



**Patient  
Information  
Forum**

 **the patients association  
Forum**



# Removing barriers to shared decision-making

**A co-production project in  
Nottingham and Nottinghamshire ICB**

AbbVie has provided funding support for this project.  
Editorial control has remained with the project authors.

Published April 2023

# Introduction

The Patient Information Forum and the Patients Association worked with NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) to look at ways of making it easier for patients to take part in shared decision-making.

Together we delivered a co-production programme with the My Life Choices panel of local people and the NHS Nottingham and Nottinghamshire personalised care team. The project ran throughout 2022. We developed and implemented patient information to support people with hip, knee, and joint pain to make treatment decisions.

My Life Choices had input into the development of this report to ensure patient and public overview of the findings. We are grateful for the detailed comments received on the drafts.

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## Why did we do this piece of work?

Research by the Patients Association published in 2021 found barriers to shared decision-making for patients and healthcare professionals (HCPs). These included limited appointment time, difficulties in starting shared decision-making conversations, and some cultural resistance to personalised care and shared decision-making among doctors and patients.

PIF's research published in 2020 found the need for easy-to-understand information to support shared decision-making. This was supported by PIF's 2021 research into decisions during maternity care.

PIF has been involved in national projects with NICE and the Professional Records Standards Body (PRSB) to help support professionals put shared decision-making into practice.

The Patients Association undertakes a number of national projects with patients and healthcare professionals to embed shared decision making in all care settings.

Working in partnership with the NHS and patients in Nottinghamshire presented an opportunity to put solutions into practice to remove barriers perceived by both patients and clinicians.

Although this piece of work focused on hip, knee and joint pain, most of the findings can be applied to shared decision-making in general.

# Who was involved?



## The Patient Information Forum

The UK membership organisation for people working in health information and support, it is the independent voice of UK health information. PIF runs the only UK-wide quality mark for health information – the PIF TICK.

## The Patients Association

An independent charity campaigning for improvements in health and social care for all patients. Its goal is for everyone to be able to access and benefit from the health and care they need to live healthy, independent lives. It works directly with patients, who are members and supporters of the charity, and the people who benefit from its services. Anyone with an interest in health and social care join the Patients Association as a free individual member by signing up on our website.



## My Life Choices Co-production group

A group of people with lived experience of accessing health and care. They have long term health conditions, disabilities, and/or are carers of family members or friends.

They have a shared focus on personalised care and formed the core of our co-production panel.

## The Elective Care delivery group

This local multidisciplinary group works across the NHS Nottingham and Nottinghamshire Integrated Care Board on the implementation of personalised care across the elective care journey. The Patients Association and PIF are members of the group and attended monthly meetings to feedback the learning from the co-production project.

# Findings and recommendations

## 1. Simple solutions are best for patients and professionals

Prepared patients can make the most of short appointment times. Pre-appointment information in plain language was preferred by the My Life Choices panel.

Information should be co-produced with people with lived experience to ensure the tone is non-judgemental and acts to support shared decision-making. It should be available in accessible formats.

*"Having a conversation with more emphasis on personalised shared decision-making reduces the number of consultations needed. This then reduces pressure on healthcare services and clinicians."*

Debbie Draper, Head of Personalised Care – Nottingham and Nottinghamshire ICB

## 2. National level information

Information should be co-produced nationally to help people on waiting lists prepare mentally and physically for surgery. This should be added to NHS England's My Planned Care platform.

It should promote the message to patients that 'It's OK to Ask' questions in appointments and explain what is important to them as an individual.

Information on preparing for, or deciding on, surgery should meet [NHS England's content standard](#) or the [NICE Standards Framework for Decision Support Tools](#).

## 3. Adding 'About Me' information to the NHS App

The Professional Records Standards Body Standard 'About Me' form is included in the NHS Wales App. It should be added to the English NHS App to support patients and healthcare professionals have better shared decision-making conversations.

'About Me' information enables healthcare professionals to see at a glance what is important to a patient and supports them to deliver personalised care.

## 4. Shared care records

Patients are tired of having to explain their situation and conditions each time they visit a new healthcare professional because there is no shared record of their health. It can be traumatising for patients to have to repeat their problems.

A shared record system would enable anyone treating a patient to have access to their medical history.

This will free up appointment time and support personalised care.



