



Shining a spotlight on Shared Decision Making in the UK

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Foreword

The NHS *Long Term Plan*, launched in January 2019, emphasised the role personalised care can play in the health and care system, and was ambitious in its aim to make this practice 'business as usual'.

The *Comprehensive Model for Personalised Care* was launched as the delivery plan for achieving this and identifies key components to realising this vision. One of these is the principle of shared decision making. The practice of shared decision making for tests, treatments and support options opens a dialogue between patients and health care professionals that should set realistic expectations, reduce unnecessary interventions, and place the patient at the heart of their care.

This year, AbbVie brought together patient groups, health and social care services, national organisations, policymakers, and parliamentarians to a Showcase at Westminster celebrating exemplar projects that promote shared decision making practices from across the country.

We know that involving patients in decisions about their care is of fundamental importance to effectively managing long-term conditions. The Showcase is part of our Company's continued commitment to working in partnership with the health system to support excellent care and improve outcomes for patients.

It was fantastic to see the variety of innovative work patient groups and health services have undertaken to deliver shared decision making within the NHS across numerous therapy areas.

The featured projects demonstrated the value and importance of shared decision making, and yet we know that not all patients who would benefit from shared decision making are currently aware of the principles of this practice, and indeed the principles are not universally implemented by health care professionals.

The event provided an excellent opportunity to share knowledge for improving shared decision making and to raise political awareness of the need to improve access to this across services for patients with long-term conditions.

AbbVie will be continuing to work with patient organisations and the NHS to support better patient involvement in decisions about their treatment and care.

This booklet contains the posters from the projects showcased on the day. I hope you enjoy reading about the creative work taking place across the UK in the shared decision-making space, and that it inspires further great work that puts patient choice at the centre of their care.



Todd Manning
General Manager, AbbVie UK

March, 2020

“Establishing communication enables trust between practitioner and patient. Informed patients have better outcomes.”

Lymphoma Action

“Shared decision making enables patients to be pro-active and motivated to make decisions on their self-management of their arthritis.”

Arthritis Action

“Person centred care isn't possible without shared decision making.”

Picker Institute Europe

“Shared decision making increases confidence and produces better outcomes.”

Bliss

“Shared decision making = empowered patient = better outcomes = fulfilled clinicians.”

Kidney Research UK

“Shared decision making puts the person at the heart of all we do.”

MS Trust

Right Start

NRAS

Iain McNicol, Head of RA Services

The challenge

Due to increasing pressure on NHS services, access to multidisciplinary team (MDT)-led educational programmes which encourage self-management for people with long term conditions such as rheumatoid arthritis (RA), is now extremely limited and coupled with a lack of funding for and sign-posting to externally provided self-management courses. Commissioners have competing priorities for the funding of healthcare, and supported self-management is frequently not considered a priority.

NRAS has for many years designed and delivered group face to face self-management programmes that promote **shared decision making** between patients and HCPs. These have been embraced and commissioned by only a very few localities that do see the longer term benefits of supported self-management as a core strategy, improving outcomes for patients as well as resulting in a reduction in demand on services.

The vision for the project was to provide a simple model for HCPs to refer newly diagnosed RA patients to an evidence based service providing high quality education, support and access to supported self-management resources at the beginning of their treatment journey.

This aligns with Standard 3 in the NICE Quality Standards in RA which states:

‘adults with RA are given opportunities throughout the course of their disease to take part in educational activities that support self-management’



Right Start enables health professionals to comply with this quality standard.

The solution

Working with a Consultant Rheumatologist we set up a service as an NHS Quality Improvement programme. The vision was to develop a consented online referral to the NRAS national helpline team.

This process would provide the newly diagnosed patient with access to a named member of the helpline team who can provide education as well as emotional, social and RA specific support. The patient would then be provided with a tailored package of paper based and electronic resources, addressing specific issues raised during their call as well as one-to-one and community based peer support and follow up. The service also ensures the newly diagnosed patient has a relationship with the patient-led organisation that will continue to give them easy access to a range of resources underpinning supported self-management and **shared decision making**.



The outcomes

To date the project has attracted
97 referrals
in seven months, from
24 hospitals



We aim to evidence improved patient reported outcomes by people accessing the Right Start service and will achieve this through the National Early Inflammatory Arthritis Audit (NEIAA), comparing those within the audit who have received the Right Start intervention against those who have not. Data analysis, carried out independently of NRAS by the NEIAA Data Lead commenced in February 2020, and we hope to be able to publish initial results later in the year.



Shared decision making in MSK services

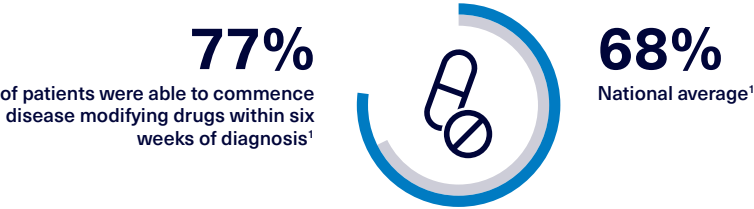
Oldham CCG and Pennine MSK Partnership

David Pilbury, Lead Physiotherapist/ Clinical Specialist Physiotherapist – Rheumatology; MSK Champion for Versus Arthritis

The challenge

Pennine MSK Partnership Limited is a service commissioned by Oldham CCG to provide care for the patients of Oldham in orthopaedics, rheumatology and chronic pain in a community setting across several sites in and around Oldham. This clinic receives all primary care referrals for musculoskeletal problems in the CCG area, to provide assessments, treatments, and, if necessary, referrals to other services, such as to orthopaedic surgeons.

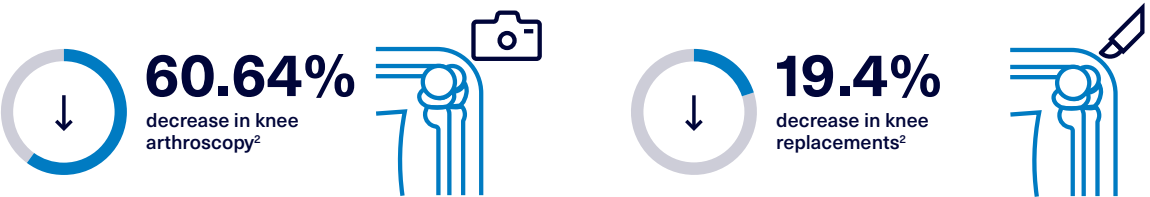
Early access to specialist services means that 77% of patients were able to commence disease modifying drugs within six weeks of diagnosis compared with 68% nationally. Early access to combination treatment is crucial to improve pain, maintain function, aid work retention, and protect joints from irreversible damage in early disease.



