how this fits with shared decision-making."

"We [public health] need to communicate with patients and public about how evidence is collected and used to support decision-making - self-help tools, web based, NICE made more accessible at a population level not self selected group."

"[Commissioners and public health colleagues] need to identify local routes to their population and create local dialogue ... Exploit existing relationships or forums."

One workshop participant also suggested that a risk management strategy should be developed, addressing the governance and litigation implications of shared decision-making.

7.5   Reviewing and revising the way that information is recorded, shared and communicated

At operational level, critically reviewing and improving the way that health and social care professionals and services record, share and communicate information emerged as the key to supporting and sustaining shared decision-making:

- designing information sharing protocols - different services sitting down and agreeing how to share information;
- redesigning documentation;
- developing shared information systems that provide a safe haven for confidential information;
- recording patient's illness perceptions, decision-making wishes and communications needs on general practice registration;
- reviewing and personalising methods and modes of communication with patients, and their advocates where relevant;
- improving the speed and accuracy and communication between practitioners;
- establishing IT systems that document shared decision-making within clinical records;
- introducing patient-held records to be carried across boundaries and disciplines, containing all shared decision-making information;
- otherwise enabling and supporting patients' access to their medical records
- enabling patients 'write' and 'edit' access to their own medical records;
- establishing efficient and effective feedback mechanisms for all participants in shared decision-making;
- establishing systems to enable therapists to provide regular updates regarding available therapies and expected outcomes to clinicians and patients, "*so that decisions are made with the same information*".

7.6 Embedding and resourcing shared decision-making within professional education, training and continuing professional development

Throughout the project, professional education training and continuing professional development also emerged as a key 'success' factor in implementing shared decision-making in practice. Within the workshops, participants described a need to embed shared decision-making within:

- pre- and post-qualification education and training for nurses, allied health professionals and doctors;
- in-service training for all staff who have direct contact with patients *"We need to ensure that in-service training is provided to allow staff to be able to explain shared decision-making to patients"*;
- skills training programmes for NHS managers, Human Resources teams and Board members;
- induction programmes and staff updates;
- professional support systems and resources;
- expectations of record-keeping *"Discipline - seen as essential or mandatory as writing a prescription"*;
- job descriptions and person specifications.

As many project participants pointed out, integrating shared decision-making into education and training will require dedicated resources, including staff time. It will also require the development of appropriate and accessible training programmes for people working in different roles and organisations.

7.7 Improving the availability, accessibility and quality of information for patients, service users and the public

Patients, services users and the public of course cannot participate in shared decision-making without access to the information they need to understand their medical condition and to choose between available options.

Overall, the impression from the workshops was that supporting shared decision-making as the norm means the NHS must improve the way it collates and provides information, how it signposts further reliable information sources and resources, and how it supports patients to assess the quality and reliability of information and information sources.

Specific recommendations from the workshop participants were as follows:

- *information about outcomes from treatment options needs to be written 'plain' form and targeted at the understanding/capacity of the patient/their carer/family;*

- *Public Health England, NICE or equivalent need to ensure clear information is available in ONE place to support decisions;*

- *set minimum standards on providing diagnosis ... the diagnosis MUST come with an explanation;*

- *healthcare providers need to give patients a list of approved health resources "health care professionals should signpost recommended sites to gather information, populated by local, realistic, timely info";*

- *review how general practices provide information and how they let patients know about other information sources and resources;*

- *a central information forum need to be produced to help with information-giving to assist shared decision-making - public information programme;*

- *clear and unbiased communication of risks of various treatment options - validate and approve patient information so that risk communication is consistent with best practice;*

- *written information post consultation with any key worker;*

- *good signposting to services including advocacy - training of all staff on advocacy, basic human rights;*

- *better patient information in appropriate formats - support to GPs and others in producing information guidelines, resources support, skills etc;*

- *educate patients how to know if information is accurate, non-biased and helpful.*

One workshop participant emphasised the importance of involving the right people in developing information resources:

"All information should be written collaboratively and written in a collaborative style. Ensure users and professionals are involved in production of information. Ensure it is shown to widely diverse groups before publication."

Another specifically highlighted the need to improve the provision of information for young people about cancer:

"Young people need education about cancer - its signs, symptoms and ... to know that they have choices if diagnosed. Education packages, delivered by those with knowledge - there is a package currently out there and this needs greater publicity..."