## 5. Navigating the system

It can be very difficult to navigate the health system. Integrated Care Boards need to provide patients with:

- a clear understanding of the care pathway in MSK and other conditions
- consistent information and support to embed shared decision-making
- clear information to access hospital services if a person's condition gets worse while waiting for care.



## 7. Outpatients and discharge letters

Letters sent after appointments should address the patient and summarise the personalised shared decision-making conversation that has taken place. Letters should be written in plain language, to ensure people understand the treatment options. They should include the benefits, risks, alternatives and what might happen if they choose to do nothing.

Letters should be available as hard copy and in the electronic patient record.

## 6. Shared decision-making earlier in the pathway

Shared decision-making early in the pathway can help patients:

- make decisions about lower risk treatment options available, or
- be supported to help get fitter for surgery, using the waiting time as preparation time.

***In 2022, those who were offline reported the NHS as the most difficult service to interact with.***

## 8. Digital inclusion

As the NHS develops more digital services it must find ways to support people who are digitally excluded to fully participate in shared decision-making. The inability to use digital tools should be seen as a 'health vital sign' noted in a shared care record.

This would alert NHS staff to make adjustments for the person's care in the same way as would be done for someone who is housebound or has communication needs.

# MSK patient journey and shared decision-making – the problem

Knee, hip and joint pain are grouped together under musculoskeletal conditions, often called MSK conditions. For some patients with MSK conditions, joint replacement is the treatment of choice.

However, post-Covid-19 waiting times for surgery are long. While on the waiting list patients' general health may worsen.

This puts people at greater risk of complications and a lower chance of a successful outcome from surgery.

The worst outcome for patients is to spend a long time on the waiting list and find they are unfit for surgery at the pre-operative assessment.

This was the experience of one member of the group, Debra Dulake. See Debra's story below.

**Good shared decision-making early in the care pathway can identify issues to help patients:**

- make decisions about lower risk treatment options available, or
- be supported to get fitter for surgery – using waiting time as preparation time.

## My experience of shared decision-making



**Watch Deb's story**

[youtu.be/g5B1D5y35x8](https://youtu.be/g5B1D5y35x8)

*"This is an emotive subject for me – being that person who is obese. Being told I had to wait until I was 50 for my new hip, then reaching that age and being told I was too fat sent me into a spiral where I ended up putting on more weight and feeling suicidal.*

*I saw another doctor who supported me and together we 'pinky promised' that I would lose the weight and he would do the operation. I did it and had my surgery."*

Debra Dulake, My Life Choices

# What did we do?

We ran 6 co-production meetings with My Life Choices during March, May, June, July, and October 2022. Some of the participants had lived experience of MSK services and surgery. All had an interest in shared decision-making and personalised care.

We presented patient resources being developed for use by the NHS in Nottingham and Nottinghamshire. We discussed as a group if they were useful and how they could be improved.

We then made these changes and showed them to NHS staff. There were some areas where the input of staff was needed in the co-production meetings.

Together we created an evaluation framework for the project to meet the needs of patients and professionals.