The solution

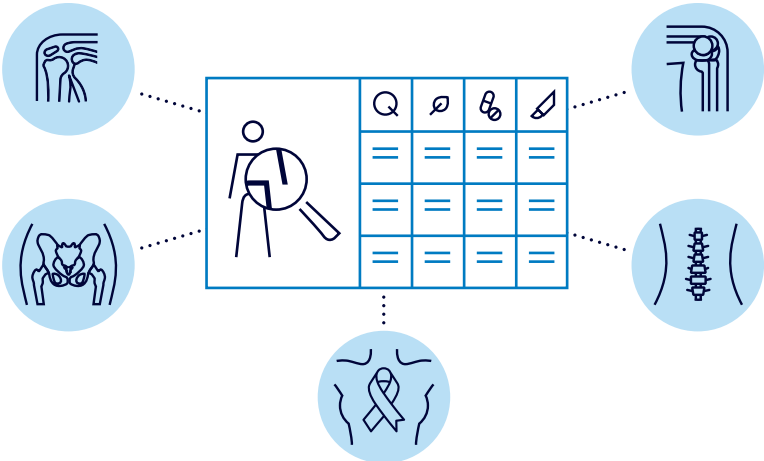
In 2015, the Pennine MSK Partnership introduced 'option grids' as a **shared decision making** tool in order to change the culture of decision making. The option grids list pros and cons for each option to treat a condition and encourage patients to make the correct choice from an informed perspective.

Since the introduction of the option grids and other **shared decision making** practices, Pennine MSK Partnership has seen at its clinic a:



The outcomes

There are currently over 20 option grids to inform treatment choices, including for pain in shoulders, knees, hips, lower back, and breast cancer. The option grids are also now available online to NHS employees to use beyond the Oldham CCG catchment area.



1. Public Health England (2016) 'Commissioning for Value Long Term Conditions Pack'. Available at: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2016/08/cv-scenario-and-rugby-llc.pdf> Last accessed: January 2022. Source data available from Pennine MSK Partnership

Shared decision-making booklets for treatment of urinary incontinence and recurrent UTIs

West Suffolk CCG

Georgina Wilson, Consultant Urologist

The challenge

Urinary incontinence affects between three and six million people in the UK, and it is a condition almost twice as many women as men live with. In 2015, West Suffolk CCG published a booklet on urinary incontinence to aid **shared decision making** in treatment choice.

Affects between
3 and 6 million
people the UK¹



2x

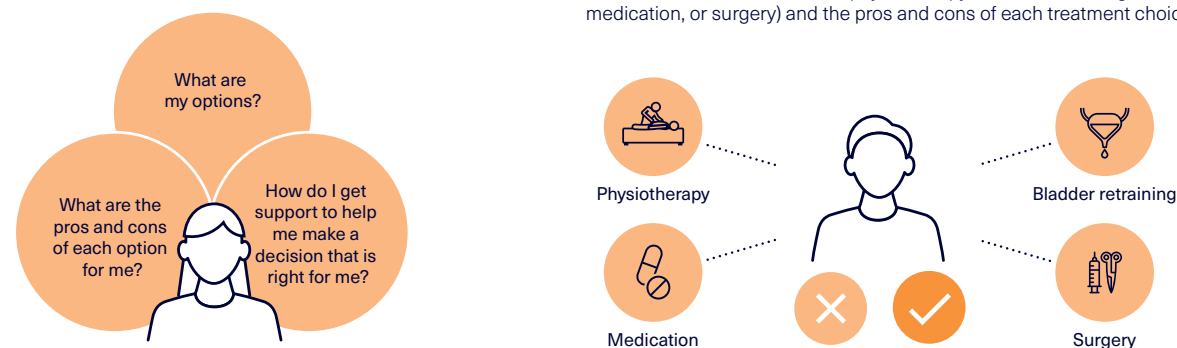
as many women as men live with urinary incontinence¹



The solution

The booklet was created after consultation with patients and primary care clinicians on what they would like in a booklet that would encourage patients to ask more questions about their condition.

The booklet outlines information about urinary incontinence and has exercises for patients to fill out such as a bladder diary, a symptoms questionnaire, and questions to answer on lifestyle choices. The booklet also details treatment choices (physiotherapy, bladder retraining, medication, or surgery) and the pros and cons of each treatment choice.



The outcomes

Following the success of the urinary incontinence booklet, in February 2018 NHS England asked West Suffolk CCG to do some work on quality improvement as part of the 100-day urology challenge, which evolved into a quality improvement project on improving care for recurrent urinary tract infections (UTIs) by using a **shared decision making** booklet.

Recurrent UTIs affect up to one in five women, but this is often not understood as a chronic condition. Patients consulted the content of this booklet, which includes information on UTIs, self-help tips, and treatment options. The booklet was trialled in GP practices before being extended to primary care networks. The booklet helps patients to start a dialogue about their recurrent UTIs as a chronic condition, rather than an acute condition. The National BAUS GIRFT Urology review praised this booklet as an exemplar of innovative practice.

Booklets enabled **shared decision making** by:

- Providing patients with an understanding of what their chronic condition is, which made them keener to ask questions about their condition they hadn't necessarily thought about
- Empowering patients to make decisions on their treatment choices
- Helping physiotherapists and incontinence advisors to understand the patient's whole journey thus giving the patient joined up care between the hospital, physiotherapists, and incontinence advisors



West Suffolk
Clinical Commissioning Group

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Follow Me

The Hepatitis C Trust

Stuart Smith, Director of Community Services

The challenge

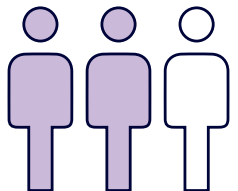
Currently around two-thirds of the 143,000 people in the UK with hepatitis C are undiagnosed. Most (90%) new transmissions result from the sharing of injecting paraphernalia for drug use, this population is highly marginalised and often struggles to engage with traditional health services. Within this there is an even harder to reach and engage group who sit outside the statutory healthcare system.

Uptake of hepatitis C testing can also be low, even in settings like prisons where opt-out testing is implemented. This is often because of stigma, lack of awareness and misinformation around treatment options.

As well as impacting on testing, these factors also contribute to a high ratio of 'did not attends' for appointments for treatment; one hospital reported a rate of attendance at appointments of less than 50%.

Getting people onto medication involves additional challenges such as ensuring people attend appointments in secondary care when they have other conflicting priorities on their time, a lack of trust of health services following previous negative experiences, and misinformation about the side-effects of the medication.

Around
two-thirds of the 143,000
people in the UK with hepatitis C are undiagnosed¹



The solution

Peer support, with its emphasis on a relationship built on shared experience and identification, plays a crucial role in overcoming these barriers. Peers from The Hepatitis C Trust use their personal stories and experience of hepatitis C and substance use to boost engagement at every stage, from awareness raising to testing through to treatment. As well as running awareness-raising workshops and offering one-to-one support, Peers are able to advocate for improvements to the care pathway, simplifying the process to increase uptake.

