

DEMOS

**PATIENT
POWER:**

UNLEASHING CHOICE
OVER ROUTINE
MEDICATIONS

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EXECUTIVE SUMMARY

When the NHS in England considers how to build back from its crisis response to the Covid-19 pandemic, there is an opportunity to reconsider the nature of the ongoing relationship between patient and doctor, and in particular the way in which routine medications are prescribed, be it in GP surgeries or hospital outpatient consulting rooms.

The hypothesis we are exploring in this work is that there is a disconnect between the policy intentions around patient choice and the lived experience that patients have regarding the choices they are able to make over their medication and other prescription treatments. We set out to ask what choice is desirable in the prescribing of routine medications, whether this fits with what people experience in practice, and, separately with what they say they want. We then explore the barriers to patient choice over medication and make specific policy recommendations designed to overcome those barriers, with the ultimate aim of improving patient outcomes (Introduction).

There has been a long-running workstream around improving patient choice of provider in the NHS which to some extent obscures the language around choice of medicine. The most relevant existing policy is 'shared decision making', often thought of as a process where the patient and

When the NHS in England considers how to build back from its crisis response to the Covid-19 pandemic, there is an opportunity to reconsider the nature of the ongoing relationship between patient and doctor, and in particular the way in which routine medications are prescribed, be it in GP surgeries or hospital outpatient consulting rooms.

doctor enter into a partnership and make a decision together - although this phrase too can sometimes overlook decisions about medications and focus on the wider treatment plans. Indeed, choice over medications specifically, and the patients' role in this is something that can feel overlooked in policy. Amongst patients, having information is consistently cited as an important prerequisite of choice. Other important themes are feeling involved, having options and ultimately agency over decisions, although for many simply being able to understand to the point that involvement becomes possible is the main aim (Chapter 1).

We found a strong case for maximum patient involvement in the choice of medication, both for reasons of financial efficiency and medical efficacy, as well as out of ethical considerations. Our poll showed a majority (61%) of the public support joint decision making but that around three-quarters of the public (74%) also consider that the final decision ultimately lies with the doctor, with around half of those (36% of the total population) believing their own views were not relevant to that decision. Those who feel the decision lies with the patient are more likely to feel strongly, be under 40 and on short-term medication. Those who prefer the doctor to make the decision may feel unqualified to do so and feel overwhelmed by the responsibility (Chapter 2).

There is little in the way of formal data collection around the extent to which patients routinely feel they have had a conversation with their doctor about options for medication treatment. Our survey showed that around a third of people who visited the doctor and were prescribed medication at least once in the last year that they were always presented with options but nearly a quarter stated they never were, with a mixed picture for the remainder. Younger people are slightly more likely to be presented with options than older people. It should be acknowledged though that even when

choices are presented, in practice they may not be meaningful (Chapter 3).

While there is strong evidence that many people are as involved in the decisions about their own medication as they want to be, there is also a significant minority of predominantly younger individuals who want to be more involved.

- 6 in 10 (62%) of the population are content with their personal level of involvement in the decision-making process around the prescribing of their most recent medication
- 3 in 10 of the population would have liked to be more involved, rising to 4 in 10 for those under 40.
- A majority (58%) of those on short-term medication wanted to be more involved, compared with just under a third (29%) of those on long-term medication.

People under 40 (50%) and those on short-term medication (66%) are more likely to disagree with their doctor than the general population (35%). While obtaining a second medical opinion is rare, it was also more common amongst younger cohorts. We also found that most patients (65%) routinely engage in a soft informal process of checking the advice they get from their doctor, indicating a generalised desire to feel more informed about the decisions that are made (Chapter 4).

Our primary research showed that although patients are sympathetic to the pressures that doctors are under, they nevertheless perceive that a lack of time with their doctor was a barrier to choice, alongside concerns around continuity of care: they can't always get an appointment with the same doctor. Other healthcare professionals such as clinical nurses and pharmacists were seen as more accessible. Structural capacity issues within Clinical Commissioning Groups (CCGs), alongside legislative complexity, may also act as a barrier to patient choice over medication (Chapter 5).

Our poll results suggest that a majority of the population (62%) are content with the amount of independent information they receive about which medication would suit them best. Younger people, however, were most likely to think there was too much independent information. This suggests that younger people perhaps feel overwhelmed by the sheer amount of uncurated information that they need to wade through to obtain the control and

agency that they seek. Our focus groups suggested a greater demand for curated information from trusted sources - be it online or from other patients (Chapter 6).

A key part of decision making is cost-effectiveness, that is whether a medical treatment presents good value for money as well as good clinical outcomes. Primarily, National Institute for Health and Care Excellence (NICE) is responsible for cost effectiveness - it is one of the primary criteria that it uses to decide if a new medicine is made available on the NHS - but in practice CCGs also put additional pressure on prescribing doctors to advocate the cheapest alternatives, in ways that patients are not necessarily aware of. Meanwhile, patients themselves are broadly supportive of cheaper alternatives being prescribed where they are equivalent, or for low stakes conditions, but are concerned that some patients with serious conditions may be deterred from choosing the medicines they need if they knew they were very expensive (Chapter 7).

Lack of patient confidence was a barrier in people feeling able to be more involved in their treatment choices, which in turn is influenced by a large number of factors including the patient's own life stage. We found little knowledge of existing patient rights but agreement amongst many participants that an awareness of such rights could be empowering for patients. Our poll suggested a reasonable public understanding of the technical role of NICE and our qualitative discussions suggested people would find the agency a credible source of information about their choices and rights (Chapter 8).

Our associated recommendations are listed on the next page.

RECOMMENDATIONS

Recommendation 1: NHS England and Clinical Commissioning Groups should make sure patients are able to access support from their pharmacist and/or clinical nurse as they consider their options throughout their care pathway [this should be reflected in pharmacists contracts].

Recommendation 2: Pharmacists should be recognised as an integral part of the patient care pathway. The discussions that pharmacists have with patients should be recorded on their files alongside those with other healthcare professionals in both primary and secondary care, such as GPs, clinical nurses and consultants. This could include the opportunity for pharmacists to recommend prescriptions for GPs to consider or sign off.

Recommendation 3: NHS England should formalise the relationship between the NHS and patient groups to provide more structured support to patients making decisions about their healthcare, subject to the groups themselves wanting to do so. This could include procuring appropriate services from charities to support patient decision making.

Recommendation 4: NHS England and NICE should extend NHS online content to provide patients with interactive tools to explain different treatment pathways and options using language that is accessible to patients. These should include explainers of the types of medical professionals they can consult to discuss options and their patient rights to NICE-approved medications under the NHS Constitution.

Recommendation 5: NHS Improvement should conduct a review of how to better include patients as a resource in the health and social care service. This should include building additional opportunities for patients to get involved in the healthcare service more generally, for example, through additional or more varied volunteering opportunities.

Recommendation 6: The Department of Health and Social Care (DHSC) and the NHS should ensure patient rights in the NHS Constitution are enforced and implemented through healthcare policy and delivery.

Recommendation 7: The Department of Health and Social Care (DHSC) should pilot including 'the right to the continuity of care' in the NHS Constitution.

Recommendation 8: The GP Patient Survey should routinely include a question on (1) whether patients would like to have been presented with more choices in decisions about their medication and (2) whether they adhered to the treatment plan or course of medication that their doctor prescribed.