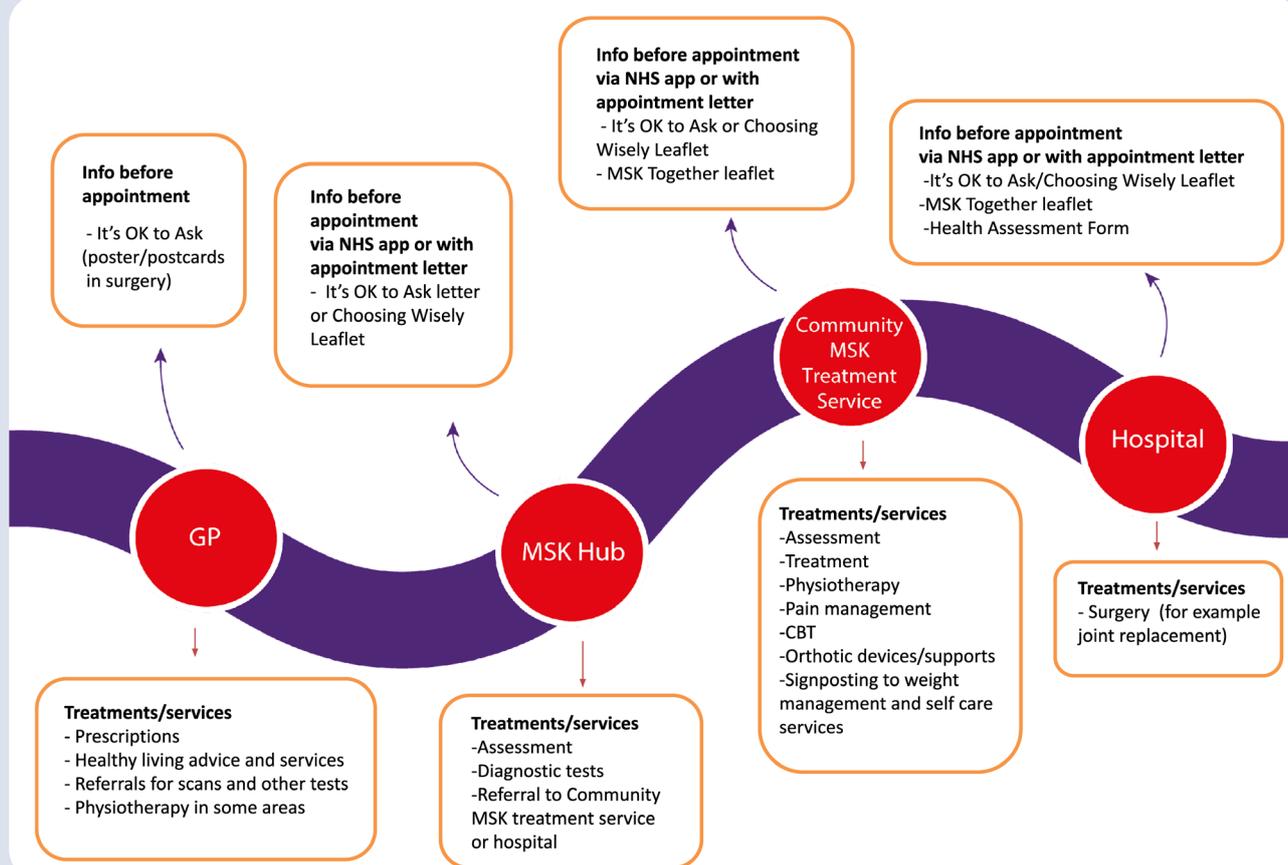


## Navigating the system

It can be very difficult to navigate the health system. We created this picture to make it easier for MSK patients to understand how the system works.

It also helped everyone understand at what stage the resources we were developing would be used by patients and health professionals.

The project brought together people working across the pathway to ensure consistent information and key messages were provided to patients navigating care.



# Resources we co-created

We worked as a group on the following resources. These are all used at different stages by patients and health professionals. Some were already developed, and some were in development.

## 'It's OK to Ask' letter

A letter encouraging people to ask questions about their health and care during appointments and think about those questions before the appointment.

## 'About Me' information

A simple template based on the PRSB Standard, setting out what matters to an individual. This can be shared before or during appointments.

## MSK Together leaflet

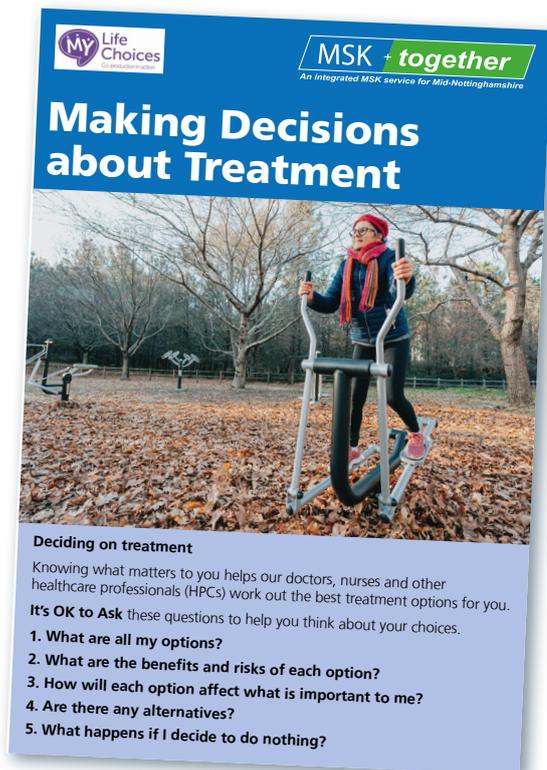
A leaflet explaining the importance of mental and physical health and wellbeing on surgical outcome. It encourages people to seek support to make healthier choices.