Coordinating such improvements necessitates close partnership-working and **shared decision making**. Peers need to work alongside hospital consultants, nurses, drug service workers and others to change systems and improve patient experience. Getting all actors to work together to improve testing and treatment uptake is central to the work of our Peers and a crucial driving force in eliminating hepatitis C in the UK.



The outcomes

Many of our peers have successfully negotiated new treatment pathways in their regions.

"We now consider the peer workers from The Hepatitis C Trust to be core members of our team [...] To attempt to achieve hepatitis C elimination without peer support would be futile."

Hepatitis C clinician

"She came to every appointment with me and supported me the whole way through the journey. Because she'd been through that process herself, I felt very comfortable with her. I suffer with anxiety so that really helped me. Without her I don't think I would have done it."

Hepatitis C patient

Many of our peers have successfully negotiated new treatment pathways in their regions: in one area we saw a 14% increase in treatment uptake which the clinical team attributed in part to the impact of **shared decision making** with our peers.

THE HEPATITIS C TRUST

abbvie

Reducing harm in transition between children and adult services/ "Supporting Transitions"

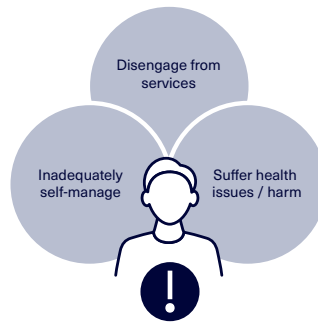
Advancing Quality Alliance (AQuA)

Rachel Bryers, Programme Manager – Shared Decision Making

The challenge

Many young people with long-term conditions are ill-prepared for the transition into adult services and for taking more responsibility for their health and self-management.

Consequently, young people:



Effective transition requires appropriate, integrated support to:



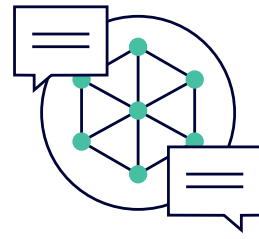
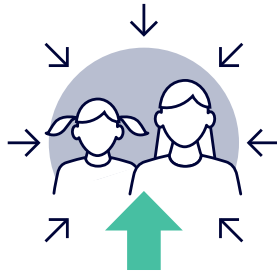
The solution

AQuA's *Supporting Transitions* two-year project was funded by The Health Foundation and focused on service redesign, using **shared decision making** and Self-Management Support as catalysts to transform transition and prevent harm. The project found that the changes that made the most improvement to transition were:

Establishment of flexible **patient-centred transition** pathways and dedicated transition clinics

Increased **cross-boundary working** between children's and adult teams / organisations

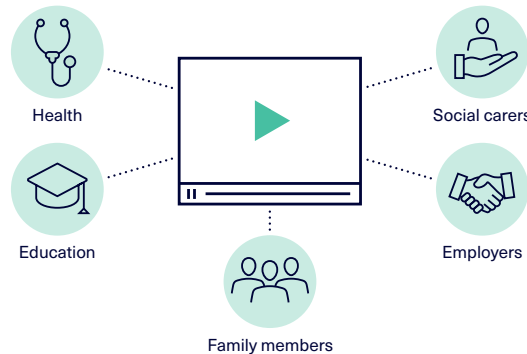
Better integration of parents and service users in pathway, using specific resources to support young people through transition



The outcomes

The AQuA *Supporting Transitions* project worked with People's Voice Media to improve the transition for young people and parent carers from paediatric services and adult services.

In this transition programme parents in a learning disability service, CAMHS (Child and Adolescent Mental Health Services) and a renal service made **short videos covering different aspects of the transition process**.



Young people and parents found these video clips useful in consultations with health, education, social care professionals and others, such as family members and employers.



AQuA's research concluded that **preparation for transition needed to be implemented much earlier**.

To support this, AQuA have developed a **child-friendly version of the existing 'Ask 3 Questions' tool** to encourage patients to ask about the options available to them and the risks and benefits to them of each option.

This is currently being piloted at Adler Hey Children's Hospital in Liverpool and Whiston Hospital in Prescot.



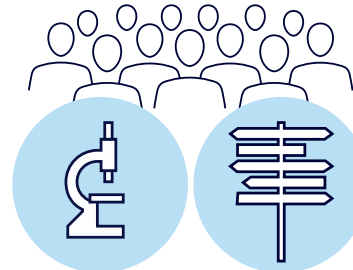
MS Decisions – shared decision making for multiple sclerosis drugs

MS Trust

Janice Sykes, Information Officer and Claire Winchester, Head of Information and Engagement

The challenge

100 people
are diagnosed with
multiple sclerosis
each week¹



There are

14 very different
drugs for relapsing
remitting MS

Decisions around treatment choice are often complex, reflecting clinical practice, patient attitude to benefits and risks, and impact on lifestyle such as work commitments or plans to start a family.

The solution

The MS Trust developed the MS Decisions resource (mstrust.org.uk/msdecisions) to provide independent, evidence-based information to support **shared decision making**. It ensures that people with MS are aware of their choices and can take a proactive role in discussions with health professionals.

People with MS, MS specialist nurses and MS neurologists were closely involved in the development of the website. The resource has three main components:

- Guide to decision making
- Frequently asked questions
- Interactive decision aid to filter and select treatments, compare up to three side-by-side, linked to in-depth information on individual treatments

The online **shared decision making** tool is complemented by a printed book with a fold out comparison grid designed to support MS specialists when discussing options with patients in the clinic.

Since introducing the tool in 2015, the MS Trust has updated MS Decisions to reflect the evolving treatment landscape, as new drugs have become available, others have been withdrawn and existing drugs have been revised.



The outcomes

"It's a bit like buying cushions from John Lewis. Choosing a DMD is serious but you want it to be easy, straight-forward, normal." *MS Patient*²

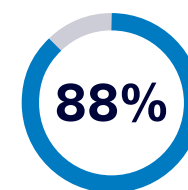
"At Addenbrooke's Hospital in Cambridge we have embedded MS Decisions into our care pathway, asking patients to look at the site and then we have further discussions about treatment options. In this way patients fully understand the risks and benefits of the different treatment options. This helps them make informed decisions in consultation with their health professionals." *MS Nurse*²

"We now have a wide and diverse range of therapies that is making choice much more complicated. MS Decisions complements the face to face discussions that people with MS have in clinic, offering a tool people can use in their own time, to come to an informed treatment decision that is appropriate to them..." *MS Neurologist*²

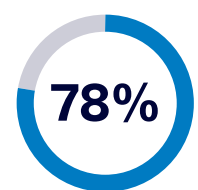
The MS Trust conducted a real world survey on the impact of MS Decisions. The results show that:



said MS Decisions increased their confidence in discussing choices with their MS team²



said MS Decisions increased their knowledge of the benefits and risks of each DMD²



said MS Decisions increased their confidence in the decision they made²

Parkinson's Advanced Symptoms Unit (PASU)

South Tees Hospitals NHS Foundation Trust and Tees Esk and Wear Valleys NHS Foundation Trust

Dr Neil Archibald, Consultant Neurologist

The challenge

Parkinson's disease is:



Common – affecting
1 in 100 over **65**



Complex – causes freezing, falls,
fractures, dementia and psychosis



Costly – results in prolonged
admissions to medical, psychiatric
and nursing care

The challenge we faced was that, with over 1,200 patients under our care, and multiple professionals involved in their care, how could we respond quickly to potential problems, prevent crisis admissions to hospital or nursing care, and ensure that all the team members were working together?