Recommendation 9: Annual data from NHS Patient surveys should be laid before Parliament to ensure that Clinical Commissioning Groups performance in delivering patients rights in the NHS is scrutinised and held to account.

Recommendation 10: Additional online content created by NICE and NHS England (see Recommendation 4) should include information about the cost-effectiveness of medications.

INTRODUCTION

2020 has probably been the hardest year for the NHS on record. In response to Covid-19, the way that the NHS delivered services changed overnight. An often bemoaned bureaucratic and unwieldy organisation managed to get rid of waiting rooms and turn many of its services digital in a matter of weeks.¹

Nonetheless, alongside this extraordinary ability to innovate and pivot, the pandemic has highlighted unacceptable inadequacies in our health and care system: our poor international standing on coronavirus death rates, the way the virus disproportionately affected the most disadvantaged groups and the particular vulnerability of people with preventable underlying health conditions like obesity, to name a few.^{2,3}

These realisations, alongside the urgent need to build back the capability to treat non-Covid conditions, provide a clear call to action for the Government to do more to transform our treasured NHS into an institution that supports healthier citizens in the long-term.⁴ One possible mechanism to help achieve that is to tap into the patient resources that already exist; ensuring that people across the UK are as resilient and self-sufficient as they can be to illness and poor health.

An essential part of any such agenda of patient empowerment is to explore the nature of the choices people have over the routine treatments and medicines they are prescribed in the everyday conversations they have with their doctors. Nearly half of the total population of England (46%) state that they are currently taking prescription medication for a long-term condition, a further 15% state that they are on prescription medication “only for a certain period of time” and three-quarters of the population as a whole has had an appointment with a doctor in the last year.⁵

On the one hand, the legislative framework for the NHS, and its governing documents, give patients

a clear right to decide their own treatment, with a corresponding duty on the commissioners of health services to promote that ability to choose. The rationale for that right is as much about outcomes as ethics: people who psychologically own their treatment plan are more likely to benefit from it.

On the ground, however, the situation often feels different. For many, the relationship they have with their doctor is essentially paternalistic, either because that’s the way they like it or due to a lack of knowledge that it could be any different. Even if patients wanted fully to exercise their own choice, there are structural barriers against it: time with their doctor, knowledge of the available options, initiatives within the NHS to promote the cheapest alternatives and sheer information overload.

The premise for this research is that this disconnect between policy and reality is a problem, and that if the public were more aware of their rights in the choice of medicines and treatments, not only would it cause a change in behaviour that would improve health outcomes, but it would also improve the democratic accountability, coherence and ultimately the effectiveness of one of the country’s most loved institutions.

In this initial introductory section, we set out the existing legislative and policy framework for patient choice over prescription medication, the case for undertaking research on this topic, our research questions and a brief description of the methodology we have used to answer those questions. The main part of this report then draws out the themes that emerged from our research, which are used to inform the policy recommendations that are proposed in the concluding section.

Throughout, we consider patient choice over medicine to be concerned with the sense of involvement and ultimate ownership of decision making in the routine discussions between doctor

1. Shaun Lintern, Coronavirus: NHS Nightingale chief says NHS must ‘never go back’ to old bureaucratic ways, *The Independent*, April 2020. Available at <https://www.independent.co.uk/news/health/coronavirus-nightingale-nhs-intensive-care-nurses-hospitals-a9487946.html>
2. John Burn-Murdoch and Chris Giles, UK suffers second-highest death rate from coronavirus, *The Financial Times*, 28 May 2020. Available at <https://www.ft.com/content/6b4c784e-c259-4ca4-9a82-648fde71bf0>
3. Gabriella Swirling and Ashley Kirk, Black people four times more likely to die from coronavirus than white people, ONS figures show, *The Telegraph*, 7 May 2020. Available at <https://www.telegraph.co.uk/news/2020/05/07/black-people-four-times-likely-die-coronavirus-white-people/>
4. Public satisfaction with the NHS and social care in 2018: Results from the British Social Attitudes survey, *The Nuffield Trust and King’s Fund*, 2018. Available at <https://www.nuffieldtrust.org.uk/research/public-satisfaction-with-the-nhs-and-social-care-in-2018>
5. Demos poll of 2,025 adults interviewed online 29 July 2020 - 7 August 2020 in England. Data are weighted to the profile of the population.

and patient around prescriptions: medicines, medications and other similar treatments that occur in a non-acute setting. Typically, these conversations take place in a GP surgery or similar one-on-one consultation environments with a qualified doctor, including routine outpatient appointments in hospitals.

In order to constrain the scope we specifically exclude conversations around end-of-life care; around the type of decisions taken rapidly in emergency or unscheduled care settings; and we also exclude the separate ongoing policy discussions around access to medicines for the most serious and/or rare conditions where there is often a less conclusive evidence base for new medicines but an urgent demand due to weak patient prognosis.

Instead we are primarily concerned with the routine prescribing process, either for short-term requirements (such as a course of antibiotics), longer-term treatments (such as control of immune conditions) or medications that are prescribed for different lengths of time for different people (such as antidepressants, painkillers or women's health prescriptions). We also confine our investigation to England given that healthcare is a devolved responsibility. The primary research for this project was conducted in summer 2020 during the Covid-19 crisis; our methodological annex describes the adjustments we made as a result.

LEGISLATIVE AND POLICY FRAMEWORK FOR PATIENT CHOICE OF MEDICINE

The process of deciding whether a drug (or procedure) is made available to an NHS patient starts with the National Institute for Health and Care Excellence (NICE). Once a major drug has been approved on clinical grounds, NICE then assesses whether it should be made available on the NHS, based on a judgement around both efficacy and also cost effectiveness, according to set criteria around the impact on patients' quality of life.^{6,7} In normal circumstances these drugs must then be

made available to patients, regardless of where they live in England and Wales, within three months of being approved.^{8,9}

From the point of view of patients, the NHS Constitution then states "you have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you."¹⁰ In legislation, the National Health Service Act 2006 contains an explicit "duty as to patient choice" that falls on CCGs, namely the sub-regional organisations that allocate resources to local health services including hospitals and GPs to meet the needs in their areas, as follows:

*Each clinical commissioning group must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them.*¹¹

This is often interpreted to mean provider choice first, before other aspects of care such as medication or medical treatments. The same legislation, however, also requires CCGs to "promote the involvement of patients, and their carers and representatives (if any) in decisions which relate to... their care or treatment".¹²

Operationally the duty on NHS bodies to promote patient choice over treatments has translated into a policy of 'shared decision making' encapsulated by the phrase "no decision about me, without me".¹³ For longer-term conditions and in the care sector, this is reinforced by a policy of personalised care designed to put the specific circumstances of the patient at the heart of the support that is offered. Both are central to the current long-term strategic goals of the NHS.^{14,15,16} The NHS Long Term Plan 2019, for example, signals its commitment to creating 'genuine partnerships' between patients and their doctors, based on the belief that what matters to someone is not the same as what's the matter *with* someone.¹⁷ It seems that this type of relationship does not necessarily happen on