## Health Assessment form

A detailed form used to support fitness for surgery assessment. People are asked to complete a medical history and give information about their general health, weight, exercise, smoking status, alcohol use and mental health. The form also seeks consent to share data and encourages people to ask questions at appointments.

## Discharge letter framework

Discharge letters are sent to a patient and their GP after an outpatient appointment. The framework identifies the type of information to be included to summarise a shared decision-making conversation.



## Using the resources

The NHS Nottingham and Nottinghamshire Personalised Care team worked in partnership with health providers to implement the co-produced resources. The plan is to extend the materials and approach in Elective Care and support self care for people with long term conditions.

The resources will be used as part of Personalised Care Institute-accredited shared decision-making training to health providers across the ICS.

My Life Choices wanted the resources to be available in digital and paper formats. Members of the group recognised the needs of people who cannot access digital health and care services due to digital poverty or because they do not have the skills and knowledge to use digital platforms.

Digital skills are now fundamental to a person's ability to access healthcare services and information.

# What we found

There were general themes arising from our work with My Life Choices, which apply to all the resources and should be considered when developing material to support shared decision-making:

## 1. Simple solutions are best for patients and professionals

Brief information plainly and simply written was preferred by the My Life Choices Co-Production Group.

The word count of all materials was reduced, the language simplified and the tone adjusted by the panel.

This approach is endorsed by the NHS England content manual, which recommends all patient-facing material is written for a reading age of 9-11 years old.

The panel found sharing brief 'About Me' profiles with health professionals improved shared decision-making conversations and patient partnership. It meant they could see at a glance what matters to a patient.

*"Sometimes the doctor or professional doesn't give the person living with the condition credit for their knowledge."*

My Life Choices panel member

### 1.1 'It's OK to Ask'

The simple message 'It's OK to Ask' had greater appeal than the phrases 'Choosing Wisely' and the 'BRAN' acronym.

The panel felt the perceived power imbalance between patients and professionals is still a barrier to people asking questions to take part in shared decision-making.

The panel worked on the 'It's OK to Ask' letter to make it shorter and appeal directly to patients.

#### Implementation

A short video featuring Keymn Whervin (below) and the My Life Choices panel explains 'It's OK to Ask' and why it is important.



[youtu.be/BihXaYPfR4o](https://youtu.be/BihXaYPfR4o)

The text of the 'It's OK to Ask' messaging has been added to letters on the MSK pathway and to other pathways. 'It's OK to Ask' has been added to the personalised care branding across the ICS.

ask what matters - listen to what matters - do what matters

**what matters to you?**

## It's OK to Ask

A conversation with your healthcare professional that aims to support you to make decisions that are right for you

[notts.icb.nhs.uk/your-health/personalised-care-2/its-ok-to-ask](https://notts.icb.nhs.uk/your-health/personalised-care-2/its-ok-to-ask)

## 1.2 The 'About Me' form

This simple form was endorsed by the panel. It quickly captures what matters most to patients.

When patients completed the template and it had been shared with their care team it changed the tone of conversation and supported shared decision-making. This helped remove barriers for professionals and patients to start a personalised conversation and made the most of limited appointment time.

The panel decided to adopt the national PRSB standard for the 'About Me' form, which was very close to the locally co-produced version.

*"You would be amazed all of a sudden, they (healthcare professionals) start asking questions about you and that is quite a shift and I think we should be pushing this as much as possible.*

*When you go in you are nervous and you don't know what to ask. Giving this piece of paper, it gives them an idea and they may ask you a few questions that might be quite surprising. There is not so much of a barrier. It is a bit more equal. It does prompt the HCP to ask questions."*

My Life Choices panel member

The form is titled 'About Me' and contains the following sections:

- What is most important to me
- People who are important to me
- How I want to communicate and how to communicate with me
- My wellness
- Please do and please don't
- How and when to support me
- Also, worth knowing about me
- Date Supported to write this by

ask what matters - listen to what matters - do what matters

what matters to you?

