

Cover Sheet

Trust Board Meeting in Public: Wednesday 10 May 2023

TB2023.39

Title: Sharing the Decisions - Making Clinical Decisions Together

Status: For Discussion

History: A patient story and perspective is presented at each Trust

Board

Board Lead: Chief Nursing Officer

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Confidential: No

Key Purpose: Strategy, Assurance, Policy, **Performance**.

Executive Summary

- 1. The purpose of the paper is to introduce 'shared decision making' as a clinical approach raising its profile across the Trust, share Dan, Julie, Jane and Zahida's story and their experience of making key healthcare decisions with their clinicians, share the experience of the Adult Congenital Heart Disease Team and describe the progress with the project and the plans for roll out across the Trust.
- 2. Shared decision making is a working collaboration between the patient and their healthcare professional, empowering people to make decisions about the care that is right for them. The UK Supreme Court ruling in 2015 (Montgomery) set the legal standard for patients with full mental capacity to be properly advised about treatment options and associated risks so they were able to make informed decisions when giving or withholding consent to treatment. The Trust is undertaking the NHS Southeast Specialist Commissioning Team's CQUIN between 2022 to 20224 to pilot shared decision making across five clinical areas.
- 3. Three patient stories describe their treatment and care, the process of making decisions with clinicians about options, weighing up the best treatment to take and the impact on their lives. The Adult Congenital Heart Disease Team's perspective explains how shared decision making is a core part of their practice. They discuss how they are making reasonable adjustments to ensure people with learning disabilities can be included in making decisions about their care.
- 4. The Trust used the SDMQ-9 (Shared Decision-Making Questionnaire 9) to establish the baseline of shared decision making in the five pilot areas and is using the national shared decision-making tools developed by NHS England and Aqua. These are being translated into easy read to empower and include patients with learning disabilities.
- 5. We learned that using nationally produced resources enabled us to spend more time implementing shared decision making with clinical teams allowing flexibility to take account for the different ways teams supported their patients and developed the therapeutic partnership. Developing partnerships with a Trust with more experience has enabled us to learn from them and to provide a helpful sounding board to problem solve.
- 6. The CQUIN year two implementation will focus on implementing the six questions in the NHS England guidance, include transition/ moving to adult services and strengthen the data collection to 100 completed and submitted SDMQ-9 per speciality.
- 7. Recommendations: The Trust Board is asked to note the contents of the report.

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Sharing the Decisions - Making Clinical Decisions Together

1. Purpose

- 1.1. The purpose of the paper is to:
 - Introduce 'shared decision making' as a clinical approach and raise the profile across the Trust.
 - Share the patients stories and their experience of making key decisions about their healthcare with their clinicians.
 - Share the experience of the Adult Congenital Heart Disease Team.
 - Describe the progress with the project and the plans for roll out across the Trust.

2. Background

- 2.1. The NHS constitution states that patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment¹.
- 2.2. Shared decision making is a working collaboration between a patient and their healthcare professional to reach a joint decision about care whether this is needed straightaway, or in the future. It means making sure the person understands the benefits, harms, and possible consequences of different options through discussion and information sharing. This joint process empowers patients to make decisions about the care that is right for them at that time including the option of choosing not to have treatment.
- 2.3. In 2015 the UK Supreme Court ruled in the 'Montgomery' case, setting the legal standard whereby patients with full mental capacity must be properly advised about their treatment options and associated risks, including those most pertinent to the patient, to enable them to make informed decisions when giving or withholding consent to treatment. In 2019, NHS England and Improvement, launched Universal Personalised Care² aiming to give patients greater control over the way their care is planned and delivered, based on what matters to them and their individual strengths, needs and preferences³.