6. Clinical assessment is provided by the Medicines and Healthcare Products Regulatory Agency or the European Medical Agency following medical trials.
7. Timmins, Nicholas; Rawlins, Sir Michael; Appleby, John (2016). A Terrible Beauty: A Short History of NICE The National Institute of Health and Care Excellence. ISBN 978-616-11-2821-0.
8. This takes the form of a regulation requiring CCGs to comply with NICE recommendations. <http://www.legislation.gov.uk/uksi/2012/2996/regulation/34/made>
9. Leo Ewbank, David Omojomi, o Kane Sullivan and Helen McKenna, The rising cost of medicines to the NHS: what's the story? The King's Fund, (2018), p.5. Available at <https://www.kingsfund.org.uk/publications/rising-cost-medicines-nhs>
10. NHS, NHS Constitution, NHS, 2020. Available at <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>
11. National Health Service Act 2006 section 14V as amended: <http://www.legislation.gov.uk/ukpga/2006/41/section/14V>
12. National Health Service Act 2006 section 14U as amended: <http://www.legislation.gov.uk/ukpga/2006/41/section/14U>
13. The Department for Health, Equity and excellence: Liberating the NHS, 2010. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf
14. Patient Choice, NHS. Available at: <https://www.england.nhs.uk/patient-choice/>
15. Delivering Universal Personalised Care. NHS. Available at: <https://www.england.nhs.uk/personalisedcare/upc/>
16. NHS, NHS Constitution, NHS, 2020. Available at: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>
17. The NHS Long Term Plan. NHS, 2019. p24, Available at: [longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf](https://www.gov.uk/government/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf)

the ground - one of our key findings being that a significant proportion think the doctor should lead without the patient's involvement - suggesting minimal implementation.

In practical terms the NICE guidance (see box) recommends that doctors should work out how much involvement a patient wants (or is able to have) over their treatment and then proceed on that basis.

The right to choice however does not cover all NHS patients. Those that are not entitled include, but are not limited to, 'formal' mental health patients, or those who are detained under the Mental Health Act 1983,¹⁸ patients who are detained or on temporary release from prison, and those in an immigration removal centre.¹⁹ However recent guidance from the General Medical Council emphasises that for everybody else, the starting point is that patients are able to make their own decisions:

Doctors must start from the presumption that all adult patients have capacity to make decisions about their treatment and care. A patient can only be judged to lack capacity after assessment in line with legal requirements.

General Medical Council ²⁰

Our interviews with senior practitioners during the course of this research demonstrated that this shared decision making model is popular in the profession, and can be viewed as a common-sense solution in an environment where different patients want to be involved in their own healthcare decisions to differing extents.

The challenge, however, comes in ascertaining how involved a patient wants to be, whether the patient themselves understands that they have the right to decide their level of involvement, and who ultimately should be the person who makes the final decision. The guidance (see box) simultaneously sets out the duty of healthcare professionals to help the patient make decisions about their treatment, and also advises practitioners to establish what level of involvement the patient would like; it is silent about whether a patient deciding to always do as the doctor proposes is a desirable outcome in itself. As a result, there is the potential for

NICE guidelines on patient involvement in decisions about medicines ²¹ (our emphasis)

1.1.7 Offer all patients the opportunity to be involved in making decisions about prescribed medicines. Establish what level of involvement in decision-making the patient would like.

1.1.8 Discuss with the patient why they might benefit from the treatment. Clearly explain the disease or condition and how the medicine will influence this.

1.1.9 Explain the medical aims of the treatment to patients and openly discuss the pros and cons of proposed medicines. The discussion should be at the level preferred by the patient.

1.1.10 Clarify what the patient hopes the treatment will achieve.

1.1.11 Avoid making assumptions about patient preferences about treatment. Talk to the patient to find out their preferences, and note any non-verbal cues that may indicate you need to explore the patient's perspective further.

1.1.12 Healthcare professionals have a duty to help patients to make decisions about their treatment based on an understanding of the likely benefits and risks rather than on misconceptions.

1.1.13 Accept that patients may have different views from healthcare professionals about the balance of risks, benefits and side effects of medicines.

1.1.14 Be aware that increasing patient involvement may mean that the patient decides not to take or to stop taking a medicine. If in the healthcare professional's view this could have an adverse effect, then the information provided to the patient on risks and benefits and the patient's decision should be recorded.

1.1.15 Accept that the patient has the right to decide not to take a medicine, even if you do not agree with the decision, as long as the patient has the capacity to make an informed decision and has been provided with the information needed to make such a decision.

18. This is someone who is being detained in hospital under a section of the Mental Health Act, and is therefore not free to leave secondary care. See: Mental Health Act 1983, Mind, Webpage, 2020. Available at <https://www.mind.org.uk/information-support/legal-rights/mental-health-act-1983/about-the-mha-1983/>

19. A Guide to the Law on Patient Choice, Landmark Chambers, 2018. Online at <https://www.landmarkchambers.co.uk/wp-content/uploads/2018/07/Guide-to-Patient-Choice-Rights.pdf>

20. Shared decision making is key to good patient care - GMC guidance, The General Medical Council, September 2020.

Available at <https://www.gmc-uk.org/news/news-archive/shared-decision-making-is-key-to-good-patient-care---gmc-guidance>

21. <https://www.nice.org.uk/guidance/cg76/chapter/1-Guidance#patient-involvement-in-decisions-about-medicines>

Our interviews with senior practitioners during the course of this research demonstrated that this shared decision making model is popular in the profession, and can be viewed as a common-sense solution in an environment where different patients want to be involved in their own healthcare decisions to differing extents.

confusion, where a traditional paternalistic attitude of deference and 'doctor knows best' clashes with the empowered anxiety of an internet age, where people have become accustomed to having knowledge, understanding and control at the tips of their fingers.

Meanwhile at a policy level, while choice is promoted, official documentation appears more concerned with providing a choice of provider for a first hospital appointment than ensuring there is choice of medicines or treatments.²² Combine this with the opportunity that the pandemic provides to consider how we want the NHS to operate in the future, alongside the recent guidance from the GMC that attempts to clarify that the final decision should lie with the patient (as quoted on page 10), and we felt that the time was right to explore the desirability of patient choice over medicines they are prescribed, how the reality of patient experience fits with their expectations and desires, and the implications for health practitioners and policy-makers.

RESEARCH QUESTIONS

Following an initial scoping exercise, we therefore prioritised the following questions:

- To what extent do patients have - and feel they have - a meaningful choice over their treatment/medicine in conversations with their GP or consultant?
- How strongly do patients desire greater choice over their treatment and medication?
- What actions do patients take to address the asymmetries in information (e.g. online search, second opinion)?
- How do attitudes to choice of medicine vary according to demographic and socio-economic variables?

- What are the barriers to patients having more choice over the type of medicine they are offered?
- What are the implications for policy makers?