## About Me

*A way of telling us once, what matters and what is important to you*



## Implementation

Nottinghamshire has the first integration with the NHS App and a personal health record, Patients Know Best (PKB) creating a digital front door to NHS services. The Personalised Care team is working with Digital Notts to add the 'About Me' form to the NHS App via a patient held record.

More importantly, the team is working to ensure that it links into the NHS Shared Care Record. Patients can update this information and it can be accessed by any healthcare professionals involved in their care.

## National implementation

Digital Notts, the Personalised Care team, PIF and the Patients Association supported the PRSB pitch to NHS Digital to add 'About Me' to the NHS App. The NHS App in England has more than 30 million users and presents a secure gateway for people to see and use their data. We believe the NHS should make this app work for everyone.

The NHS Wales App is currently in beta testing and includes About Me information as standard.

### 1.3 Consultant decision and discharge letters

Letters are sent to patients and copied to their GPs after an out-patient appointment providing a summary of the consultation.

Often these letters are too complex for patients to understand and can be filled with medical terminology.

The Nottingham and Nottinghamshire ICB has created a framework for doctors to use to ensure the relevant details of the shared decision-making conversations are recorded in plain language.

#### The framework includes:

- the medical issue the patient is seeking help with
- what is most important to the patient in terms of outcomes
- benefits, risks and alternatives discussed and what would happen if the patient did nothing
- the shared decision reached.

My Life Choices reviewed the framework and a sample letter created using it. They all responded positively to the sample letter but felt healthcare professionals would need support to use the framework.

#### Implementation

The framework is being implemented and a content evaluation of consultant letters will be carried out to evaluate its impact.

"Another cultural shift needs to come in here. We can say what a good letter feels like for us but we can't tell them what a good framework is.

What we need to do is look at this with the HCPs and co-design this with them."

Helen Hassell, My Life Choices

"It's a great summary of the two-way conversation you've had. If both of you filled in this framework it would reflect the conversation."

Debra Dulake, My Life Choices

**Shared Decision-Making Framework**

**BRAN (Benefits, Risks, Alternatives, Nothing) model**

1. What matters to the patient? What do they want to get out of the treatment?  
*(For example, analgesia, mobility, better quality of life, symptom control)*
2. What are the patient's concerns or outcomes they want to avoid?  
*(For example, loss of functional independence, inability to garden/drive/work, not be able to care for a family member)*
3. What are the options for treatment and the Benefits, Risks Alternatives and if you do Nothing? *(List in the table below with reference to the patient factors above)*

	Treatment Option 1 xxxxx	Treatment Option 2 xxxxx
<b>Benefits</b> What are the benefits of the treatment? What can I expect to gain from the treatment? What is the chance of the treatment being successful?		
<b>Risks</b> What are the risks? What is the chance the treatment won't work? What are the possible side effects? What are the possible complications? How might the treatment affect my quality of life?		
<b>Alternatives</b> What are the alternatives? What are the other treatment options? What are benefits and risks of the other treatment options? Which treatment options should be used first?		
<b>Nothing</b> What if I do nothing? How will my condition change if I don't have treatment? Will my condition be more difficult to treat later?		

## 2. Data flows within the NHS

The Health Assessment Form used for pre-surgical assessment asked patients to recall their medical history. Patients assume that this data would be shared within the NHS. This highlighted the need for an NHS Shared Care Record.

The co-production group expressed frustration about repeating medical history and had concerns about fully recalling details.

*"We need to get to the stage where we have one form we fill in, everyone can look at it and share it with permission. The NHS should be able to share around hospitals.*

*If you are knocked out, you can't share this information anyway. We should stop giving information repeatedly and do it just once.*

*We are giving the same info all the time, it doesn't seem to be looked at. There's no sharing of information."*

Bev Jones, My Life Choices

### 2.1 Health assessment form

Changes were made to the health assessment form to make it easier to use for patients. It was also simplified, but this is still a complex form given the amount of medical history needed.

Lack of data sharing is a barrier to patients completing pre-appointment forms. It is important patients are told why the data are being requested and how they will be used in their appointment.

#### Implementation

The members of the Personalised Care Team are considering how the updated health assessment form can be used via the NHS App and in non-digital formats.

#### National implementation

Conversations about data sharing in the NHS have been badly communicated to the public. There is confusion about data sharing for patient care and data sharing for research purposes.