² NHS England » Universal Personalised Care: Implementing the Comprehensive Model

¹ NHS Constitution for England

³ Making decisions together: the implications of the Montgomery judgment - ethical learning material - GMC (gmc-uk.org)

- 2.4. The National Institute of Clinical Excellence guidance (NICE 197) ^{4 and 5} advises that shared decision making should be part of everyday practice across all healthcare settings.
- 2.5. The NHS England Shared Decision-Making Summary Guide⁶ is intended for people leading local implementation of shared decision making. It enables:
 - increased understanding of what good, shared decision-making looks like and how it ensures that we commission and provide systems and services that informed individuals want
 - commissioning of local shared decision-making initiatives and embedding them in care pathways
 - providers to have better conversations with people using services, thereby supporting them to make more informed choices based on their personal values and preferences and what is known of the risks, benefits, and consequences of the options available to them.
- 2.6. The Trust is undertaking the NHS Southeast Specialist Commissioning Team's CQUIN⁷ between 2022 and 2024 to pilot shared decision making across five clinical areas. The CQUIN is supported by the NICE Guidance 197 and the goal is to achieve 65% 75% compliance across the five clinical areas. The Trust Teams involved are Adult congenital Heart Disease, Renal Dialysis, Neurosurgery, Atrial Fibrillation (AF) Ablation and Systemic Anti-Cancer Therapy (SACT).

3. What is Shared Decision Making?

3.1. This video, below, has been developed by NHS England and Aqua and is available in the Renal Cardiology outpatients and will be available across the remaining five pilot clinical teams and gives an overall introduction to shared decision making.



⁴ Shared decision making underpins good healthcare | News | News | NICE

⁵ NICE Guideline

⁶ NHS England » Shared Decision-Making: Summary Guide

⁷ Commissioning for Quality and Innovation

3.2. The nationally developed shared decision-making resources⁸ are shown in Appendix 2. These are available in nine additional languages (Dutch, French, Portuguese, Greek, Croatian, Russian, Turkish, Spanish and Chinese).

4. Dan and Julie's story

Dan: I am Dan and Julie is my Mum. I am 27 years old, I'm a Dad, and a social worker. My Mum and Dad have lived this with me since I was 18 months old.

I have been looked after in four hospitals and had surgery in two. I was 18 months old when I had my first surgery. I had regular check-ups and I remember being told that I would need an operation, but it was always in the future, and it became part of the routine conversation in my outpatient appointments.

When I was 16, I had an appointment with the Hepatology team⁹, and I was diagnosed with Abernethy syndrome¹⁰. This process took a long time and in the year before my surgery, the growths in my liver grew dramatically with the big concern that it could be cancer. I went for a routine ultrasound; the healthcare professional came into the waiting room and gave me a letter saying you have multiple growths in your liver. I was sent to another hospital for an appointment, but when I arrived and met the doctor, I was told that the Multi-Disciplinary Team had decided that the original plan would never have worked, and I would need a transplant. This was all during a 20-minute consultation. It was a real shock and it felt mismanaged.

I still went to Reading Festival that weekend, what else could I do.

Julie: I felt we needed a second opinion from another Liver Centre and so we organised that, but no one said you can have this. Over the next two years I contacted the Liver Trust¹¹, and they put me in touch with the Childrens Liver Disease Foundation¹² and that was a massive help.

Dan: My Dad offered to be the donor and when we were getting ready for the surgery, the surgeon clearly explained what was happening, gave me the pros and cons of the procedure and helpfully explained why it hadn't been picked up earlier (my condition was rare). I felt that although there was strong medical opinion and recommendations, it was my final decision, I consented to the

⁸ Shared Decision Making & Ask Three Questions - TIER Network (readysteadygo.net)

⁹ The Complete Guide To Becoming A Hepatology Doctor | BMJ Careers

¹⁰ A rare vascular malformation known as **Congenital Extra-hepatic Portosystemic Shunt (CEPS)** wherein, the portal venous system drains directly into the systemic vein bypassing the liver completely or partially.

¹¹ British Liver Trust - Pioneering Liver Health

¹² Children's Liver Disease Foundation | Liver Disease Research and Support (childliverdisease.org)

surgery and not my parents. I had the transplant in 2014, when I was 18 years old. Getting back on track was difficult after this, as I delayed my A levels and resat the year. Being at school without my friends wasn't ideal as I didn't really know anyone, my usual support had gone. With hindsight, counselling might have been a good idea to help me adjust and make sense of what had just happened.