METHODOLOGY

We started the project with a desk-based review of previous literature, research and policy documentation in order to frame and situate our research. Our primary research then consisted of:

- A nationally representative poll of 2,025 adults living in England conducted online in the period 29th July- 7th August 2020. This is the base for all the poll results we present, unless otherwise stated. The poll was deployed in-house, with participants recruited through an agency partner. Data were weighted to be representative of the population by gender, age, region, social grade, education, past votes in the 2019 general election and EU referendum. The polling questionnaire is included in Appendix 1.
- Twelve semi-structured interviews with patients on long-term medication for a variety of different immunology conditions during the period between August-September 2020. The interviews were conducted by phone or video call, and lasted around one hour each. The participants were recruited by adverts on Twitter and screened to provide diversity and balance in terms of how much choice they felt they had over their own medication, the nature of their relationship with their doctor, their medical condition as well as their age, gender and region. The topic guide for the interviews was drawn from that of the focus groups.
- Two focus groups in the week beginning 17th August 2020. The participants were recruited through an agency partner and the focus groups were conducted in-house over zoom. The first focus group consisted of six participants on medication for a long-term condition with an additional stipulation that two of the group be over 45 and two under 45 to ensure age balance. The second had five participants all of whom were on medication for an immunology condition such as type 1 diabetes, rheumatoid arthritis, lupus, crohn's disease or psoriatic arthritis with no other restrictions. Each group lasted 90 minutes; the discussion guide is included in Appendix 1.

22. See for example Securing meaningful choice for patients: CCG planning and improvement guide, NHS England and NHS Improvement. NHS England, 2016. Available at <https://www.england.nhs.uk/wp-content/uploads/2017/01/choice-planning-guidance.pdf>

- Ten semi-structured expert interviews with a range of health practitioners speaking in their personal capacity including representatives from patient groups, GPs, industry bodies, NHS England, hospital trusts, other think-tanks and academia. These were conducted by telephone or zoom in August and September 2020 and the individuals concerned also had the opportunity to provide comments on an early draft of the write-up; we are very grateful to those individuals who gave freely of their time.

Each stage of the research was written up separately as an interim output. These were then used to inform internal Demos brainstorming exercises to consider the implications of our findings and draw out the policy conclusions. The final write-up was then undertaken in September-October 2020. Further detail on the methodology and the implications of undertaking primary research on health policy during the pandemic is given in Appendix 1.

In the next sections we present the main findings of our research. Section 1 starts by exploring what “patient choice” means, both to patients themselves and how this compares to what health professionals understand by the phrase. The following chapters then explore whether it is - in principle - desirable to have high levels of patient choice over the medications that are prescribed, whether patients themselves feel that in practice they do exercise a choice and finally whether people would like more choice than they currently have.

Section 2 then reports our findings on the barriers that act against patient choice of medication, broken down into four main categories: time and structural barriers (encompassing NHS supply-side issues); information barriers experienced by patients; barriers relating to costs and financial pressures; and patient knowledge of their rights and their sense of empowerment. Finally, the concluding section draws out recommendations to policymakers around how patient outcomes could be improved in the light of our findings.

SECTION 1

CHAPTER 1: DEFINING PATIENT CHOICE

KEY FINDINGS

- The long-running workstream around improving patient choice of provider in the NHS to some extent obscures the language around choice of medicine.
- The most relevant existing policy is 'shared decision making', often thought of as a process where the patient and doctor enter into a partnership and make a decision together - although this phrase too can sometimes overlook decisions about medications and focus on the wider treatment plans.
- Amongst patients, having information is consistently cited as an important prerequisite of choice.
- Other important themes are feeling involved, having options and ultimately agency over decisions.
- For many patients, simply being able to understand to the point that involvement becomes possible is the main aim.

For a few of our expert interviewees the concept of patient choice was primarily political and economic.

We found some confusion in the literature around what the simple phrase "patient choice" means in the healthcare sector.²³ It appears possible that this is a semantic point, deriving from a parallel workstream stretching back to the late 1990s designed to increase patient choice over provider - such as the hospital or clinic where a procedure is undertaken through the 'choose and book' system, or the right to change GP - in an attempt to drive up standards and increase capacity. A description of policy changes since 1997, including but not limited to the introduction of an internal market in the healthcare sector is included as Appendix 2 to this report. The effect of the words 'patient choice' being more commonly used in the context of choice of provider rather than the choice of treatment or the medicine itself has led to a lack of coherence in what choice means across the healthcare sector, that could work against effective implementation.²⁴

As a result, we asked patients and experts to define what patient choice meant to them. We found that definitions of patient choice were extremely varied among both experts and participants.

For a few of our expert interviewees the concept of patient choice was primarily political and economic. For example, one expert argued that patient choice was primarily a "market definition", where consumer choice is a "mechanism to improve the supply side" in addition to being something that patients might value, epitomised by the right to choose a healthcare provider, be it a GP or the hospital to which you are referred. For those taking

23. See for example Improving GP services: commissioners and patient choice, Monitor, 2015. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/431317/GP_services.pdf; Exploring patient choice in GP services, Ipsos Mori, (2014) Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/430776/Exploring_choice_in_GP_services_Ipsos_MORI_survey.pdf; NHS England & Monitor Outpatient Appointment Referrals (2015). Available at <https://www.england.nhs.uk/wp-content/uploads/2015/09/monitor-nhse-outpatient-appointments-summary.pdf>

24. Downie, R., & Randall, F. Choice and responsibility in the NHS. *Clinical medicine* (London, England), 2008, 8(2), 182-185. Available at: <https://doi.org/10.7861/clinmedicine.8-2-182>

this view, patient choice over medication was seen as very risky, because it opened the door to patients being persuaded through advertising to choose certain medications rather than working with their doctor to do so.

So, what if the patient wants something else? They might be wrong!

Expert interviewee

Aside from this interpretation, we found consensus that patient choice over medication should in practice mean the existing policy of 'shared decision making', described as a process where the patient and doctor enter into a partnership and make a decision together, embracing the benefits of the patient being better informed and better invested in their care, while ensuring that the final decision is the best for the patient. However, we also picked up the sense from our expert interviewees that shared decision making was as much about wider treatment plans as about individual medications.

Patient choice is about the patient being informed and working in partnership with their doctors.

Expert interviewee

Patient choice in this sense is actually about giving patients agency over their own treatments, ensuring that they are both informed about their options and involved in the final decisions. Importantly, we picked up a sense that the doctor's role in shared decision making is to present patients with the best options available to them and for patients to then choose based on their preferences and trade-offs.

Patient choice doesn't truly exist without proper information. Uninformed patients are still subject to the recommendation of their clinician.

Expert interviewee

In this sense, patient choice is underpinned by the effective delivery of the right information to the patients in understandable terms.

Patient choice in this sense is actually about giving patients agency over their own treatments, ensuring that they are both informed about their options and involved in the final decisions.

...it means that you are actually discussing the choices available/clinically appropriate to the patient. If there are four choices available to them - you have to lay them out with efficacy and side effects.

Expert interviewee

When we explored with patients what having a choice over treatments meant in practice, a number of themes emerged as important, on a scale from having information, feeling involved, having choices and ultimately having agency and control.

However it was notable that while some people were sure that they needed clear options and agency, suggesting that the final decision should lie with them, for others 'patient choice' was actually more about having the necessary information to understand the doctor's decision and have a sense of involvement in that process, rather than having the final say.

HAVING INFORMATION

Most participants agreed that information was an important prerequisite for choice. This included being able to understand their conditions, the types of treatment that were available to them and why the doctor might decide to recommend a treatment or not. As one woman explained, the primary component of patient choice was being adequately informed:

I think for me it is being given enough information from the medical professionals to be able to make the choice yourself and make an informed choice.