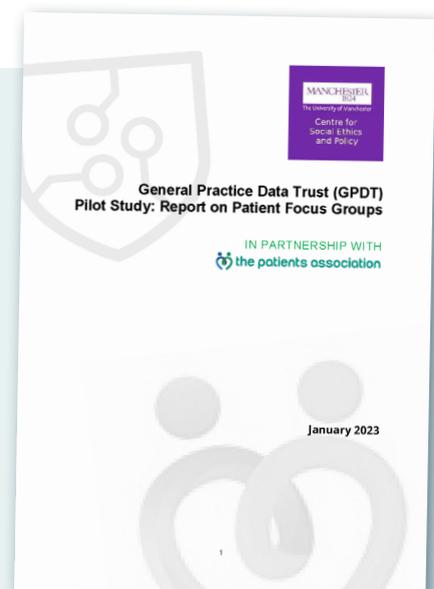
There needs to be a national conversation about the use and sharing of patient data in the NHS.

### GP Data Trust Pilot Study: Patient Focus Groups

Research by the Patients Association found patients lacked trust in organisations, including the NHS, to keep data secure, record data accurately, and only use it for ethical purposes.

People wanted more information about what their health data would be used for if they shared it and how the data would be kept secure. Participants wanted ongoing control over the use of their health data for research.

The report recommends using a legal Trust to hold patient data for research. Trustees should include patients, medical and data experts. A Trust could control how health data are shared and patients' wishes respected.



[patients-association.org.uk/  
blog/gpdt-pilot-study-report](https://patients-association.org.uk/blog/gpdt-pilot-study-report)

### 3. The value of co-production – getting the right tone and content

The co-production panel found issues with the tone and content of material, making it less likely patients would engage and act on the information provided.

***"Doctors and surgeons have their way of doing things and you feel as a patient you have done something wrong. Any information we get should not be a judgement. It should be a statement not a judgement, as that starts a conversation."***

Michelle Evans, My Life Choices

***"The one thing I thought was interesting was the 'change your mind'. If you were going in for serious surgery and had to be in a right mindset, those issues with wellbeing, things you might not have thought about."***

***"That out of everything should be at the top. Until your mind is in the right place you can't do anything."***

Bev Jones, My Life Choices

***"People don't make a decision to live an unhealthy life. They get there from a multitude of reasons. I have been judged every step of the journey. You aren't meeting me where I am. You're telling me where you want me to be."***

Helen Hassell, My Life Choices

#### 3.1 Value judgements

Questions about people's weight, body mass index (BMI), levels of physical activity, smoking and alcohol habits, and mental wellbeing are sensitive. People can very easily feel their lifestyle is being judged and be overwhelmed by the difficult changes they are being asked to make.

Many of these may be linked to wider social determinants of health and existing health inequalities over which people feel they have little control.

#### The panel found key barriers:

- people need access to supportive services, health and wellbeing coaches and social prescribing to support them with behavioural change
- mental health gets in the way of behaviour change to improve physical health.

The panel completely reworked the content about lifestyle changes in the MSK Together leaflet and health assessment form so it 'met people where they were at'. The word count was reduced, and graphics added.

The biggest change to tone centred on three themes:

- being mentally prepared to make changes must come first with an acknowledgment that making the change can be very hard
- being offered support to make changes via support services
- understanding the impact of small changes on outcome, in terms of improving existing symptoms and reducing surgical risk.

## 3.2 Body mass index (BMI) – a contentious issue

BMI was mentioned in much of the draft material. Trust in BMI as a credible measurement had been diminished by debate in the media. There are differences in BMI measurement related to ethnicity and for people who have athletic builds.

The use of BMI in the draft material undermined trust in the information overall. However, BMI is still a key measurement in the assessment of surgical risk.

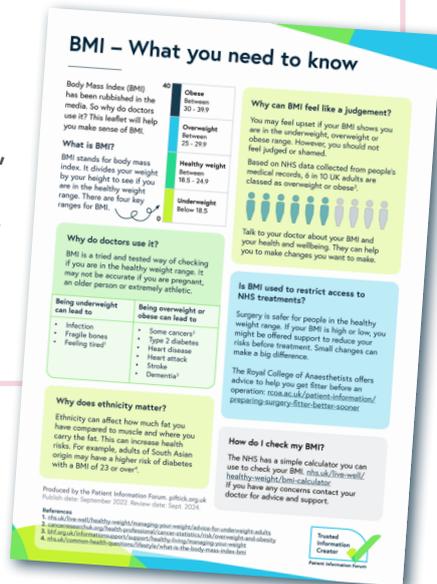
Dr Rebecca Barker, Consultant Anaesthetist at Sherwood Forest Hospital attended a co-production meeting to explain the role of BMI in surgical assessment. The panel then used this information to provide context on why BMI is a relevant and necessary measure.

