abbvie

Empowering Conversations:

Making shared decision making a reality for patients in an evolving NHS

The findings and recommendations of this report were developed at non-promotional roundtable discussions, organised and funded by AbbVie, and attended by patients groups and health organisations; a list is provided on page 18. Attendees were not paid for their involvement.

Job bag number: UK-ABBV-210039
Date of preparation: March 2021

People.
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Contents

Foreword

Todd Manning

AbbVie UK

Shared Decision Making (SDM) is widely agreed to be an important part of ensuring the right decision is made for the right patient, at the right time. Its importance has been highlighted in several national policies. Most notably the NHS Long Term Plan in 2019, the General Medical Council's (GMC) latest guidance on SDM and the recent NICE Shared Decision Making consultation.

The COVID-19 pandemic has seen extraordinary pressures put on the NHS. It has highlighted the importance of the need to identify and implement practices, such as SDM to help effectively manage long-term conditions and help achieve the best possible outcome for patients.

Throughout 2020, AbbVie started work to shine a light on the importance of SDM. We brought together key stakeholders from the NHS, patient and advocacy groups, professional organisations and health bodies, to discuss the barriers and opportunities to embed SDM into routine practice within the NHS. Through this collaborative discussion, AbbVie uncovered three main areas for health system reform:

- Recovery after COVID-19 and NHS service redesign at a local and national level
- Supporting empowered conversations for both healthcare professionals and patients
- Securing system 'buy-in' on the business case for SDM

AbbVie will now seek to work in partnership with key stakeholders from the NHS, patient and advocacy groups, professional organisations and health bodies to drive forward these recommendations for SDM within the NHS so that a future where patients are empowered partners in decisions about their care and treatment is realised.

Baroness Judith Jolly

Liberal Democrat and Member of the House of Lords

I have been part of AbbVie's shared decision making process since their showcase in March 2020; an impressive collaboration that brought together 16 examples of best practice across our health and care system. In November, I chaired a policy roundtable that led to the policy recommendations contained within this report.

Shared decision making is an important part of our healthcare system. When done well, it allows patients to feel empowered, articulate their personal treatment goals and to make informed choices about their care. Patient centric approaches in maternity, informed consent measures in surgical specialities as well as the use of personalised care plans for some chronic conditions show us the difference shared decision making can make. Further implementation of SDM across the NHS is an opportunity for better shared understanding between more patients and health care professionals as they navigate their treatment and care options.

We have seen COVID-19 transform our health service significantly, with the pandemic highlighting many challenges that have existed for some time, as well as causing acute issues that point to an opportunity to build greater resilience into the system.

This report highlights the challenges exacerbated by the pandemic, as well as opportunities to improve the way shared decision making is carried out in our current, and post-COVID, world.

In evaluating these challenges and opportunities, we have been able to suggest detailed policy recommendations that would put our health and care system on the path for positive change to continue to empower patients and make shared decision making an essential element of the *'new normal'*.

The Patient's Perspective

"Establishing communication enables trust between practitioners and patient, family and carers. We enable shared decision making by providing information, support and education for people affected by lymphoma because we know informed and engaged patients have better outcomes. Through shared decision making everyone affected by lymphoma will receive the best possible support, treatment and care that is right for them."

Stephen Stowcroft

Lymphoma action

"Decisions about treatment and care change people's lives for better or worse. It is a fundamentally right that people have access to information and support to make decisions about treatment based on their personal, preferences and a clear idea of risk and benefit. COVID-19 has had a huge impact on people's experience of care. At the same time national discussion of clinical evidence, trust in clinical data, ways to communicate risk and people's preferences for or against a course of action have become topics of intense national debate.

The experience of the pandemic has taught us a lot about shared decision making, people need and want trustworthy information they can understand and act on, they must trust the professional supporting them and feel their personal values, views, preferences and attitudes to risk are respected. It is vital that these principles of shared decision making and personalised care are embedded into the post pandemic NHS. Shared decision making and personalised care should be part of the solution to tackle health inequality, not entrench it."

Sophie Randall

Patient Information Forum

"It's now a well accepted principle that patients should have an active role in their care, and shared decision making is vital to achieving this. Patients who have been active participants in making decisions about their care typically enjoy better outcomes, are less likely to regret decisions they've made, and often opt for less invasive procedures."