The solution

Realising that we needed a different approach, we set up the Parkinson's Advanced Symptoms Unit (PASU). This is staffed by a team of Parkinson's experts able to deal, in a timely manner, with both physical and mental health challenges that are considered to be of importance by patients themselves. We are based in Redcar Primary Care Hospital but, in addition to seeing patients in clinic, also deliver interventions at home. Being under one roof means seamless communication and better team working.

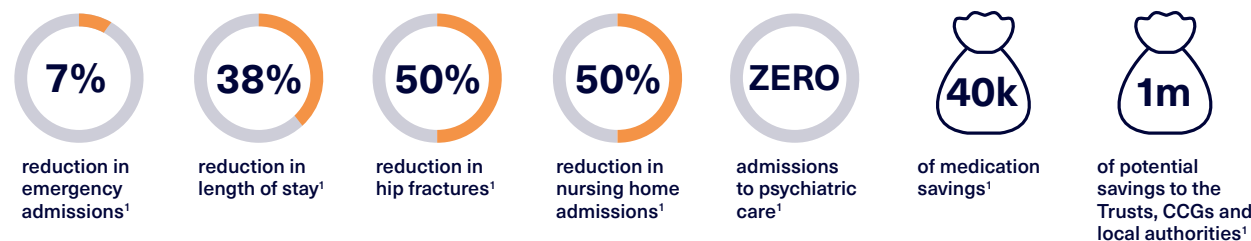
We target key issues that drive emergency admissions, such as declining mobility, falls, dementia and hallucinations. We assess patient and carer mental well-being and provide a comprehensive medication review at each visit. We also collect data on complications such as hospital admissions, length of stay, hip fracture rates and nursing home admissions.

We also deliver interventions to improve well-being and **self-management**, such as the Parkinson's choir, yoga group, exercise bootcamp and dance classes. These help to combat the social isolation of having a chronic neurological condition like Parkinson's. Lastly, we have trained over 100 members of the community therapy teams so that specialist knowledge is even closer to the patients that need it.



The outcomes

Our summary of service metrics for the past two years shows:



The unit has won a number of national awards, including:

- National Patient Safety Award for Long-term conditions (2016)
- National Parkinson's Excellence Network Award (2017 & 2019)
- Big Ideas for Better Health Award (2018)

"If we had not been able to access PASU I believe my father would now be housebound and possibly in full time care. I honestly think it has made all the difference" *Child of a PASU Clinic User*

"PASU is a great leap forwards. Its multidisciplinary team treat Parkinson's holistically and it produces better outcomes for patients. Everyone saves time and money, paperwork and travel are reduced and everything is better coordinated and more productive. I would say that the value of PASU is far greater than the sum of its parts" *PASU Clinic User*

Patient Experiences of Shared Decision Making in Dermatology Care

Picker Institute Europe

Amy Tallett (PhD), Head of Research and Esther Ainley (PhD), Senior Research Associate

Background

Shared decision making puts patients at the centre of decisions regarding their treatment and care, and is particularly important for the self-management of chronic conditions. However, previous studies have shown that some patients report a lack of involvement in treatment decisions.^{1,2}

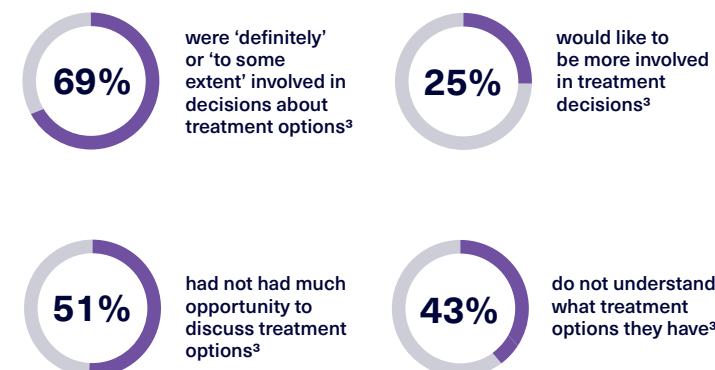
AbbVie commissioned Picker to explore this further with dermatology patients by conducting **research to understand the experiences of patients** living with moderate-severe atopic dermatitis, hidradenitis suppurativa (HS) and psoriasis. We conducted an online survey (n=1122) and in-depth interviews (n=37) with people living with one of these skin conditions across the UK.



Results

Factors that appeared to affect patients' involvement in treatment decisions were:

- opportunity for discussion with a healthcare professional
- information provided on treatment options
- healthcare professionals understanding of patients' individual needs



Those seeing a dermatologist report more involvement in their care



"It's 100% partnership...It's always been my decision. He's [dermatologist] just given me the information that I need to make an educated decision."

Interviewee with atopic dermatitis

"..Sometimes I wish they would talk to you more because it is your decision rather than just what they want to do all the time."

Interviewee with psoriasis

Recommendations

Dermatology patients report varied experiences of **shared decision making**. Some patients may need greater support and encouragement from healthcare professionals in making decisions jointly about their treatment to ensure that it best meets their needs.

To help support **shared decision making** and ensure patients remain engaged in their care, it is important that patients are given enough information about treatment options and are offered the opportunity to discuss these with a healthcare professional. Healthcare professionals should also understand patients' individual needs and what is important to them in order to advise on the most appropriate treatment options.



Shared Decision Making in Prehabilitation Oncology Services

MacMillan Cancer Support

Dany Bell, Strategic Advisor Treatment, New Medicines and Genomics;
June F Davis, Adviser for Allied Health Professionals

Background

During 2017 MacMillan Cancer Support developed a strategic evidence and insight report on prehabilitation in oncology in collaboration with internal and external stakeholders. Through discussion with clinical and academic leaders and looking at the research findings, it was agreed that it would be highly beneficial to service users, commissioners and service providers, to develop UK wide principles and guidance for prehabilitation in oncology.

This poster gives an overview of an engagement event held for people living with or beyond a cancer diagnosis. The aim of the event was to ascertain what people with a lived experience of cancer felt were the important elements of prehabilitation, as well as the purpose, benefits, and opportunities for better **shared decision making**.