Female focus group participant, 27

In fact, for a few participants, 'patient choice' did not mean anything more than being informed. To an extent, the idea of having the final choice did not exist for those patients: they thought the doctor should be the one in principle to make the final decision.

Every time I have had to go on any medication... they talk about it and they give me information about it... they have always sat there and explained to me the good, the bad, the ugly.

Female focus group participant, 58

For these participants, the idea of going further than simply being informed to the point that the patient made a conscious choice if anything

undermined the judgement and medical expertise of the doctor. The important part for them was being able to understand how and why the doctor was making decisions. As one participant explained, because a patient would never be as medically aware as a doctor, the next best thing for a patient was being able to discuss treatment and understand them as best you can to give your consent:

Even though you are not going to be anywhere near as informed as your doctor, at least you can be comfortable enough and able to discuss how you feel about something.

Male, focus group participant, 29

Conversely, people can feel disempowered through a lack of information. In this sense, not being armed with the facts was what had removed the possibility of making a choice over their medication or treatment: knowledge is a prerequisite for choice.

We found some direct personal, and sometimes painful, impacts as a result of not being adequately informed about the drugs patients had been taking. A few of our interviewees and focus group participants recounted that they had not been made fully aware of the side effects of a drug which then had caused them unexpected discomfort. As one 45-year-old woman explained:

My stomach ballooned up, and I was bad tempered all the time, suicidal, kind of really severe side effects. They didn't really discuss it with me.

Female focus group participant, 45

Similarly, a 75-year-old woman felt part of the reason why she had been on a drug for too long was because the doctor had not explained to her what she was taking and the side-effects that came with it:

I carried on for years and years taking that particular drug....They did not say, "We have found that this causes osteoporosis and you should stop," they just kept on prescribing it because it is easier.

Female focus group participant, 75

Others expressed frustration at not being involved in the process, as much as the final treatment decisions - reinforcing the idea that patients want to be involved throughout the decision making

journey, not just at the moment in which the decision to prescribe a medication or treatment is decided. This made them feel anxious and out of control during the diagnosis process.

I went in 3 times a week, but it was never really explained to me what these different tests were for.

Male interviewee, 28

Another interviewee had a similar experience when referred by a GP to other doctors without being informed why, and the types of conditions he might have:

[...] it was not being explained what was happening... It didn't come from a malicious or a lazy place, I think it was probably just a misjudgement from that GP as to how much information I might have wanted.

Male interviewee, 28

FEELING INVOLVED

In comparison, many participants felt that the phrase 'patient choice' went further than simply having the information to be actively involved in the decision. It should be noted that this did not mean that they thought the final decision necessarily lay with the patients but instead that they should be involved in the process of getting to the point at which the final decision was made. This definition took a less temporarily specific approach and saw choice more as a process in which the patient has a voice. For example, a 53-year-old man explained, patient choice meant a "two-way street", it was not necessarily a moment, but a dynamic between patient and doctor:

...it is about actually having a say in all stages of your treatment, not necessarily right at the beginning or, "I want X", whatever. I think it is a two-way street, and interaction between patient and doctor for the duration of that treatment, covering all aspects of it.

Male focus group participant, 53

I think it kind of means that we, or the patient, should have an opinion over our care or our medication that we are being prescribed.

Female focus group participant, 27

A number of participants defined this in terms of their relationship with their doctor and being able

to collaboratively work together to choose the right medication.

To me, it would mean being a partner in a relationship with your care team...I don't think it's like a paternalistic relationship anymore.

Female interviewee, 48, Ulcerative Colitis & IBD

In this sense some of the patients we spoke to defined patient choice in terms closer to 'shared decision making', where patients and doctors come to a decision together, with equal stakes in the final outcome:

I probably just want it to be more of a joint decision than going in and feeling like I am being told what to do. I want to make the decisions together with my GP.

Female focus group participant, 50

HAVING OPTIONS

Other participants took a more literal definition of patient choice, that it meant being presented with a number of options and offered a final decision over the one that was most appealing to them. As a 39-year-old interviewee explained, he felt that for patients to have choice, they needed to have options and to understand the pros and cons of each one:

...being given the two options of the drugs and being explained what the benefits and the negatives for both are, and then she can weigh it up herself.

Male focus group participant, 39

Many imagined being presented with a list of choices:

I like to be presented with information; I like choices...If there are other ways of doing it you should explore them. I hate being told what to do.

Male focus group participant, 53

...it would be the ability to choose options in an informed way.

Male interviewee, 23

And for those that were presented with clear options, the process can work well:

Yes, I think he was pretty clear in giving me the options and the side effects of each...he would prescribe me whichever one I chose.

Female focus group participant, 27

HAVING AGENCY

The strongest understanding of patient choice was that it should be synonymous with 'agency' and being the person who makes the final decision.

[choice is about] Having agency in the medical decisions that impact you.

Female interviewee, 23

...patient choice means that you have the ability and the agency to make your own decisions.

Male focus group participant, 29

[choice is about] having autonomy to make the decisions that's best for you as the patient but, kind of, in partnership with your clinical team.

Female interviewee, 29

Already we can see how different patients want to be involved to differing extents in how their medication is prescribed: some people feel they should be presented with options for ultimate patient decision, while others are primarily motivated by wanting to understand rather than decide. This begs the question of what level of patient choice is desirable in principle, the subject of the next chapter.

CHAPTER 2: IS PATIENT CHOICE OVER MEDICATION DESIRABLE?

KEY FINDINGS

- There is a strong case for maximum patient involvement in the choice of medication, both for reasons of financial efficiency and medical efficacy, as well as for ethical reasons.
- Our poll showed a majority (61%) of the public support joint decision making between patient and doctor over routine prescriptions.
- Separately, around three-quarters (74%) consider that the final decision ultimately lies with the doctor, with around half of those (36% of the total) believing their own views were not relevant to that decision.
- Those who feel the decision lies with the patient are more likely to feel strongly, be under 40 and on short-term medication.
- Those who prefer the doctor to make the decision may feel unqualified to do so and be overwhelmed by the responsibility.

There is a strong ethical case for patient involvement in decisions around their own health; the alternative - that they should have no involvement - goes against the fundamental principles of autonomy and dignity, not to mention bodily integrity.²⁵ There is also a significant body of academic literature that identifies its medical benefits.^{26,27,28} NHS England is explicit about the benefits of involving patients: their 2019 policy document on implementing comprehensive personalised care states that having “shared decision making about tests, treatments and support options” leads to “more realistic expectations [from patients], a better match between individuals’ values and treatment choices, and fewer unnecessary interventions”.²⁹ And the statutory guidance for NHS England clinical commissioning groups states:

By involving people in decisions about their health and care we will improve health and wellbeing, improve the quality of care and ensure people make informed use of available healthcare resources. Involving people in their own health and care not only adds value to people’s lives, it creates value for the taxpayer.³⁰

25. Davies B. Responsibility and the limits of patient choice. *Bioethics* 2020;34:459–466. Available at: <https://doi.org/10.1111/bioe.12693>

26. Elwyn G et al. Implementing Shared Decision Making. *BMJ*, 2010. Volume 341, *BMJ*. Available at: <https://repository.ubn.ru.nl/bitstream/handle/2066/88140/88140.pdf> p971,

27. Stacey D, Murray M, Légaré F, Sandy D, Menard P, O’Connor A. Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy. *Worldviews Evid Based Nurs* 2008;5:25-35.