I was looked after on an adult ward, and this felt like a gap and a jolt as I went from being a child to an adult in an instant. I was being looked after alongside people who were much older than me and some with alcohol problems. There were no pictures of Peter Pan on the walls and no play station in the waiting room. It felt harsher even though I was 18, I guess it felt as though I was treated more softly as a child. I don't think I could have had my surgery at a different time, but I wish it could have been different as that year was very tough.

I am not sure I like seeing different doctors all the time, but I do understand they are trying to share patients, but it would be helpful to explain that. You need to form a relationship and build trust otherwise it feels impersonal.

Julie: When Dan was younger, I can remember thinking - I don't know these people, and I need to trust and have faith in them so I can hand over my precious child. As Dan became older, I stepped back a bit so that he could go to consultations, trusting that he would have the self-confidence to ask the right questions. This was a balancing act and complex to manage. Communication hasn't always been easy, and which can make things complex to navigate however the transplant coordination has been fantastic and the Heart Centre is excellent. I never worry that Dan might get lost as the specialist nurses are always available and will follow up to see how Dan is.

Dan: My last surgery for a heart valve replacement was in August last year and I had to delay my degree for a while. I'd had routine follow up appointments for three years and I remember expecting more of the same at this particular outpatient appointment when I was told I needed surgery and within four days I was booked in.

I wish I could have set the time for both my operations, but that wasn't to be as my conditions didn't always follow a straightforward path. I didn't feel in control all the time because of this and found that hard. For example, the consultant might say now is the time to go ahead but the surgeon may say no – you can't control that.

My surgery lasted 12 hours and I was in an induced coma for 24 hours after that. The surgeon phoned my Mum and Dad to say I was out of surgery and in intensive care. They were beside themselves as they thought the surgery was going to take between five and seven hours.

Looking after your mental health is a massive part of this process and my Mum describes it as 'mind, body and soul'. I worried about things much more this time around as I was older, and I had a child to look after but I was determined that I

wasn't going to let my health re-rail me or stress me out. I talked with my family, but I think having someone else to talk with both before and after the procedure would have helped me make sense of my healthcare and unpack my worries. Having said that charities have also provided a lot of support and resources which has been invaluable.

5. Jane's story.

I remember vividly moving house when I was 60, I was carrying boxes up the stairs and I felt a massive pain in my chest. My GP referred me to the Rapid Access Clinic, and I met my consultant, and she essentially kept an eye on me – how was I, how was I doing?

I started going down hill quite quickly and we discussed the options for surgery and when it would be appropriate to have it. My consultant explained there was no evidence about the best time for the surgery, but I was very clear that I wanted it as soon as possible.

My consultant listened to me and referred me for surgery at another hospital because it isn't undertaken in Oxford. When I met the surgeon, we struck up a very interesting conversation about what the surgery would involve and he drew diagrams for me to help my understanding and answered my questions during our conversation.

I have yearly follow up appointments with my consultant in Oxford, it works well.

In terms of what went well? My consultant in Oxford referring me for surgery. It was excellent. I can walk up stairs and go for walks again. My husband could stay overnight next to the hospital site, I think in a house run by the British Heart Foundation, and it meant he could focus on me without having additional worry of finding accommodation.

I used to be a nurse, and had a knowledge of anatomy, so I wasn't so scared and that made a difference.

I can't think of anything that could have been improved, my support and care was spot on. I had the specialist nurse's telephone number so I could phone her if I had any worries — I didn't have to wait until my outpatient consultation, it was very helpful to us.

6. Zahida's story

I had a fever when I was 15 and that's where things started to go wrong. I moved to England when I was 31. About four years ago I contacted my GP and she referred me to my local hospital to see a cardiologist. He sent me to see the team in Oxford and I met my consultant.

I wanted to have a baby and they were worried about me as they thought it might be hard for me to conceive. It was very challenging as my heart problem was what you would usually see in an older person. My local hospital arranged for me to see a surgeon who told me that the best option for me was to have a certain procedure as the alternative wouldn't last as long and they wanted to avoid me having open heart surgery.

My consultant in Oxford spent along time trying to find out if an operation usually carried out on children would work for me, I met with the surgeon who thought it also was a good idea and they were happy to go ahead but said it's up to you what do you want to do?

At the same time a CT scan showed that one of my arteries was blocked and so as the team were concerned, they did both the heart and the artery operation at the same time.