Rachel Power

the patients association

"Shared decision making finally begins to respect patients as experts in our own bodies, with a valuable perspective to bring to the table, full of unique knowledge and insights. After so often feeling like passive passengers on our medical journeys, this is paradigm shift if we can make it happen. If true partnerships between healthcare professionals and patients can become the norm, we the patients will feel empowered, heard, and invested in, and we will be able to contribute to creating more effective treatment plans tailored to us as individuals."

Ellie Hopkins

CHRONICALLY AWESOME

"Shared Decision making is underpinned by all involved in the process having the right information and access to an information sharing system allowing decisions to be recorded and shared with whom patients choose. A central pillar of good SDM is open communication involving conversations not just with a patient but also with their family/carer. Facilitating involvement of family early in decision-making, as true shared decision making involves healthcare professionals working together with people and their families and carers, can help if patients are having difficulty expressing their thoughts and can help them feel supported."

Dany Bell

MACMILLAN CANCER SUPPORT

"This is a very important contribution to the discussion about involving patients in their own care. It is timely as so many services are being re-engineered for a post-COVID-19 world. Much good will come from this but the patient must remain at the centre of the new order."

Cathy Yelf

Macular Society
Beating Macular Disease

Section 01

Introduction

There needs to be a way we can look at ‘what matters to the patient as an individual. That’s what SDM is for.

Patient organisation

The importance of shared decision making

The NHS *Universal Personalised Care Plan* explains that shared decision making (SDM) allows people to be supported to understand the care, treatment and support options available, as well as the risks, benefits and consequences of those options.[1] With SDM in place, patients are more able to decide on a preferred course of action, based on evidence-based, good quality information and their personal preferences. Simply put, the Patients Association explains SDM is about patient's having the right to be involved in making choices about their medical treatment and care.[2]

Indeed, SDM has been a central tenet in health and care services in England for several years and there is growing evidence of the benefits of SDM on patient experience and outcomes.[3] The Montgomery Supreme Court ruling of 2015, which centred around informed consent, was a key moment in UK law that emphasised the need for health system reform to prioritise effective SDM. Since then, several policies and plans have been established that recognise the importance of patient choice and preference, with clear targets to embed SDM into practice.

This includes the 2019 NHS England and Improvement (NHSE/I) *Long Term Plan* which highlighted the importance of SDM in its ambition to make personalised care 'business as usual'.[4] The most recent General Medical Council (GMC) guidance[5] also echoes this ambition and lists several principles for SDM, including the right of a patient to be involved in decisions about treatment and care as well as being supported to make informed decisions.[6]

Since March this year, COVID-19 has changed the world and health services significantly. NHS England has demonstrated great agility, moving rapidly to an emergency footing, and adapting services to respond to the crisis. Unfortunately, this has also meant many patients have had their routine care significantly disrupted.

AbbVie's work in shared decision making

To inform this paper, AbbVie undertook a consultation process with stakeholders from across the healthcare system including the NHS, Royal Colleges, Professional Bodies and Patient and Advocacy groups. The findings and recommendations in this report were developed at non-promotional roundtable discussions, organised and funded by AbbVie, and attended by patient groups and health organisations.

Spring 2020

A reception in the House of Commons hosted by AbbVie showcasing 16 best practice projects in SDM.

September 2020

The first of two roundtables was held with attendees building consensus on what immediate action and system change is needed for SDM and explored the current barriers to SDM, including the impact of COVID-19.

November 2020

The second roundtable was held with stakeholders developing recommendations for SDM in the NHS.

2021

Ongoing work to support the implementation of SDM across NHS and for specific pathways and patient groups.

[1] *Universal Personalised Care. NHS England*. 2019. p7. https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf. [Last accessed January 2021]

[2] *Shared Decision Making. The Patient's Association*, https://www.patients-association.org.uk/shared-decision-making. [Last accessed January 2021]

[3] *Shared Decision Making to Improve Health Outcomes*. NHS England. https://www.england.nhs.uk/shared-decision-making/why-is-shared-decision-making-important/shared-decision-making-to-improve-health-outcomes/ [Last accessed January 2021]

[4] *The NHS Long Term Plan. NHS England*. 2019. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf [Last accessed January 2021]

[5] *Decision Making and Consent. The General Medical Council*. https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent [Last accessed January 2021]

[6] *No Decision about me, without me.* NHS England 2021. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf [Last accessed February 2021]

Section 02

Findings

Several recent and on-going initiatives to support this ambition to make SDM a reality across the NHS, include:

The current state of play for SDM

The National Institute of Care and Excellence's (NICE) Decision Making Collaborative (2016) is a collaboration of 27 partners to encourage SDM as an everyday practice of healthcare.