7.8　Developing support systems and structures for patients, service users, carers and families

Workshop participants were clear that patients, services users and carers would need support, as well as information, to participate in shared decision-making. Specific suggestions were as follows:

- developing 'buddying' and 'expert companion' systems for patients *"for patients to learn from/pair up with more 'empowered' users"*;
- developing advocacy and liaison services, including liaison with community partners and other established services and *"involving other 'advocates' other than GP to avoid overstretching clinical time"*;
- developing the role of voluntary and community sector organisations to support shared decision-making:
  - *"patient groups/3rd sector [provide] patient support for patients wanting shared decision-making - develop link workers/champions to support patient groups to understand the concept"*;

- o *"patient groups/3rd sector - encourage patients to help develop shared decision-making tools";*
- national roll-out of 'co-creating health' training;
- make shared decision-making a 'killer-app' for mobiles.

There were some specific recommendations regarding the development and dissemination of generic, condition specific and personalised Patient Decision Aids, including:

- *put 'shared decision-making' Patient Decision Aids on the Map of Medicine*
- *clinicians to help develop new shared decision-making aids - liaise/communicate with clinicians to see who wants to get involved through clinical networks etc*
- *produce generic Patient Decision Aids to encourage decision-making generally*
- *produce range of Patient Decision Aids for different audiences*
- *offer variable levels of Patient Decision Aids, not one size fits all*

Participants also described a need to integrate the principles of shared decision-making into education within schools and higher and further education establishments:

- *educate patients on what level of care they should expect and how to challenge in the right way*
- *long term, embedded ideas need to be overcome. The public's perception of how it gets into health services are entrenched and based on the idea of not knowing best and not being able to question - school/university education*

There were also specific recommendations regarding increasing awareness and proper application of the Capacity Act 2005:

"Staff and services value the carers in the decision-making process including how to use the Capacity Act 2005 assessment/values in the process."

"Staff are aware of the Capacity Act 2005 via local co-ordinators (in place). Staff are taught how to make appropriate therapeutic goals which include therapeutic risk taking."

7.9 Integrating shared decision-making into care plans and pathways

Supporting shared decision-making clearly includes integrating it – in principle and in practice - into care plans and pathways. From workshop participants' contributions, integrating shared decision-making has implications for the design, documentation, accessibility, implementation, monitoring and future development of plans and pathways:

- *Engage primary/secondary clinical teams in developing predictable patient pathways.*

- *Clinicians and managers to identify where patient decision aids are appropriate in various patient pathways. Clinicians to agree most beneficial areas to implement shared decision-making and agree in collaboration locally, best location in pathway - could be different in different* [pathways].

- *Patients/carers need to be made aware of the full treatment process which might involve several appointments to different departments - pathways* [need to be] *made more accessible and information given verbally and in writing before appointments accepted through choose and book.*

- *Patients, carers, families share development of care planning - monitoring of care plans; care plans signed off at reviews by patient/carer/advocate.*

- *Every clinician expects to review shared decision-making at that point in the pathway - and expect that it may change. Patient record – changes to mandatory* [requirements] *to record conversation took place and outcome, written in patient's style of vocabulary.*

- *Care plans are well written and clear ... standard format to be followed. Key staff responsibility to be agreed and monitored. Feedback forms for carers and patients to be included in care plan.*

- *We need to add prompts to documentation in order to be able to audit compliance. This would be easier if the right information was at hand and confidence sufficient to deal with the issues.*

- *We need to ensure we populate the long term condition generic commissioning pathway with exemplars and background documents within the shared decision-making box at each level of the pathway.*

- *Patients with long term conditions need an individual care and treatment plan to enable them to understand the limitations of conditions so that they can discuss options with any clinician.*

- *Show patients a personalised care plan, explain how to use it and allow them to hold it. For future, commission provision of web based individualised care plans.*

- *Staff are encouraged to develop care plans/agreed contracts with patients. These contracts can be changed but they record changes in direction for/by the patient and staff. Staff and services are taught that people can change their minds and they don't have to have a reason; to be open to the reason non-judgemental e.g. I'm scared.*

- *There needs to be a process to allow the patient to have time to discuss concerns before facing decisions - including carer/relative input - without jeopardising their care.*

- *Staff are encouraged to undertake a Holistic Assessment. By understanding a patient roles/relationships/pressure and goals; the decisions that are made by the patient and their intent is more transparent. There is a decision on the Common Assessment Framework (Adults).*

- *The 'system' develops an agreed place to have a service users care plan e.g. Common Assessment Framework (Adults). There is an agreed place to 'put' the shared care plan for a patient.*

7.10 Developing information resources and support for health professionals and services

Workshop participants were clear that supporting shared decision-making means ensuring that health professionals and services have the right information at the right time.