For the first two days after surgery, I wasn't very well and had too much fluid in my lungs. I stayed in hospital for two weeks and was able to walk out when I was discharged - it was amazing.

I saw my consultant in Oxford six months after my surgery and I was able to stop all my medication, even the Aspirin! The best news was discussing that if we wanted to, we could try for a baby. I conceived after two months; the team were so lovely and said please let us know how you are doing and if you have any worries at all – please get in touch. There were no problems and 14 months ago I had a little boy.

I have just been for my yearly follow up and my consultant and I discussed me and my husband being able to try for another baby. My husband and I are so happy.

I have gone from having a damaged heart and a blocked artery to a wonderful life. My consultant listened to me - it wasn't just about my heart; it was about my life and my family. My consultant is amazing, and I will always be very grateful to her.

7. Adult Congenital Heart Disease team

As a multidisciplinary team of doctors and nurses, it's the way we work, it's our patients lives not ours. It is important that we work in a way that gives confidence, builds trust and enables patients and their families to make the discussion that's right for them. These decisions are often complex and take a while to think through.

We have put the shared decision-making video on the TV screens in the outpatient's department, so that patients and their families can see it whilst they are waiting.

About 10% of our patients have a learning disability and so as a team we are keen to have the shared decision-making resources translated into Easy Read¹³.

¹³ Easy Read | My Life My Choice

My Life My Choice¹⁴ are translating them for us and their Health Champions are checking that the information will make sense for our patients who have a learning disability and enable them to discuss their care with confidence – and asking the questions that are important to them.

Emma: I have been a specialist nurse for 10 years and have looked after inpatients in the cardiac wards before that. Shared Decision making is the way we work – as many patients have experience of their condition from childhood and so have complete awareness of their condition.

Shared decision making extends to tests that the patients need to have to monitor their health and their heart effectively. Patients are in first instance offered to undertake particular test and, if they decline for any reason e.g. at they are claustrophobic, or they are not able to tolerate wearing a mask, they are offered alternative option.

My job in the clinic is to meet and greet patients, spend time with them, providing support, asking them how they appointment went that day and talk with them and their family about the decisions they are considering.

As a team we have always been very open and encouraging patients to speak with us about the options available to them, this could be an ICD¹⁵ or a pacemaker¹⁶.

Cynthia: I am new to the team, but I can see that our patients are very much involved as shared decision makers and part of the multidisciplinary team. This isn't always easy, the decisions patients are facing are complicated and can be frightening or challenging for them, if a patient contacts us because they have concerns about the decisions they are facing, we make sure the consultants know straight away so the patient can discuss thing further in a supportive environment.

Since I have qualified and become a registered nurse, my practice to support patients in the decision making about their healthcare has changed considerably, as nurses we are closely involved in discussing sensitive information with patients, how they feel about their decision and their options which will impact greatly on their life and that of their family.

We don't tell patients what to do anymore, instead we discuss with them the decision that needs to be made, how they want to be involved, help them weigh up the available options, select the best option and agree how to proceed together.

¹⁴ My Life My Choice | Home. my Life My Choice is a charity run by and for people with learning disabilities in Oxfordshire.

¹⁵ Implantable Cardiac Defibrillator Implantable cardioverter defibrillator (ICD) - BHF

¹⁶ Pacemakers - how do pacemakers work - how are they fitted - BHF

8. Common themes

- 8.1. There are several common themes identified from all involved which show the change in emphasis from a healthcare led model to a partnership.
 - trust, partnership and forming a relationship
 - communication discussion, weighing up options together
 - empowerment the patient is involved in decision making
 - mental health and emotional support
 - putting patients and their families in touch with patient led organisations
 - supporting the transition to adult services
- 8.2. Shared decision facilitates these common themes by a healthcare professional and patient working together. The CQUIN is designed to
 - help Trust's initially assess how well shared decision is working
 - introduce patient decision-making aids/ shared decision-making resources to empower patients
 - retest the experience of shared decision making once patient decision making aids have been introduced