Since the launch of their action plan, work to drive forward SDM has included updating the way NICE guidance is developed to include SDM, incorporating SDM in the General Medical Council's (GMC) professional capabilities frameworks for clinical training, and Health Education England (HEE) publishing a personalised care core skills and education framework, *Person-Centred Approaches*. NICE is also publishing new Shared Decision Making guidance in June 2021 which includes recommendations on training for HCPs, benefits of SDM, using decision aids, and guidance on how to embed shared decision making in organisational culture and practices.[7]

Similarly, NHSE/I and the Royal Colleges' The Personalised Care Institute (2020) looks to include SDM resources and training to support the implementation of the *NHS Long Term Plan's* goals for personalised care, including leading local implementation of shared decision making using the NHS Shared Decision Making Implementation Checklist.

This is helping NHS staff develop the knowledge and skills to make personalised care models, including SDM, standard practice in the NHS. Through this work, they are setting quality standards for training and supporting the development of training programmes for the current workforce.

They have set out new roles identified within **Primary Care Networks** as part of the *NHS Long Term Plan* and are working to ensure that personalised care is represented in relevant undergraduate and post-graduate curricula.

AbbVie also welcomes the new Standard for SDM being developed by the **Professional Record Standards Body (PRSB)**, due for publication in June 2021.

Although progress to introduce SDM across the NHS is being made, our **roundtables** shed light on how at the time of writing, there remain barriers within the system that are limiting the opportunities to embed it fully into routine practice.

This delay in progress has also been understandably exacerbated by COVID-19 over the last year. We engaged in a dedicated discussion that shone a light on the impact of the pandemic and the need for specific short-term action to improve patient involvement as routine NHS services return to a more 'normal' footing.

Consequently, AbbVie's roundtables highlighted significant consensus around the need for SDM to properly be embedded in the NHS with more that can be done to support and build on the progress achieved to-date.

Attendees at these discussions reached broad agreement on two main priorities to help embed SDM further in the NHS: **Enabling Empowered Conversations, and Securing System Buy-in**.

[7] *The National Institute for Care and Excellence, Shared Decision Making: Draft for consultation.* 2020, page 1. Available at https://www.nice.org.uk/guidance/gid-ng10120/documents/draft-guideline [Last accessed: February 2021].

Enabling Empowered Conversations

Our conversations called out the need for further work and effort to support empowered conversations for both healthcare professionals and patients in order to achieve effective SDM. In some cases, healthcare professionals would benefit from upskilling on SDM principles and being equipped with the appropriate tools and resources to make this standard practice.

Currently, SDM is observed in the Royal College of General Practitioners' (RCGP) registrar exams, through discussion in Clinical Skills Assessment (CSA) exams, however it is not a requisite of passing. The GMC has recently published updated guidance for doctors on *Decision Making and Consent*[8] which sets out seven principles, including that patients have the right to be involved in decisions, with the relevant information and that doctors should try to find out what matters to patients.[9]

Likewise, the guidance sets out how healthcare systems need to be accountable in supporting healthcare teams to embed SDM principles in the delivery of care, including having the time and direction to prioritise SDM conversations as part of consultations.

This should include providing patients with health literate information that meets different language requirements, as well as appropriate decision support by well-trained health care professionals (HCPs) to enable them to make informed decisions about their preferred treatment and care pathway. Patient organisations flagged to AbbVie how the ability to self-advocate isn't necessarily a skill all people will have or use in their day-to-day life, with patients requiring support to develop the confidence to participate in SDM. It was suggested providing patients with a list of question prompts to think about before they have an appointment might support such patients' need to engage in a shared decision.

"Get rid of the stereotypes around SDM. Previous research saw SDM as more of a 'middle-class' conversation. We need to move that into the health inequalities agenda because as we start asking 'what matters to you?' we may find out a lot more."