With regard to information, the primary recommendation from workshop participants was to establish systems for ensuring that services are kept well-informed and up-to-date about:

- what other services offer, including the options available to patients who might be referred onward
- care pathways

"[The patient's] *consultant needs to know what choices are there for teenage and young adult* [cancer] *patients, then they can share these choices. Produce literature that educates consultants about what is out there and why* [it is] *important.*"

Services should have a 'directory' of services [and] care pathways. *This may overcome the problems of lack of professional knowledge about options for service users. Map of Medicine has a directory of services → link to NHS directory. Local directory of services → funding agencies know who/what they fund.*

Recommended support for health professional and services includes teaching, training and coaching; the development of service standards; assessing adherence to shared decision-making within governance and management systems:

- *We* [the NHS] *need to be honest with public and patients about limitations of evidence change organisational culture, use coaching techniques to build awareness and self confidence or leaders/staff.*
- *Senior clinicians need to teach and explain their thought processes / decision-making / risk strategy to junior colleagues. … Starts with clinical leads of service - cascade into risk modelling.*
- *Training available to support process.*
- *All staff need to understand how to assess mental capacity i.e.* [the] *patient may not be able to make informed choice.*
- *Develop good practice standards and principles. Standards for involvement.*

- *Assessing shared decision-making – governance, appraisal, revalidation, peer review.*
- *Build shared decision-making into clinical governance and revalidation.*
- *Services and staff are encouraged to be peer reviewed. Supervision is not only about processes and outcomes it includes values/communication skills of services/staff. Staff are encouraged to complete their Continuing Professional Development. Services support CPD and supervision.*

Building on the shared decision-making 'champion' recommendations from the focus groups, one workshop participant suggested establishing a central source of support:

- *Support to all parties involved in the shared decision-making - central hub.*

Another recommending focusing, in the first instance, on shared decision-making within general practitioner services:

- *As 90% of access to the NHS is via a GP - start with GPs. Training, contract monitoring, etc.*

7.11 Resourcing and incentivising shared decision-making as the norm

Resourcing

Some focus group and workshops participants argued that a cultural shift towards shared decision-making, while not necessarily cost-free, is about thinking differently rather than '*all about money'*:

"Yeah but people always think it's about more money, you know and people saying "oh money, money's being cut, it's all about money", I'm not saying that isn't an issue because it is but sometimes it's about culturally thinking about how you do things."

While this is evidently true, reviewing participants' recommendations (regarding what needs to be in place, what needs to be done and what would help) demonstrates that achieving shared decision-making as the norm will require both 'pump-priming' and ongoing investment to be sustainable.

Questions about how shared decision-making as the norm would be funded arose very many times during the focus groups and workshops. There were essentially four different considerations:

- whether, how and by whom the shift to shared decision-making as the norm will be resourced at local and national levels
- whether shared decision-making is more costly, cost-neutral or cost-effective than 'usual practice'
- whether shared decision-making as the norm can be expected reduce NHS costs in the longer term
- whether shared decision-making risks creating expectations which cannot be met, by the implying that the NHS can offer unlimited choice:

Participants did question whether necessary resources could be found or made available, given the prevailing and likely future economic climate:

"… everything that's going on at the moment, all the changes, the proposed changes, just the way the environment's changing so very, very fast and so dramatically, it doesn't necessarily lend itself to implementing shared decision-making, it doesn't lend itself to patient choice. If anything the fat's being cut off the bone and we're herding people in specific directions when it somehow contradicts what we're … … this is what we say we should be doing but what we're actually doing and being covertly told to do is pushing people in another direction. I just don't think it helps."

With regard to cost-effectiveness and longer term impact on use of NHS resources, as described in the preceding sections of this report, participants emphasised the need to make and communicate the cost:benefit case for shared decision-making to achieve the necessary 'buy-in'.

From the discussions, it will be important to address NHS practitioners' and managers' concerns that shared decision-making takes more time than 'usual practice' and that it does not fit with 'how things are done'. The following exchange, for example, discusses how shared decisions making as the norm might have wide-ranging implications for how the NHS allocates and uses clinical time and patients' time:

(A) *"Obviously I look at this whole proposal from a completely different objective so, well as a patient also I was really interested because I'm probably one of those people that would be empowered and would be involved, but at the same time from a manager point of view I'm thinking consultation times, I'm thinking the repercussions of patients having access to their medical records, there's all sorts of nuts and bolts issues that are popping through my head, that consultation times specifically would be my concern because it, you know, in your allotted ten minutes that essentially is somebody saying "this is the problem I've got" and you saying "this is what I propose"...*
(B) *Does it have to be that? You say your allotted ten minutes as though your allotted ten minutes is an immutable...?*
(A) *No, that's the point, that's the first thing that throws up in my mind; it's going to have to be turned on its head isn't it? It's not going to be possible because it involves discussion."*

On the whole, participants who were advocates of shared decision-making were convinced that it saves time:

"In my experience, actually, it cuts down on time when it's very well done."