Methodology

The event was held in London. The session ran for 2.5 hours. Attendees were given an overview of prehabilitation and insights into the why and how of the guidance being developed. Participants were asked to answer questions writing their responses on post-it notes which were then collected and grouped into themes. There was then a facilitated conversation around each question. A visual muralist was also in attendance on the day to capture the concepts. There were 9 attendees at the event. All had a personal experience of cancer.

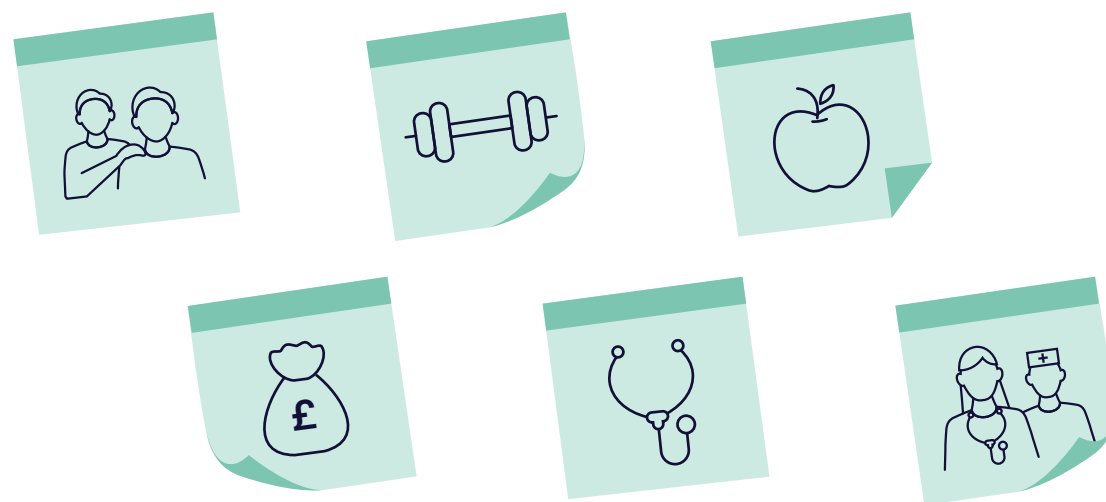
Results

Participants reported the subject areas addressed by the guidance were important aspects of prehabilitation (psychological support, physical activity and diet). Identified needs provide opportunities for **shared decision making** and included practical and financial advice; having a better understanding of medical interventions, the health system, the roles of health professionals as well as, 'what is going to happen to me'.

Participants felt the purpose and benefits of prehabilitation included: better treatment outcomes, quicker recovery, improved health and wellbeing, better integration of medical and non-medical services and better timed interventions and integration of care. Empowerment to self-manage, the ability to do something positive, and the provision of good mental preparation for upcoming treatment, were also identified.

Attendees were also asked what they wish they had known before starting treatment. Key themes included: the possibility of and how to manage treatment side effects, including long term and late effects; the amount of fear that comes with a cancer diagnosis and the importance of deciding what treatment options are right for each person through **shared decision making**.

There was no clear consensus from the group around when prehabilitation should be introduced, but the group felt it should be within a clear coordinated plan of care and support should continue through treatment and into recovery/ living with cancer/end of life care.



Conclusion

Information collected will act as a sound basis for the working groups as they commence development of the guidelines with a focus on **shared decision making**. Three of the participants have also agreed to be patient representatives for the overall project. The visual mural will be used throughout the development of the guidelines and in the dissemination and implementation of these.

Shared Decision Making for Inflammatory Arthritis

Portsmouth Hospitals NHS Foundation Trust

Steven Young Min, Consultant Rheumatologist; Colin Beevor, Matron

The challenge

At its best, the care of patients with inflammatory arthritis is an equal partnership between healthcare professionals and the patient with their carers and/ or family. It is a considerable challenge to meet this ideal. The Portsmouth Rheumatology department, have, over a number of years, worked towards ensuring that patients feel informed and empowered to **ensure that they fully share in all the decision making that occurs**.



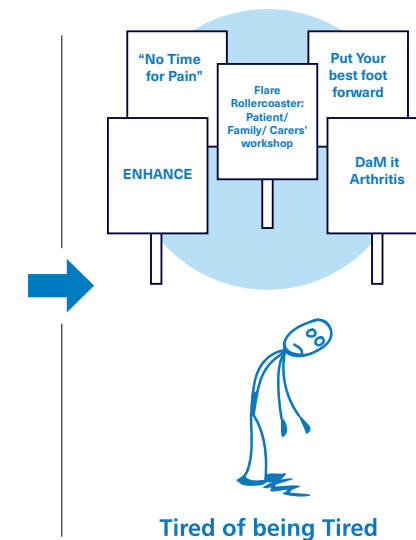
The solution

At every stage of the patient pathway, we have focused on patient education, consultation and involvement. This has arisen out of the **patient choice agenda**, a desire to deliver the best care and through consultation with our patient expert group. From the moment of diagnosis, the deployment of ultrasound helps the patient visualise and validate what is occurring in their joints. We try our best, wherever possible to **involve our patients** in nationally recognized (NIHR) research to give them the best opportunities for treatment. Education and patient held care pathways activate and engage the patient in their care and supports self-management. We then go on to hold teaching sessions for family and carers and the wider community to try to be genuinely holistic and supportive.

1. Patient Activation



2. Supporting Self-Management



3. Community Awareness



The outcomes

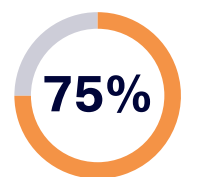
Through our approach of supporting **shared decision making** and **self-management** our patients achieve optimum outcomes in the management of arthritis. We have received awards from national charities for our patient focused care and have been celebrated by the National Rheumatoid Arthritis Society (NRAS) and the National Ankylosing Spondylitis Society (NASS). Our contributions have also recently been celebrated by external bodies such as the Royal College of Nursing and the Care Quality Commission.

Improving Access to Healthcare for Autistic Children and Young People

Ambitious About Autism Sarah O'Brien-Quilty, Participation and Policy Officer and Juli Salgado, Participation Assistant

The challenge

75% of patients feel misunderstood by their doctor because they're autistic.¹ Autistic people often struggle to access healthcare; their experiences are shaped by a lack of knowledge of autism amongst healthcare professionals and their sensory, information processing and communication needs are not met. Whittington Health NHS Trust knew that they needed support in improving services for their autistic patients to ensure equality of healthcare outcomes and could not achieve this without the expertise of autistic people themselves. They have been working with Ambitious about Autism since 2016.



of patients feel misunderstood by their doctor because they're autistic



The solution

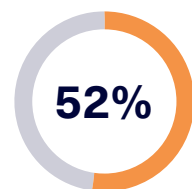
The co-produced project on improving access to and experiences of healthcare for autistic patients is led by the Ambitious about Autism Youth Patrons and the trust-wide Children and Young People Learning Disability and Autism Working Group. Outputs have included: youth-led ward inspections, co-produced resources (visual stories, hospital

passports and information posters), the launch of an autism-specific website, staff study days, staff interviews to gauge levels of knowledge around autism and the formation and running of an autistic patient experience Health Panel. **Decisions are shared between healthcare staff and autistic people** and are regularly monitored and held to account by both groups.