Patient organisation

For patients, particularly those with long-term or chronic conditions, to feel involved in care and treatment choices with their care team, feedback stressed the importance of personalised care plans, a tool which supports SDM by allowing the patient to set out their personal goals for treatment and enable them to think and plan ahead. As an output from ongoing discussions huge variation in the access to these plans was noted. The Neurological Alliance highlighted their recent patient survey, which found that only 10% of patients were offered a personalised care plan, despite this being a central ambition of both the *NHSE/I Long Term Plan* and *NHS Universal Personalised Care Plan*.[10] Furthermore, the survey found 43% were not given written information which would have helped inform patient choice.[11] Public Health England and the UCL Institute of Health Equity state that this number rises to 61% when numeracy skills are required.[12] This particularly affects people with long term conditions and multiple morbidities, as they are engaging with a wide range of professionals across different specialties, making SDM much more difficult to achieve.

Furthermore, a recent Demos report,[13] supported by AbbVie, found that many patients are not fully aware of the level of control they are entitled to when it comes to choosing medication and found that although a large majority (62%) of the population were satisfied with their personal level of involvement, a significant proportion (30%) wanted to be more involved in decisions around their medication options in primary care. Attendees saw an opportunity for a better shared understanding of what SDM is and how it can be utilised to properly navigate treatment options.

[8] *Decision Making and Consent. The General Medical Council.* https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent [Last accessed January 2021]

[9] Ibid.

[10] *Neuro Patience: The National Neurology Patient Experience Survey. The Neurological Alliance.* https://www.neural.org.uk/wp-content/uploads/2019/07/Download-key-findings.pdf [Last accessed: January 2021]

[11] Ibid.

[12] *Local action on health inequalities: Improving health literacy to reduce health inequalities.* Public Health England and UCL Institute of Health Equity, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf [Last accessed February 2021]

[13] *The Demos Report.* Lasko-Skinner, Oakes and Usser, p32, 42. 2020 https://demos.co.uk/wp-content/uploads/2020/11/Patient-Power.pdf [Last accessed January 2021]

"HCPs need to be realistic, transparent and honest with patients – if it's not on the table, it's not true shared decision making."

Patient organisation

Miscommunication and unconscious bias were highlighted as challenges that may affect decision making processes for HCPs.[14] The example below, shared by one of the roundtable attendees, highlights the need for a shared decision around care and treatment to capture the patient's quality of life and long term goals:

"An elderly woman was about to have a knee operation, commented to her consultant that she was looking forward to tending her garden again. The consultant said that this would never happen again, even after the operation. At which point the lady decided the surgery was not worth it."

National health body

Finally, due to several factors, patients are not always offered or have discussions on all available treatment options for their condition. In some cases, this was because available treatments are only suitable for a subset of the patient population with the condition, and in other cases the HCP may not offer all the options to avoid giving patients false hope, or to leave options to step-up treatments if needed.

Securing System Buy-in

For SDM to be properly embedded in the NHS, our stakeholders emphasised the urgency needed to establish 'buy-in' across all levels of the NHS through increased levels of support, visibility and understanding of SDM amongst senior leadership at a health organisation, Board and national level; something that has already been expressed in NICE SDM guidance.[15]

In reference to this SDM can only be carried out effectively if this includes engaging system leaders and commissioners on the business case for SDM. Highlighting that it has the potential to deliver more favourable patient-reported health outcomes and healthcare utilisation,[16,17] as well as identifying the outcomes to be measured and monitored to set a best practice expectation for SDM at all levels of care.

Currently, this was seen to be more advanced in the surgical field as a result of existing consent measures but more needs to be done for decision points in clinical treatment pathways. For non-surgical settings, there is broad agreement that Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) are a step in the right direction, but they are still very medicalised when compared to personal goal setting and measuring progress against this.

The Patients Association has undertaken a programme of work to monitor SDM. Their pilot examined the kind of 'toolkit' that is needed in place for local systems to understand how they will track progress. In response to this, a national health body shared: ***"we see a number of tools that can be used for measuring SDM, but because we don't use them enough in standard practice, it is difficult at this current moment in time, to understand if these tools are measuring SDM in practice"***. All health sectors need to prioritise collaboration and share validated tools for measuring SDM, collecting patient experience and outcomes through a repeated survey throughout their treatment journey.

Benefits of implementing proper measurement of SDM were a focus of our discussions throughout our programme of work, and included supporting HCPs to implement and improve SDM within their practice and demonstrating whether SDM and greater patient involvement in decision making improves outcomes and reduces demand for services.