9. OUH progress with the Shared Decision Making CQUIN

- 9.1. To establish a baseline of shared decision making the team asked patients' views and experience using the publicly available SDMQ-9¹⁷. The teams' results are shown in Appendix 1.
- 9.2. The team's results were shared with them at an MDT meeting, and a plan made with the team to introduce shared decision-making resources into the clinics.
- 9.3. Having reviewed the nationally shared decision-making tools we decided to implement 'Ask 3 Questions', developed by NHS England and Aqua and as they use inclusive graphics and are easy to understand. There are two variations to this:
 - Adult congenital heart disease team require Easy Read translations to empower patients with learning disabilities
 - AF Ablation will use the nationally produced resources specifically designed for AF Ablation
- 9.4. Two pilot teams have started rolling out 'Ask 3 Questions' resources across their clinics, with the remaining three teams implementing in the next month.

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¹⁷ SDM-Q-9/SDM-Q-DOC (patient-als-partner.de)

10. What have we learned?

- Use the nationally produced questionnaire to establish the baseline as these tools have been previously tested, however, give space for a patient to share their story and this narrative adds to the richness of the implementation.
- Use the nationally produced patient decision making resources and brand¹⁸
 as they have been previously tested and are available in different languages.
 Also allow flexibility if clinical areas have access to national resources
 developed for their clinical speciality. It would be valuable to extend this to
 include the main other languages spoken by patients supported by the Trust,
 this includes Polish, Arabic, Albanian, Farsi, Indonesian and Romanian.
- The shared decision-making conversations may happen over time or in a single consultation depending on the complexity of the decision to be made.
- The nationally produced resources are very good, but people with learning disabilities have found it challenging to follow and understand.
- Teams need to have flexibility to use the shared decision-making resources at different times during the process. For example, SACT, use the resources part way through the process once patients have been given all the options and they have had time to review at home with their family.
- Partner with an NHS Trust who has more experience to learn from their implementation. The Trust has partnered with University of Southampton NHS FT, who have provided a helpful sounding board for us to problem solve learning from their experience.
- Include Transition/ moving into adult programme into the shared decision making CQUIN as children and young people with long term conditions are experts in their own healthcare and will need to be supported by adult services.
- Spend time with the clinical team to understand how they how they work and form a supportive working relationship with them. This assistance enabled the teams to implement whilst experiencing significant clinical pressures.

11. Year two CQUIN

11.1. The CQUIN has been rolled out nationally for a further year with the expectation that all Trusts will extend their shared decision making (SDM) schemes during 2023/24¹⁹. The expectations include:

¹⁸ Shared Decision Making & Ask Three Questions - TIER Network (readysteadygo.net)

¹⁹ The 2023/24 CQUIN Indicator Specifications are available on the NHSE website

- Add additional specialities or further embedding the SDM approaches into the pathways selected in 2022/23
- Support patients' using available resources such as BRAN, Ask Three
 Questions, or It's ok to Ask ²⁰ alongside patient centred shared decisionmaking conversations.
- Detailed data gathering and analysis of patient questionnaire responses (minimum response rate of 50 responses should be collected per pathway and per data collection) to understand whether there are implications for health inequalities and more in-depth evaluation of the impact of SDM and the quality of conversations, such as using the clinician SDMQ9 questionnaire.
- Implementing the SDMQ9+1 questionnaire, developed by University Hospital Southampton NHS Foundation Trust and which is particularly relevant for work with children and young people²¹ ²².
- 11.2. The six national CQUIN questions and the data submission requirements form the focus for the Trust's year 2 project plan and is summarised in Table 1, below.

Na	Submission timeline			
1.	What were the lessons learned from the 2022/23 SDM CQUIN, and what will you do differently because of the experiences in year 1 of the CQUIN?	End of Q1: 30 June 2023		
2.	How will you further embed SDM in the pathways selected in 2022/23?			
3.	How will you roll out your approach taken in 2022/23 to more pathways in 2023/24?			
•	50 SDM Q9 completed per speciality.	End of Q2: 30 September		
•	SDM Q9 healthcare professionals' questionnaire	2023		
1.	What areas for quality improvement have you identified in your approach to shared decision-making using results from the baseline data collection and other sources of data and feedback?	End of Q3: 31 December 2023		
2.	Is there anything you will do differently to collect SDMQ9 responses in Q4?			