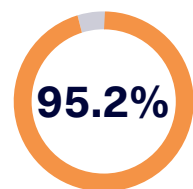
The outcomes

Before the autism awareness day:

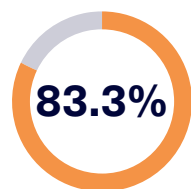


Over half of HCPs (52.0%) agreed they had previously had little training on autism²

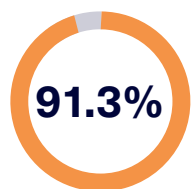
After:



of HCPs agreed that they felt they could communicate better with autistic patients²



of HCPs agreed that their confidence interacting with autistic patients had improved²



agreed to some extent that they had better specific knowledge of autism after the awareness day²

The session with the highest-rated evaluation score in learning outcomes was the panel with young people and parents of autistic children sharing their experiences of healthcare, proving the value of co-production. The project has a national reputation as an example of co-production best practice.

Live Your Life – Living with and Beyond Lymphoma

Lymphoma Action

Stephen Scowcroft, Director of Operations and External Affairs

The challenge

Lymphoma Action questioned over 600 people affected by lymphoma and found that 89%¹ did not completely understand their lymphoma and wanted further support initiatives. They had concerns and anxiety around what to do following specific treatment or while on active monitoring. Clinical Nurse Specialists (CNSs) across the NHS are not all sufficiently resourced to completely meet the very different needs

of people affected by lymphoma and are required to provide some kind of intervention to support health and wellbeing as part of the National Cancer Survivorship Initiative (NCSI). To support a **shared decision making** approach around living with and beyond lymphoma we developed this person-centred support programme.



of 600 people questioned

89%

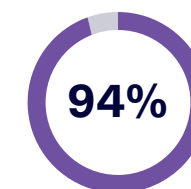
did not completely understand their lymphoma and wanted further support initiatives¹

The solution

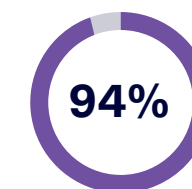
The programme provides people affected by lymphoma information and support needed to 'move-on' and manage their health after treatment. The framework for the programme focuses on key areas of lymphoma specific information and support including exercise, diet, self-help techniques for psychological support, relationships and communication, self-health management. Family, friends and carers are actively encouraged to participate in the session in order support themselves as well as provide **shared decision making** and support. Participants are empowered to be active self-managers of their long-term health and well-being and are able to make informed decisions that fit with their individual priorities.



The outcomes



'I feel I can better manage the physical side effects of my treatment'²



'I feel better able to cope with the emotional aspects of a lymphoma diagnosis'²



of CNSs felt that the workshop helped to deliver the health and wellbeing event in the cancer recovery package²

"The best part of the day was meeting other people with the same experiences and realising I'm not alone. I learnt loads about lymphoma, ways to cope with negative emotions, and I left feeling inspired to live a more healthy, active lifestyle."

Live your Life workshop attendee, Bournemouth

Shared decision making in long term management of Inflammatory Bowel Disease

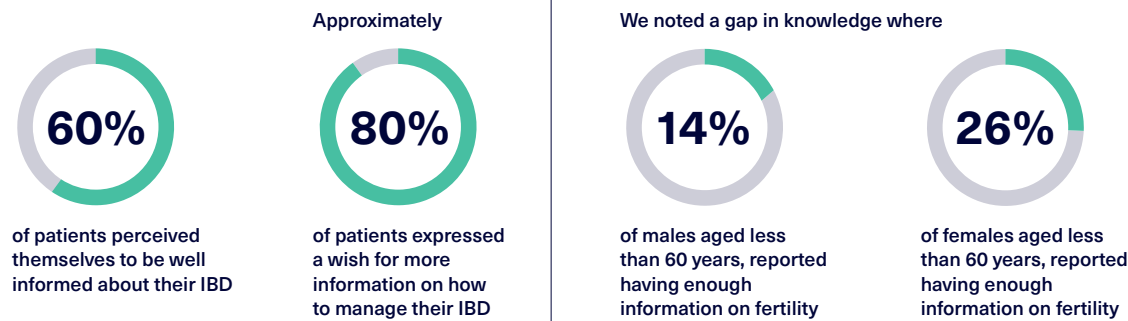
Patient Information Forum and St Mark's Institution

Sophie Randall, Head of Strategy and Partnerships; Dr Naila Arebi, Consultant Gastroenterologist, Hospital and Academic Clinical Lead IBD Service; Dr Lovesh Dyal, Specialist Trainee Gastroenterologist; Tracey Tyrell, Advanced Nurse Practitioner in IBD

The challenge

Inflammatory Bowel Disease (IBD) is a lifelong inflammatory gut condition, characterised by periods of relapses and remission. Patient centred care is one dimension of high-quality care and included in IBD Standards Care Statements.¹ **Shared decision making** is one aspect of patient centred care that depends on disease education.

In a recent survey of 150 patients attending St Mark's Hospital, London, 60% of patients perceived themselves to be well informed about their condition and yet reported low levels of knowledge on self-management during a flare. There was no framework by which to offer regular education to support **shared decision making** early in the disease course.