[14] *Implicit bias in healthcare professionals: a systematic review*. FitzGerald C, Hurst S. BMC Med Ethics. 2017. p19. doi:10.1186/s12910-017-0179-8

[15] *The National Institute for Care and Excellence, Shared Decision Making: Draft for consultation.* 2020, page 4. Available at https://www.nice.org.uk/guidance/gid-ng10120/documents/draft-guideline [Last accessed: February 2021].

[16] *Shared Decision Making to Improve Health Outcomes.* NHS England. https://www.england.nhs.uk/shared-decision-making/why-is-shared-decision-making-important/shared-decision-making-to-improve-health-outcomes/ [Last accessed January 2021].

[17] *Association of shared decision-making on patient-reported health outcomes and healthcare utilization.* Hughes TM, Merath K, Chen Q, Sun S, Palmer E, Idrees JJ, Okunrintemi V, Squires M, Beal EW, Pawlik TM. Am J Surg. 2018 Jul. 7-12. https://pubmed.ncbi.nlm.nih.gov/29395026/

Section 03

The Impact of COVID-19 and Redesign of NHS Services

While the barriers set out previously were believed by most attendees to have existed prior to 2020, our discussions highlighted the specific impact the COVID-19 pandemic has had on the involvement of patients in their treatment and care.

With the pace and impact of COVID the NHS had to adapt and respond quickly. Our discussions suggest this has exacerbated existing barriers and created new ones. However, they also highlighted COVID-19 may provide opportunities going forward to review and adapt pathways, and in many cases, this has benefited patients.

For example, patient advocacy groups reported how some patients had found virtual appointments beneficial, the main reasons including: convenience and removing the need for travel which is particularly important for patients who have frequent or multiple appointments; a reduced risk of exposure to the virus, which was critical for those who were shielding; and virtual appointment's ability to allow access to a wider range of HCPs, as patients were not restricted by geography.

However, AbbVie equally heard from stakeholders how virtual appointments led some patients to feel less involved in decisions about their treatment and care; for some, there was a preference for face-to-face contact, as well as ability to show/discuss their symptoms in person. Older cohorts of patients have said they find virtual appointments harder to use and struggle with technology. Central to this, we heard how the health and digital literacy needs of local populations need to be prioritised.

"At the beginning of the pandemic, when the Secretary of State confirmed that all GP appointments must move to become virtual, we [left] behind a huge number of people."

Patient organisation

Participants warned against a reliance on a one-size fits all approach to digital services which could widen health inequalities. As such, participants called for a more tailored, personalised care approach to avoid the gap in health inequalities to grow further. Work to enable this is already underway but should have at its heart a principle of supporting SDM and support consistent implementation consistently across England.

The availability of services and treatments was also seen as a prominent issue during COVID-19, where usual services were affected. It was noted that as staff were redeployed in to COVID-response roles, this reduced or limited access to routine appointments. It was found that due to the deployment of staff, assessments and initiations for treatment options could not be conducted virtually, limiting choice. For example, Parkinson's UK reported that staff capacity and redeployment meant that even digital pathways were not always feasible, with only 25% of services for this patient group able to offer video consultations.[18]

A central focus of our discussions was the need for recovery plans developed by the NHS to serve as an opportunity to re-centre the patient voice so that services are re-designed around their needs.[19] It was stressed that this involvement should not be 'tokenism' but that patients should have key roles in service redesign. For example, The Cancer Recovery Taskforce set up by NHS England has included patient groups to ensure their involvement is central to its work.[20] For this, achieving buy-in amongst NHS leadership, mentioned in the key themes above, was also noted to be particularly important as NHS phased recovery programmes begin. There was a significant concern that with health organisation's boards working to maximise recovery in high-volume clinical pathway systems,[21] individual needs of patients' risk being lost in attempts to reduce the backlog and recover capacity quickly.

18 *Standards of Care for Parkinson's – Parliament Written Evidence*. Parkinson's UK. 2020. p2. https://committees.parliament.uk/writtenevidence/4407/pdf/ [Last accessed January 2021]

19 *Letter from Chief Executive Sir Simon Stevens & Chief Operating Officer Amanda Pritchard to NHS Chief Executive and Regional Directors*. 2020. https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/07/20200731-Phase-3-letter-final-1.pdf [Last accessed January 2021]

20 *Cancer Recovery Taskforce, Terms of Reference*. NHSEI https://www.england.nhs.uk/wp-content/uploads/2019/09/Cancer-Recovery-Taskforce-ToR-20200820.pdf [Last accessed February 2021]

21 *Letter from Chief Executive and Chief Operating Officer*, Amanda Prtchard and NHS Chief Financial Officer Julian Kelly on Operational Priorities for winter and 2021/22. 2020. https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/12/important-for-action-operational-priorities-winter-and-2021-22-sent-23-december-2020.pdf [Last accessed January 2021]

Embedding SDM in NHS recovery plans

Our consultation process identified necessary actions that would ensure SDM is properly considered in NHSE/I's work to recover and restart services.