The updated NHS England BMI calculator provides a more personalised measurement than standard tools and is signposted in the material.

PIF has produced a [simple BMI fact sheet](#) to help the public make sense of BMI, prompted by the findings of this project and concerns raised by other PIF member organisations.

It was shared with the team in Nottinghamshire, which is using it in this and wider programmes of work.

[piftick.org.uk/  
finding-trusted-  
health-information/  
tips-and-guides/  
bmi-what-you-need-  
to-know](http://piftick.org.uk/finding-trusted-health-information/tips-and-guides/bmi-what-you-need-to-know)



*"There's two mentions of BMI but I thought the healthcare system was moving away from BMI because its old and passee."*

Helen Hassell, My Life Choices

## Implementation

The updated MSK Together leaflet has been printed and distributed along the MSK pathway. The findings of the co-production work were shared with the teams developing information for My Planned Care at Sherwood Forest Hospital and Queen's Medical Centre, the two hospitals providing MSK services in Nottinghamshire.

## National implementation: My Planned Care

My Planned Care is an NHS platform giving advice and support to patients waiting for a hospital consultation, treatment, or surgery.

Each hospital supplies advice on waiting times for a specialty and can add supporting information. The two Nottingham hospitals supply broadly consistent general health advice to patients on the waiting list about preparing for surgery.

However, not all hospitals in England provide this vital information to patients. Where it is provided, it varies in content, accessibility, and tone. While some of the information is specific to the locality, much is generic.

To support shared decision-making specific to MSK, NHS England should develop national level content on health and wellbeing to sit on the landing page of My Planned Care.

Content on My Planned Care should include culturally appropriate and accessible advice on weight, diet, exercise, smoking and alcohol.

This should be created working in partnership with patients, the Centre for Perioperative Care, the Personalised Care Institute and the partners in this project.

This information should meet the NHS England content standard for health information. The [NHS England content standard](#) is based on the PIF TICK criteria.

## PIF TICK

The [PIF TICK](#) is the UK quality standard for health information. More than 100 cross sector organisations, including the Patients Association have joined the scheme. Both the NHSE content standard and the PIF TICK criteria have a firm evidence base, user need and inclusive content as core requirements.



## Evaluation

The evaluation of these resources consists of a short survey and was co-produced with My Life Choices. Surveys have been developed for all care settings.

The evaluation of this project will sit within a wider evaluation of personalised care within the Nottingham and Nottinghamshire Integrated Care Board.

## Conclusion

Early results from our project work in Nottingham show simple solutions can be used to support better shared decision-making but barriers remain.

Action on our recommendations at a national level could help remove the barriers to shared decision-making for patients and healthcare professionals alike.

## About the Patient Information Forum

**PIF is the independent UK membership body for people working in health information and support. PIF runs the only UK-wide quality mark for health information – the PIF TICK.**

PIF represents more than 300 organisations across the NHS, voluntary, academic, freelance and commercial sectors. Our expert guidance on the production of high-quality health information supports an improved healthcare experience for patients and the public.

## About the Patients Association

**The Patients Association is an independent charity campaigning for improvements in health and social care for all patients.**

Its goal is for everyone to be able to access and benefit from the health and care they need to live healthy, independent lives. It works directly with patients, who are members and supporters of the charity, and the people who benefit from its services. Anyone with an interest in health and social care join the Patients Association as a free individual member by signing up on our website.

Published by the Patient Information Forum  
483 Green Lanes, London, N13 4BS

[pifonline.org.uk](http://pifonline.org.uk)  
[info@pifonline.org.uk](mailto:info@pifonline.org.uk)

 @PIFonline  
 @PIFonline

[patients-association.org.uk](http://patients-association.org.uk)  
[mailbox@patients-association.org.uk](mailto:mailbox@patients-association.org.uk)

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