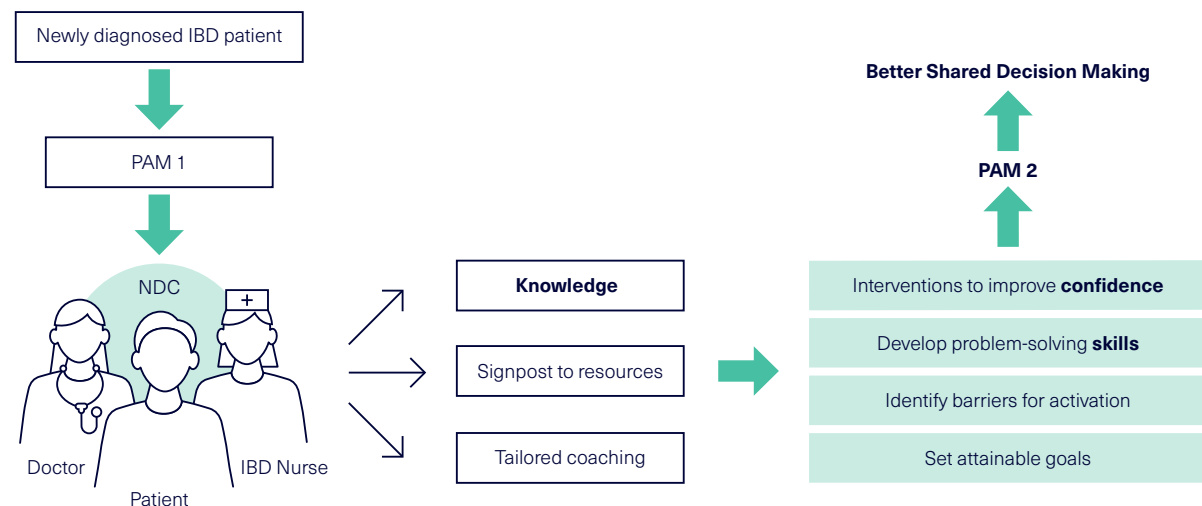
The solution

Patient empowerment with knowledge, skills and confidence ('patient activation') is associated with better outcomes in many chronic diseases, including IBD.^{2,3} A study of 1222 patients with diabetes showed that higher levels of patient activation were associated with better **shared decision making** outcomes.⁴ A New Diagnosis Clinic (NDC) was set up at St Mark's Hospital to offer patients education, and signpost to information resources. Patient empowerment was measured using the Patient Activation Measure (PAM®) tool (Insignia Health) before and after the first consultation. PAM® is a validated questionnaire that generates a score from one to four. Non-activation was defined as PAM® score one and two. Baseline demographic data and anxiety and depression (using Generalised Anxiety Disorder scale [GAD-2] and Patient Health Questionnaire [PHQ-2]) were collated at the first clinic visit.

The outcomes

28 patients completed the PAM® questionnaires at the NDC. 14 patients were non-activated before the clinic. With tailored education, **57.1% of the patients had an improved PAM® score**. GAD-2 and PHQ-2 scores were available for 16 patients. **Four patients scored for anxiety and/or depression**, and were found to have non-activated PAM® scores. **Twelve patients out of 16 were deemed to be non-anxious/depressed**. Of those, **50% had an activated PAM® score**. **Anxiety and depression should therefore be recognised as a potential barrier to patient empowerment**.

In conclusion, the majority of non-activated patients showed an improvement in their levels of activation by attending the NDC, and having tailored education. The diagram below shows how PAM® is being used in our new diagnosis IBD clinics to improve on **shared decision making**.



2019 UK Parkinson's Audit

UK Parkinson's Excellence Network

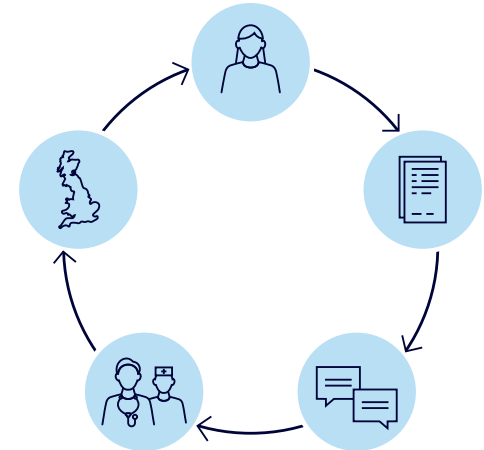
audit@parkinsons.org.uk

What we set out to find

The UK Parkinson's Audit is the recognised, biennial quality improvement tool for Parkinson's healthcare services. It allows measurement of practice against evidence-based standards and patient feedback, which feeds into a continuous cycle of improvement as services create improvement plans based on their results.

This UK-wide audit takes a multi-disciplinary approach, and, crucially, audits patient experience. Services audited are: Elderly Care and Neurology consultant teams, Parkinson's specialist nurses, occupational therapists, physiotherapists and speech and language therapists who care for people with Parkinson's.

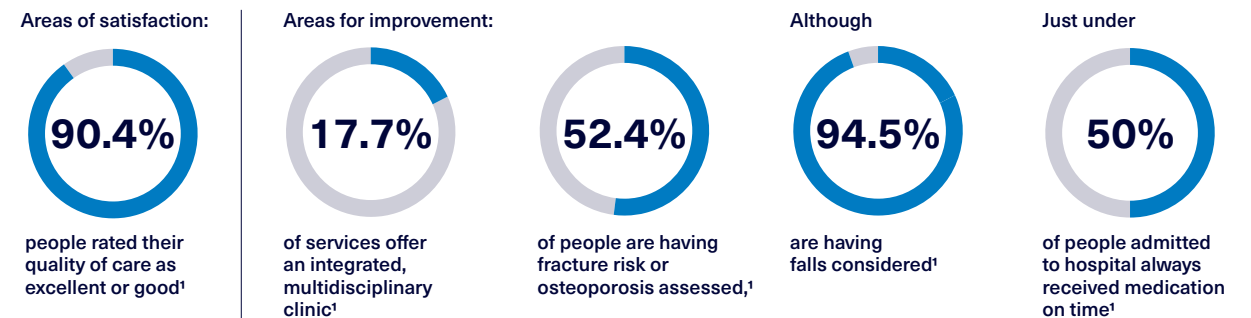
The 2019 UK Parkinson's Audit set out to increase data collection on previous years, to continue providing the largest, most robust, data set on Parkinson's practice in the UK.



What we found

The 2019 Audit provides the largest ever dataset on the quality of care provided to people with Parkinson's. The five month data collection period gathered extensive data from:

- 580 services, seeing 10,335 people with Parkinson's
- 8,247 people with Parkinson's and their carers via Patient Reported Experience Measures questionnaires (PREM)



- Patient performance management score has not significantly improved from 2017 (these scores are summed from seven PREM questions, including whether a person feels they are involved in decisions)

Recommendations

The UK Parkinson's Excellence Network, a Parkinson's UK, service user and healthcare professional partnership, will support the Parkinson's workforce to develop evidence based service improvement initiatives based on the audit results, including PREM data.