Firstly, it was agreed NHS organisations and services could be encouraged by central NHS England and Improvement to actively examine and demonstrate how patients have been involved in longer term planning of the restarted and reshaped NHS, such as through patient outreach or consultation. It was highlighted that a proactive SDM approach should be considered where suitable, to review with patients on waiting lists whether this was still the appropriate and desired option for them to support resource and capacity planning as part of NHS Restart.

The NHS Restart process presents an opportunity to re-engineer pathways and processes; to provide more care and support outside of the clinics and create capacity in the system. Where appropriate, stakeholders supported the use of remote consultations where this provided benefit for both clinician capacity and patient convenience. However, this approach will not work for all patients, especially those with low levels of literacy, limited digital access and technical proficiency. As such, the importance of adequate physical, in-person treatment pathways was emphasised for all patients for whom digital pathways are not appropriate or preferable.

"Not everyone can use digital services and it is about having the space to have an honest conversation in a safe space about what is going to work for the patient; whether it's going to be digital, whether it's going to be face-to-face."

Patient organisation representative reflecting on the use of virtual appointments during COVID-19

Section 04

Policy Recommendations

AbbVie proposes the following recommendations for enabling empowered conversations between patients and their healthcare teams, securing system buy-in for and COVID-19 service recovery and redesign for shared decision making in the NHS.

1.

Enabling Empowered Conversations

1.1

Health Education England (HEE) is recommended to partner and collaborate with professional and patient groups, such as the Personalised Care Institute (PCI) and the Patient Information Forum (PIF) to embed SDM into the curriculum for clinical communication training programs.

1.2

NHS England and Improvement is advised to continue ongoing work to support the system to develop, implement and assure SDM tools and resources.

1.3

As NICE continues work to embed shared decision making in condition and pathway specific guidelines, consideration could be given to highlighting key treatment decision-making points alongside the information needed to support these. As patient information and decision support tools are developed, these could be signposted to, and made available via, NICE Evidence.

1.4

Patient advocacy groups and health bodies are recommended to participate in the on-going development and implementation of the upcoming NICE ‘Shared Decision Making’ to help support its impact.

2.

Securing System Buy-in

2.1

NHS Confederation, in partnership with NHS England and Improvement, could help to establish and publicise the business case and benefits of SDM to engage national and local system leaders and support system buy-in for prioritising SDM.

2.2

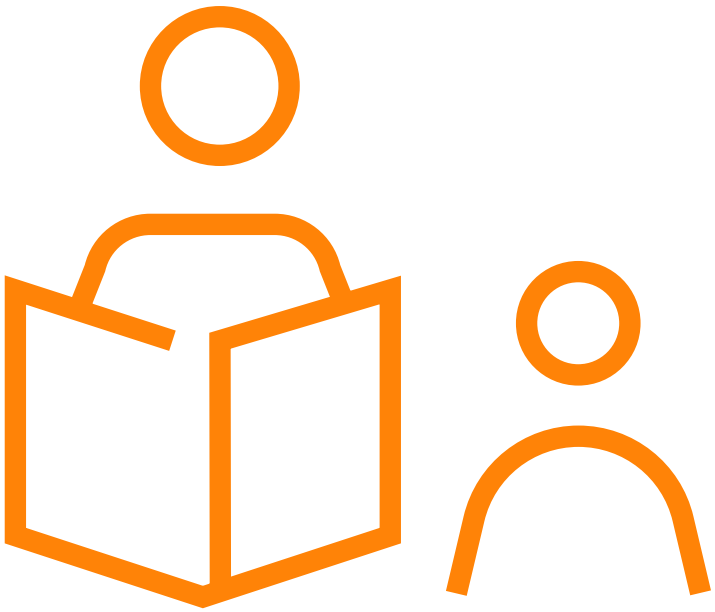
NHS England should consider the development of system level metrics and mechanisms to monitor and incentivise SDM and patient choice. This could include blended payment tariffs or similar payment models that reward quality outcomes and any frameworks developed to replace the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) as ICS's are embedded. The upcoming SDM Standard, developed by PRSB in collaboration with NHS England and Improvement, NHSX, the Academy of Medical Royal Colleges, the Centre for Peri-Operative Care, PIF and EIDO, is likely to provide a good starting point to move this forward and its implementation should be supported by the NHS at all levels.