²⁰ NICE Standards framework for shared decision making support tools including patient decision aids

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²¹ https://www.readysteadygo.net/shared-decision-making--ask-three-questions.html

²² NICE guideline on babies, children and young people's experience of care

Na	ational CQUIN submission requirements	Submission timeline
3.	How do you plan to sustain the improvements that are being made beyond 2023/24?	
•	50 SDM Q9 completed per speciality. SDM Q9 healthcare professionals' questionnaire	End of Q1: 31 March 2023

Table 1: National CQUIN submission requirements and timeline for submission

11.3. The year two CQUIN plan is shown in Appendix 2.

12. Conclusion

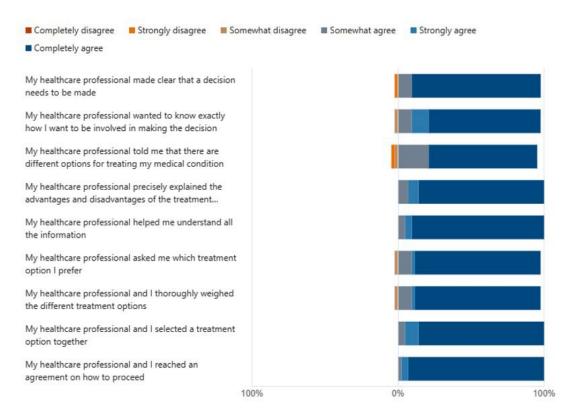
- 12.1. This paper has shared Dan and Julie, Jane, Zahida and the Adult Congenital Heart Disease Multi-disciplinary Team's stories, described the implementation of the Shared Decision Making CQUIN and the year two CQUIN plan across the Trust during 2023/24.
- 12.2. The lessons learned have been considerable and shown the importance of supporting clinical teams when implementing a new project, enabling a more sustainable outcome for both patients and their clinical teams.

13. Recommendations

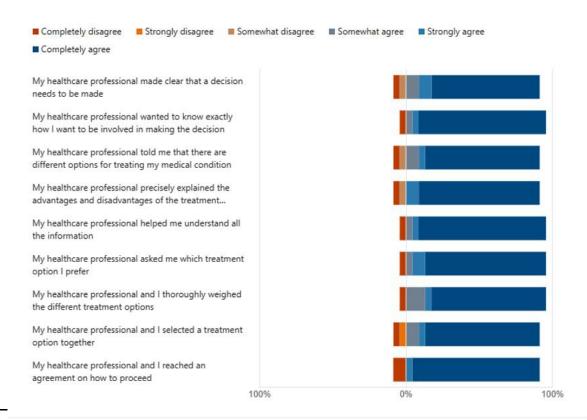
The Trust Board is asked to note the contents of the report.

Appendix 1. Shared Decision Making Q9 baseline results from the CQUIN in year one.

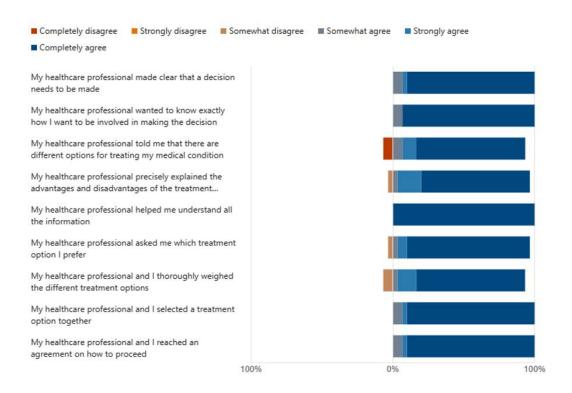
1. Adult Congenital Heart Disease Team baseline results. 43 patients interviewed.



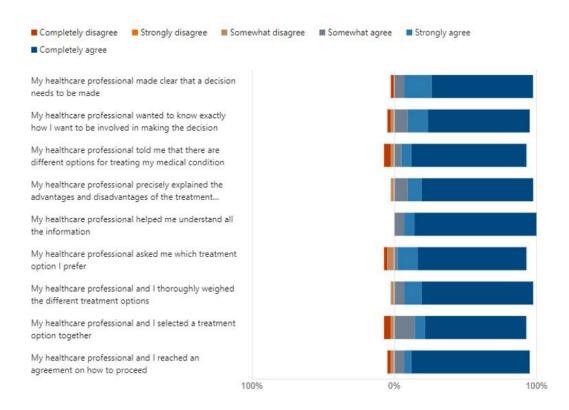
2. AF Ablation baseline results 28 patients interviewed.