UK-wide, the Excellence Network has launched a unique, collaborative multicentre approach to support rapid improvements in key areas identified in the audit and PREM data, which includes:

- A grant assisted UK-wide project to improve bone health for people with Parkinson's
- Development of resources to consistently induct and support therapists specialising in Parkinson's across all disciplines,
- Development of consistent opportunities to improve medication management in hospitals via the Parkinson's UK Get It On Time campaign



1. Kapasi R, Glatter J, Lami CA, et al. Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK. Frontline Gastroenterology 2019; C11-10. doi:10.1136/flgastro-2019-101260.2. Hibbard JH and Greene J. What the Evidence Shows About Patient Activation: Better Health Outcomes and Care Experiences. Fewer Data on Costs. Health Affairs. Volume 32, Number 2, 2013; 207-214.3. Barnes E, Long MD, Kappelman MD, Martin CF, Sandler RS (2019). High Patient Activation is Associated With Remission in Patients With Inflammatory Bowel Disease. Inflamm Bowel Dis. Volume 25, Number 7, July 2019.4. Poon B, Y., Shortell, S.M., & Rodriguez, H.P. (2019). Patient Activation as a Pathway to Shared Decision-making for Adults with Diabetes or Cardiovascular Disease. Journal of General Internal Medicine. doi:10.1007/s11368-019-03501-6

1. Parkinson's UK (2019) Parkinson's UK Audit 2019, available from: www.parkinsons.org.uk/audit

Growing Home

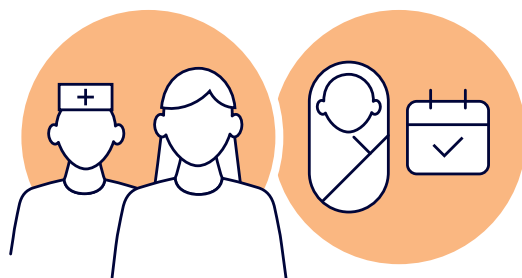
Evelina London

Aisling Phillips, Lead Nurse for Neonatal Outreach Team

The challenge

Neonatal intensive care cots are a scarce resource. The flow out of the intensive care unit at Evelina London can be delayed by lack of lower dependency cots which could only be freed up by earlier discharge.

Evelina London ideally would like to reduce corrected age at discharge of babies born between 30 – 36 weeks, while also improving parent and nurse engagement in discharge planning.



Reduce corrected age at discharge for babies born between

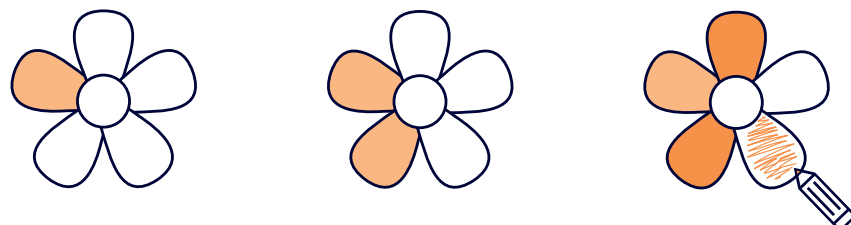
30 – 36 weeks

Improving parent and nurse engagement in discharge planning

The solution

The solution was implementing "Growing Home" which is a hand held record for parents, rolled out in May 2017. Growing Home helps parents to be involved in the daily decision making for their baby during their stay on the Neonatal Unit, thus promoting **shared decision making**. Growing Home provides an estimated date for

parents of their baby going home which helps prevent anxiety. This hand held record is completed by the parents as their baby progresses through the Neonatal Unit. Each day the parents discuss what they can achieve with their baby to reduce their stay on the Neonatal Unit. This is visual and interactive, as they complete the different colours on the flowers.



The outcomes

The outcome has been amazing. We have managed to reduce the length of stay of babies born between 30 – 36 weeks. This has increased our neonatal intensive care cot availability as there are now more beds in lower dependency area.

Parental involvement in shared decision making has made the parents much more confident and prepared when taking a premature baby home, and a parent feedback survey rated the Growing Home initiative as 'excellent'.

Dialysis Decision Aid (DDA)

Kidney Research UK

Peter Storey, Research Programme Lead

The challenge

Patients with kidney disease face complex choices about renal replacement therapies.

Physicians believe most patients are eligible for both haemodialysis (HD) and peritoneal dialysis (PD) and that PD would be patients' initial choice. Patient preference studies suggest about 45%¹ would choose peritoneal dialysis. Despite these data, there is variation in PD:HD uptake rates², with a year-on-year reduction on those therapies patients choose to have at home (10.1% on peritoneal dialysis, 1.1% home haemodialysis) (*statistics at the time of the DDA development*).



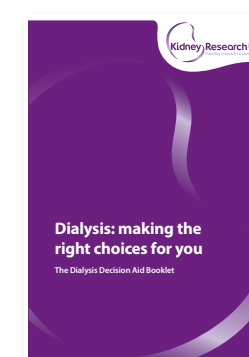
The solution

We developed an evidence-based booklet (the DDA) that enables staff to support patients making informed decisions between dialysis treatments when given out as part of usual pre-dialysis education practices.

The DDA was developed through a Kidney Research UK supported study by the Yorkshire Dialysis Decision Aid research team (Dr Hilary Bekker, Anna Winterbottom and others). The study was run in collaboration with:

- Baxter Healthcare Ltd.
- The British Renal Society and Renal Association
- Decision scientists and healthcare professionals (HCPs) from NHS Hospital Trusts at Leeds, Sheffield, Doncaster, Bradford, York, Hull and North Staffordshire

1. Develop a decision aid by reviewing research findings relevant to patients making dialysis modality treatment choices
2. Evaluate a decision aid to help renal patients make dialysis modality choices more effectively
3. Develop a questionnaire assessing a) the effectiveness of patients' dialysis modality choices and b) service delivery and patient experience factors affecting informed choice



The outcomes

For the first half of the study (before-DDA), patients had usual pre-dialysis care; during the second half (after-DDA), all patients had usual pre-dialysis care plus DDA. Patients reading DDA had higher ratings for their satisfaction with: **1.** pre-dialysis services **2.** usefulness of the information to help them understand kidney disease and dialysis treatments **3.** sharing dialysis decision making with family **4.** making a dialysis choice.

Following the conclusion of the study, we have found the DDA booklet is accessed independently by patients and/or via renal professionals using Kidney Research UK's website. Feedback indicates it is a valued resource and enables patients to think differently about dialysis treatment decisions in the context of their life and illness management. It meets clinical guidelines enabling staff to support patients making informed decisions between dialysis options.

Of those that received the DDA during the study:



Most services

(4 out of 6)

found DDA a valuable addition to their pre-dialysis education



"This booklet gives so many answers about dialysis which I didn't have when I was first on it. It talks you through all the different options in clear language and, while it can't give you everything, it gives you a really good basic understanding of how dialysis works." *DDA user*

"A wonderful booklet that details the options available. I have seen nothing else like it available and I am pleased to see something written so well and accurately that is particularly patient friendly." *DDA user*

"I wish I could have had access to the sort of information that this booklet offers in terms of making all the choices available for people to read. I believe it will help a lot of new patients and their families make informed choices on the treatment right for them." *DDA user*

Over the last five years, the DDA has become one of the most successful partnerships in helping patients and services have access to an evidence-based patient decision aid. A third of UK renal units use it routinely to enhance their care.

Contact

To find out more about AbbVie's work in Shared Decision Making, please visit:
www.abbvie.co.uk/sdm

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Or send us an email at:
AbbvieSharedDecision@mhpc.com