2.3

As Integrated Care Systems (ICSs) develop, NHS England should set out requirements for their delivery plans to understand local population health literacy and levels and support them to do this.

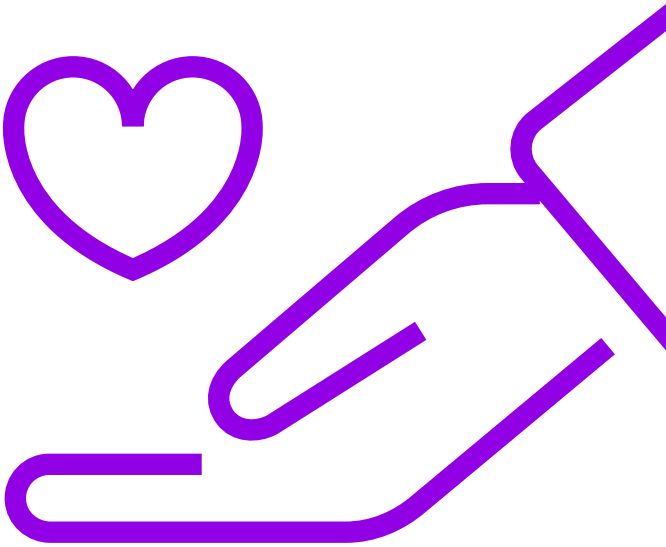
2.4

Improvement and transformation programmes operating across the NHS, such as Getting It Right First Time (GIRFT), Right Care and the Outpatients Transformation Programme should include consideration of and support for shared decision making behaviours and practice.



3.

Recovery after COVID-19 and NHS Service Redesign



3.1

NHS England and Improvement should work to support and oversee the next phase of recovery plans developed by Integrated Care Systems (ICSs)/CCGs to ensure patient choice and priorities are understood and planned for. This could include co-production in recovery and redesign plans and engagement with local patient advocacy groups.

3.2

As services increase the use of digital pathways and appointments, NHS England and Improvement and DHSC should work with NHS Trusts to ensure that sufficient physical, in-person treatment pathways are maintained and available for all patients for whom digital pathways are not appropriate and that face-to-face appointments are sufficiently available to maintain needed access to care and treatments that cannot be delivered digitally.

3.3

System buy-in is about SDM as part of the ongoing transformation of services. For example, SDM should be considered as central to the Patient Initiated Follow Up (PIFU) pathways currently being developed by NHS England as part of COVID-19 recovery planning. Guidance could also be produced for services where patients are assessed for their suitability for PIFU pathways on a case by case basis. Services should consider providing information and support to patients to enable them to seek a follow-up and aid decision-making in the resulting consultation. Appropriate support and guidance for patients should also be made available to assist them in fully understanding the changes to their care pathway.

Thank you

Thank you to all the participants who supported the development of this policy report.

The findings were developed at roundtable discussions, organised and funded by AbbVie and attended by patient groups and health organisations including:

- AQuA
- Bladder Health UK
- Chronically Awesome
- Dystonia UK
- Lymphoma Action
- Macmillan Cancer Support
- The Macular Society
- The National Institute for Care and Excellence
- National Voices
- Neurological Alliance
- NHS England and Improvement
- Parkinson's UK
- Patient's Information Forum
- The Patient's Association
- Policy Connect
- Professional Record Standards Body
- The Reading Agency
- The Royal College of General Practitioners

The recommendations have been developed by AbbVie and endorsed by:

aqua
Shape Change Inspire Quality Transform Care

Bladder Health UK

CHRONICALLY AWESOME

Lymphoma action

MACMILLAN CANCER SUPPORT

Macular Society
Beating Macular Disease

Patient Information Forum

PRSB
Professional Record Standards Body

the patients association

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Job bag number: UK-ABBV-210039
Date of preparation: March 2021

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