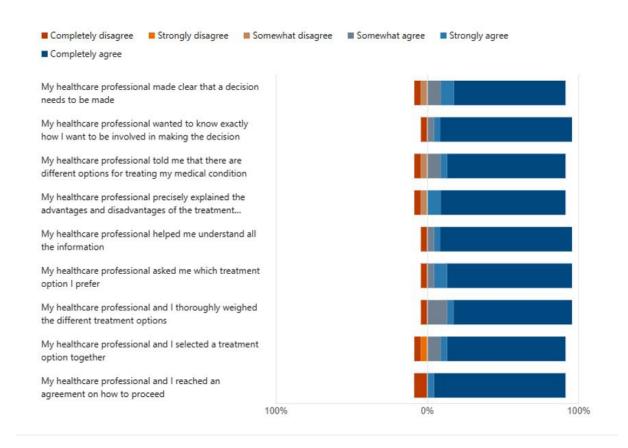
3. Systemic Anti-Cancer Therapy 30 patients interviewed.



4. Renal Team 42 patients interviewed.



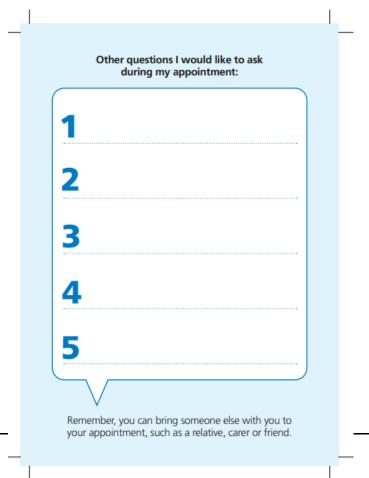
5. Neurosurgery Team 33 patients interviewed.





Appendix 2. National Shared Decision-making resources.











Appendix 3. Shared Decision-Making Project Plan.

	CQUIN: Year two. 2023/24. Action	Lead												
			April	Мау	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
	Complete Q4 report to conclude year one.	PE team												
1	 What were the lessons learned from the 2022/23 SDM CQUIN, and what will you do differently because of the experiences in year 1 of the CQUIN? How will you further embed SDM in the pathways selected in 2022/23? How will you roll out your approach taken in 2022/23 to more pathways in 2023/24? 													
ď	Complete one story for all specialities per quarter													
	Incorporate transition/ moving into adult servcies in to SDM year two.													
	Develop internal and external communications plan – Now@OUH, Junior Doctors forum, story campaign.													
	Develop QI plan (QI stand up and QI Clinic) and inclusion into clinical strategy.													

CQUIN: Year two. 2023/24. Action		Lead												
	Ogont. Tour two. 2020/24. Action	Loud	April	Мау	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
	Develop Trust SDM leadership, governance, and reporting													
	Establish feasibility of extending Aqua shared decision making resources to the main languages spoken by Trust patients - Polish, Arabic, Albanian, Farsi, Indonesian, Romanian. Establish if this can be achieved nationally in the first instance.													
Q2	 50 SDM Q9 completed per speciality. SDM Q9 healthcare professionals' questionnaire <u>SDM-Q-Doc English version (patient-als-partner.de)</u> Complete one story for all specialities per quarter 													
Q3	 What areas for quality improvement have you identified in your approach to shared decision-making using results from the baseline data collection and other sources of data and feedback? Is there anything you will do differently to collect SDMQ9 responses in Q4? How do you plan to sustain the improvements that are being made beyond 2023/24? 													
Q4	 Complete one story for all specialities per quarter 50 SDM Q9 completed per speciality. SDM Q9 healthcare professionals' questionnaire <u>SDM-Q-Doc English version (patient-als-partner.de)</u> Complete one story for all specialities per quarter 													