28. Kennedy A, Sculpher M, Coulter A, Dwyer N, Rees M, Abrams K, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial. *JAMA* 2002;288:2701-8.

29. NHS England, *Universal Personalised Care: Implementing the Comprehensive Model*, 2019, p.7. Available at <https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf>

30. NHS England. *Involving people in their own health and care: Statutory Guidance for Clinical Commissioning Groups and NHS England*. Available at pp13-17 <https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-care-guidance.pdf>

The idea that there is an intrinsic value to patients having a significant say over their medications is one that was reflected by many participants in our qualitative research. This touched on the idea that being an informed agent in your own healthcare was something that was valuable in and of itself. Patients did not want to feel as though decisions were being forced upon them, regardless of what the decision was.

I probably just want it to be more of a joint decision than going in and feeling like I am being told what to do. I want to make the decisions together with my GP.

Female focus group participant, 27

For many participants, there was a strong ethical argument in favour of being involved, and as a result, a duty for doctors to show faith in their patients to know what was best for themselves, and make decisions on their own behalf, at least to an extent. People mentioned the knock-on benefits for their overall satisfaction and wellbeing in that patients would be more comfortable and speak freely if they felt their doctor trusted them, and would therefore feel more positive about their treatments.

I think it's to be open, the fact that you can openly say how you feel, what your fears might be so there is nothing being hidden.

Male interviewee, 53

PATIENT INVOLVEMENT AFFECTS OUTCOMES - AND ADHERENCE

At a healthcare system level, there is also evidence that greater choice can help use resources more efficiently and reduce the rate of unnecessary treatments that have poor outcomes.³¹ One of the mechanisms through which these positive effects occur is this direct connection between a patient's health and their sense of empowerment and confidence.³²

For many participants, there was a strong ethical argument in favour of being involved, and as a result, a duty for doctors to show faith in their patients to know what was best for themselves, and make decisions on their own behalf, at least to an extent

A randomised control trial in the US found, for example, that more informed patient decisions could reduce overuse of hip replacements, simultaneously relieving cost pressures and improving health outcomes.³³ The most recent (2020) GP patient survey shows that out of patients with long term conditions who have had the conversations necessary to agree a treatment plan with a healthcare professional, almost all (94%) said this plan was helpful in managing their condition(s).³⁴ There is also evidence that patients who are less involved in their health decisions have worse outcomes: research by National Voices, the coalition of health and social care charities, in 2017 concluded starkly that "the strongest correlation to ill-health... is health literacy".³⁵

There is also evidence that patients who have been more involved in their choice of medicine may be more likely to complete the treatment course: a relevant factor when the bill to the taxpayer from wasted medicines runs to hundreds of millions of pounds.³⁶ A 2015 survey found that two-thirds of people forget to take their medicines, costing around £500 million in lost health benefits and £300 million in wasted drugs.³⁷ Currently, there is a lack of awareness on the causes of nonadherence in patients.³⁸ It is, however, accepted that patients' involvement in decisions and good communication between patient and doctor, for example by ensuring that patients have more opportunities

31. O'Connor, A. M., Wennberg, J. E., Legare, F., Llewellyn-Thomas, H. A., Moulton, B. W., Sepucha, K. R., ... & King, J. S. (2007). Toward the 'tipping point': decision aids and informed patient choice. *Health affairs*, 26(3), 716-725. Available at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.26.3.716>

32. Person-centred care made simple: What everyone should know about person-centred care, Quick Guide, The Health Foundation. (2016). Available at <https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf>; Helping people share decision making: A review of the evidence considering whether shared decision making is worthwhile, The Health Foundation, (2012). <https://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf>; Elshaug, A. G., Rosenthal, M. B., Lavis, J. N., Brownlee, S., Schmidt, H., Nagpal, S., ... & Saini, V. (2017). Levers for addressing medical underuse and overuse: achieving high-value health care. *The Lancet*, 390 (10090), 191-202.

33. Arterburn, D., Wellman, R., Westbrook, E., Rutter, C., Ross, T., McCulloch, D., ... & Jung, C. (2012). Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Affairs*, 31(9), 2094-2104. <https://www.ncbi.nlm.nih.gov/pubmed/22949460>

34. NHS England. GP Patient Survey 2020. NHS England, 2020. Available at: <https://www.england.nhs.uk/statistics/2020/07/09/gp-patient-survey-2020/>

35. People and Communities Board to the Chief Executive of NHS England. A new relationship with people and communities: Actions for delivering Chapter 2 of the NHS Five Year Forward View. National Voices, 2017. Available at: <https://www.nationalvoices.org.uk/publications/our-publications/new-relationship-people-and-communities>

36. Hazell B & Robson R. Pharmaceutical waste reduction in the NHS. NHS England, 2015. Available at: <https://www.england.nhs.uk/wp-content/uploads/2015/06/pharmaceutical-waste-reduction.pdf> [accessed 01/08/2020].

37. Oswald, K. Non-adherence: medicine's weakest link. *Pharmaceutical Journal*, 2018. Available at: https://www.pharmaceutical-journal.com/news-and-analysis/features/non-adherence-medicines-weakest-link/20204378.article#fn_4 [accessed 28/09/2020]

38. Kassavou, A and Sutton, S. Reasons for non-adherence to cardiometabolic medications, and acceptability of an interactive voice response intervention in patients with hypertension and type 2 diabetes in primary care: a qualitative study, *BMJ Open*, Volume 7, Issue 8, 2017. Available at <https://bmjopen.bmj.com/content/7/8/e015597#ref-4>

to ask questions, are important to solving patient nonadherence.^{39,40}

We didn't ask a question specifically about non-adherence in our poll, but our qualitative research did pick up a sense that some people who either had not been adequately informed about their prescription, or involved in the decision to prescribe, had subsequently felt their only option was to 'vote with their feet' by not taking the drug, rather than to go back to their doctor. Importantly, those participants who described this type of voting with their feet were also participants who felt that it was not their place to be involved in decisions about their healthcare. This finding in itself provides both a health and financial reason to raise patient confidence in their choice of treatments as a policy aim.

They gave me these drugs, and it was not until I got back home and researched the drugs, and they were antidepressants. I was like, "Why are they giving me antidepressants?" I was fuming and I stopped them straight away.

Male focus group participant, 28

A rationale for patient involvement in the modern NHS can therefore be built around the double imperative of efficiency gains and improved healthcare outcomes. As the NHS begins to implement its recovery plan from the Covid-19 crisis, this point has not been lost: one of the

ways in which demand on services is being managed from autumn 2020 is to allow follow-up appointments after operations to be initiated by patients, should they want them, rather than the usual practice of making them mandatory.⁴¹ It should be noted that this relies on patients being empowered to take initiative to reach out, which could intensify health inequalities between those that take initiative and those that do not if it is not well-managed.