There was however general agreement that use of time is often different in shared decision-making as compared to 'usual practice', typically taking more time at the beginning of decision-making processes.

The following exchange is included as an example of discussions between participants regarding the challenges of making the transition from 'usual practice' to shared decision-making with the same patient population, and the implications for time spent:

(A) *"There's no evidence in my mind to support what you're saying except you're very busy and you've got a lot of patients but actually the evidence is absolutely the other way, you'll have more time...*
(B) *But there's a transition period.*
(A)*...and there's a transition period, yeah.*
(B) *I think the transition for some patients and in some circumstances would be stormy, but I do think that you're right in where the end point is. That's certainly my experience."*

There was no consensus among focus group or workshop participants regarding the likelihood of shared decision-making increasing patient expectations and consequently increasing NHS costs. Some participants had concerns about shared decision-making creating the impression of the NHS as an unlimited resource:

"I've just got this feeling that it's about trying to embed the principles of shared decision-making but appreciating that the NHS isn't a bottomless pit, we talked about the fact that if you walk into a GP and say "I want" .. .as many [procedures] *as I want, well unfortunately you're not going to get that, whatever your shared decision approach, and that's not going to happen - so it's about embedding the processes and embedding the ideology but appreciating that it's situated within limited resource."*

Others questioned whether it necessarily followed that shared decision-making would increase demand for more costly treatment options:
"I think it's interesting about the expectation regarding costs and do we think that patients are always going to ask for the most expensive treatment or drug or whatever?"

Throughout the focus groups and workshops there were also some interesting discussions regarding the inclusion of financial information as part of shared decision-making within the context of a publicly funded health service. While this is clearly a complex issue, and arguably beyond the remit of this project, participants on the whole agreed that shared decision-making could and should include information about costs:

"And patients actually, when you do start to talk to them, they often will come back and say, yeah, I understand it's in relation to cost. And I think we, as clinicians, are a little bit nervous about talking... about the money side of it. But ... everyone budgets on a day to

day basis and I think they think, well, if there is something that's cheaper but it's the same, I mean, not... Obviously not being offered the correct treatment just because of cost is a whole other issue."

Incentivising

As would be expected, workshop participants included incentivising shared decision-making as one of the things that 'needs to happen'. Their recommendations were, essentially, that shared decision-making needs to be integrated into existing systems for incentivising, monitoring and managing performance:

- *Payment by Results, individual budgets and personal health budgets reflect principles of shared decision-making - or cost will drive practice.*

- *Patient Reported Outcomes Measures to be used in contracting services.*

- *Department of Health [needs to] build expectation of shared decision-making into standard contract (with possible consequences for non-compliance).*

- *Develop Key Performance Indicators to reward shared decision-making behaviours - both 'profs' and patients.*

Participants in the June 15 workshop were asked to list the NHS departments and functions support would be needed in working towards shared decision-making as the norm. Listed here alphabetically, they said:

- commissioning
- communication - standardisation of information resources;
- contracts & contracting (putting qualitative work into standards);
- finance;
- human resources - mission statements, job descriptions and person specifications;
- IT systems;
- joint working - health and social care;
- out-of-hours services;

- patient involvement;
- peer review;
- professional leads;
- relationship management;
- risk management.

Participants identified Commissioners and Directors of Finance, in particular, as important players in driving shared decision-making and in aligning incentives:

- *Commissioners to stipulate shared decision-making as a requirement for contracts for providers.*

- *Commissioners to make and document use of shared decision-making compulsory in all patient pathways where appropriate - work with commissioners to develop commissioning documentation to support shared decision-making and tool kits to support implementation.*

- *Monitor for unwarranted variations in pathways – standard reporting to commissioners to allow benchmarking of unwarranted variations in pathways.*

- *Directors of Finance need to align financial incentives along all pathways – i.e. remove financial incentives of Payment by Results 'to just fund the procedures to fund Private Finance Initiatives.*

- *Directors of finance need to a agree shared decision-making is an ethical imperative and develop a new way of commissioning that supports shared decision-making – i.e. block contracts, not cost per case/cost and volume.*

picker
Institute Europe

Making patients' views count