THE PUBLIC WANT DECISIONS ABOUT MEDICINES TO BE A JOINT EFFORT

Regardless of the ethical or resource implications, joint decision making is also popular. In our poll we asked a representative sample of the population which of the following four statements best represented their view regarding decisions about types of medicines or medical treatments:

- I would like to decide myself
- I would like to decide myself, informed by the doctor's advice
- I would like the doctor to decide, informed by my preferences
- I would like the doctor to decide

As Figure 1 below shows, a clear majority (61%) of the population chose one of the middle two options, where the decision is taken jointly between patient and doctor in some way, which could be

In general, which of the following statements best represents your view regarding decisions about types of medicines or medical treatments?

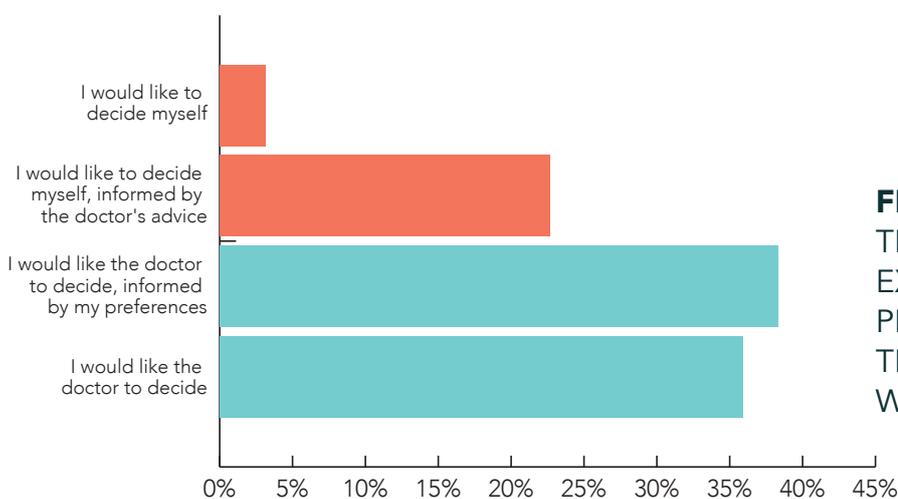


FIGURE 1. THE PUBLIC WANT AN INFORMED EXCHANGE OF ADVICE AND PREFERENCES; THREE-QUARTERS THINK THE FINAL CHOICE LIES WITH THE DOCTOR

39. Hsu, Clarissa, Jaclyn M. Lemon, Edwin S. Wong, Elizabeth Carson-Cheng, Mark Perkins, Margaret S. Nordstrom, Chuan-Fen Liu, Carol Sprague, and Christopher L. Bryson. Factors affecting medication adherence: patient perspectives from five veterans affairs facilities. BMC health services research 14, no. 1, 2014. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4239388/>

40. NICE. Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence, Clinical guideline. NICE, 2009. Available at <https://www.nice.org.uk/guidance/cg76/chapter/1-guidance>

41. NHS England. Implementing phase 3 of the NHS response to the Covid 19 pandemic. NHS England, 2020. Available at: <https://www.england.nhs.uk/wp-content/uploads/2020/08/20200807-Implementing-phase-3-jb.pdf>

interpreted as providing strong support for a “shared decision making” model. Within this we found that people on medication - both for short and long-term conditions - were more likely (65%) to choose one of the middle options than people on no medication (59%).

The importance of a joint decision was shared by many in our focus groups. For example, one participant recounted that she had had two different treatment options, one of which was higher risk and more invasive but had the potential for more immediate benefits than the other. She explained that she had gone for the riskier option because her personal priority was knowing whether the treatment was working and being able to see immediate effects. For her, her involvement was essential because she and the doctor had different expertise that were both important:

They're the experts in what's clinically right. But I'm the expert in what I want.

Female interviewee, 29

Similarly, other participants felt that trust needed to cut both ways: patients needed to trust doctors but doctors also needed to trust patients to know themselves and their needs.

You have to trust the patients to know themselves

Male interviewee, 28

THE POPULATION IS MORE PATERNALISTIC THAN THE OFFICIAL POLICY...

What is also notable about these headline polling results, however, is the large proportion of the population who would like the ultimate decision to be made by the doctor. Three-quarters of the population (74%) said that the ultimate decision lies with the doctor, of which half (38%) think the doctor's decision should be informed by their preferences, meaning that over a third (36%) of the population want the doctor to decide without their own preferences even being part of the equation.

In our poll, people on short-term prescriptions emerged as particularly likely to think that the final decision lies with the doctor (83%) compared to those with long-term conditions (75%) and those on no medication (71%).

These results are in stark contrast to the definitions of patient choice and shared decision making that

emerged from our expert interviews, as reported in the previous chapter, where the consensus view was that the final decision should lie with the patient working in partnership with the doctor. They also sit uncomfortably with the words of the GMC's Medical Director and Director of Education and Standards, Professor Colin Melville who, when launching their new guidance for the key components of effective communication: “vital to help patients make decisions that are right for them”. In fact our poll showed that only 26% of the population thought the decision was ultimately theirs to make.

Our qualitative work picked up some of the reasons behind these paternalistic views: they centred on the patient not feeling equipped with sufficient medical expertise to do so.

..if I did have different views, I probably wouldn't have wanted to take them into account myself because they were ill informed and uneducated.

Male interviewee, 23

These opinions often followed from the fact that doctors trained for several years and therefore knew incomparably more than the patient when it came to understanding their condition and their medical options. In that sense many felt they needed to trust their doctor's judgement without any personal input. As one interviewee described, doctors almost by definition must be trusted to make decisions:

...they are a doctor and you have to trust them.

Male interviewee, 24

I would trust my GP to prescribe for me. I always trust them to do it.

Female focus group participant, 50

For some participants, the idea that they should be involved in decisions about their care was something that they had not even contemplated.

I think doctors study for years and years, and I have never done, so I just take their word and I would never consider looking up the contents [of the medication]

Female focus group participant, 75

This sense of lack of knowledge is understood within the profession: in discussions with experts, some explained that a knowledge imbalance was a key barrier to patients feeling able to get involved

in decisions about their healthcare - as they simply felt that they were beyond them.

It [the patient-doctor relationship] has been paternalistic, and it flows from the fact that they know much more

Expert interviewee

...PARTICULARLY AMONG OLDER PEOPLE, AND PEOPLE WITHOUT DEGREES

Having said that, we found variations in paternalistic attitudes across different demographic groups. Men were significantly more likely (41%) to want the doctor to decide without their own preferences considered than women (31%). Those in lower social grades were more likely to want the doctor to decide; 40% of people in C2DE groups wanted the doctor to decide without taking their views into account, compared to 33% of ABC1 respondents.

We also found the desire to be involved in decisions about treatments and medications

We also found the desire to be involved in decisions about treatments and medications differed across generations and education levels, with older generations and those without degrees being more inclined to want the doctor to decide without the patient.

differed across generations and education levels, with older generations and those without degrees being more inclined to want the doctor to decide without the patient (see Figure 2 and Figure 3 respectively). Given that older people in general are less likely to have had the opportunity for further education, and given the insights from our qualitative work about some people having a strong sense that their views are uninformed, we suggest that it is the levels of education that are the driving factor here.

"I would like the doctor to decide."

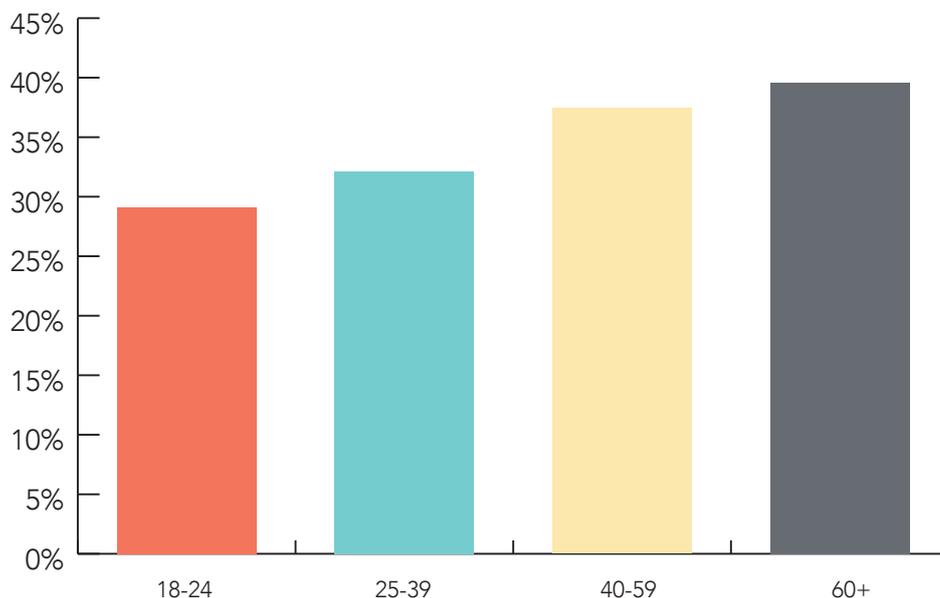
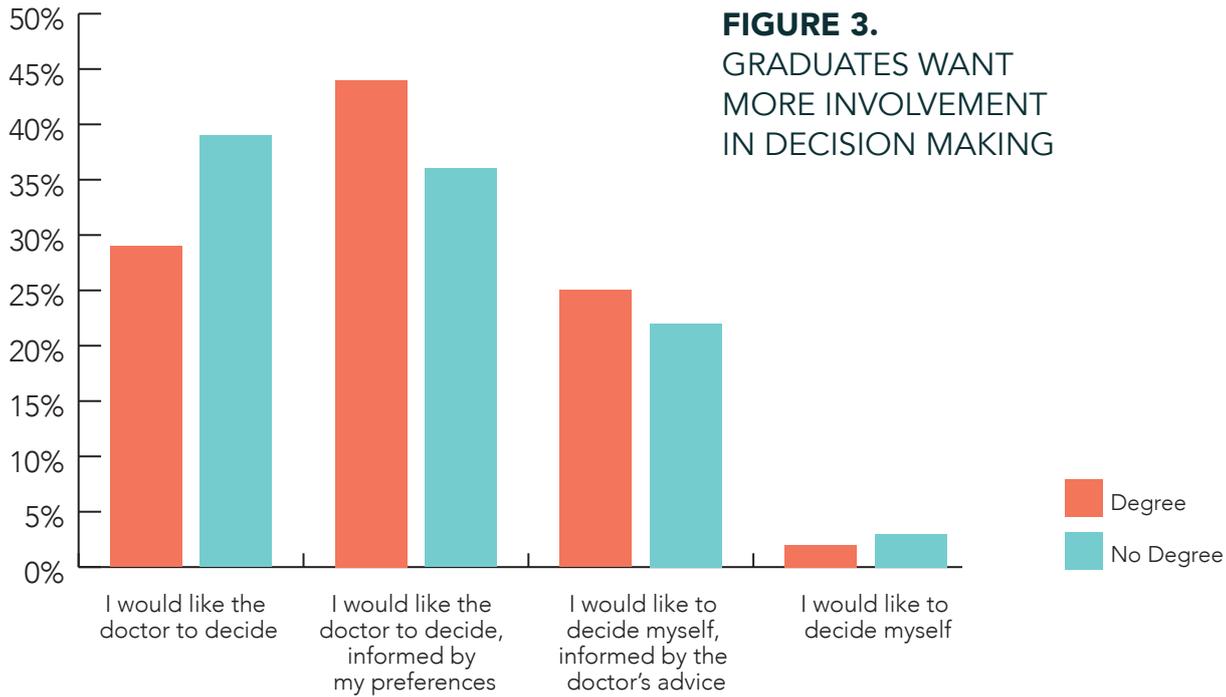


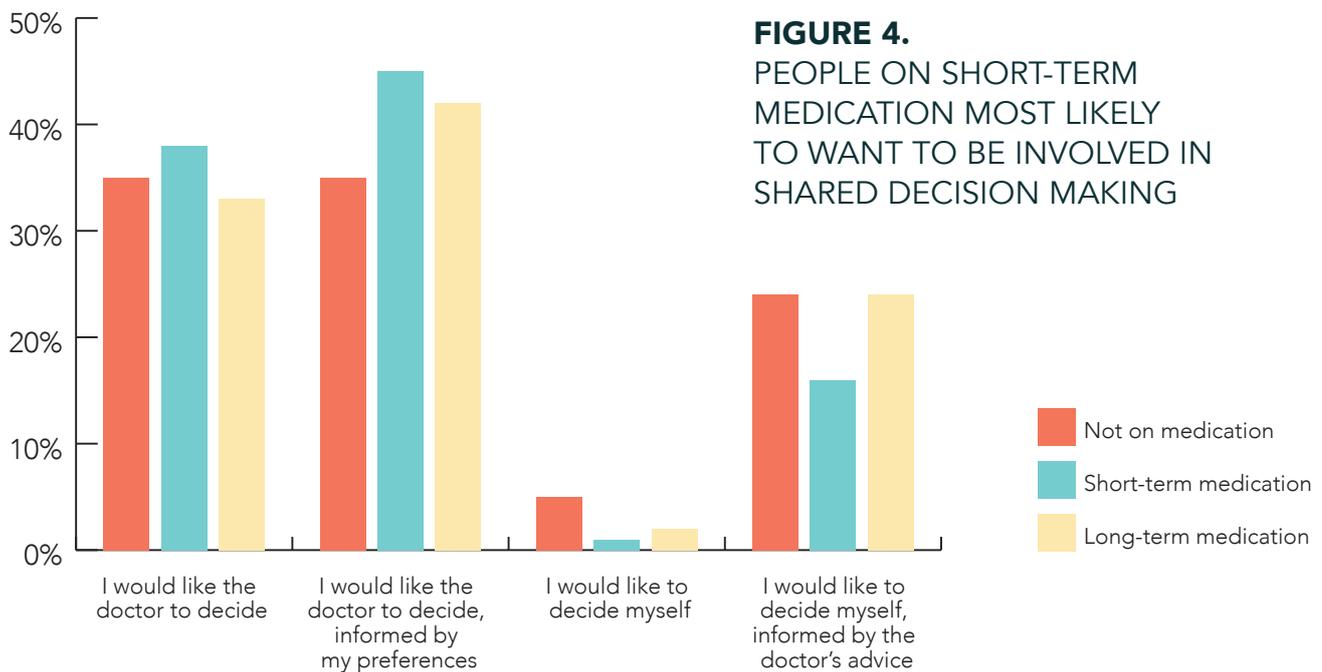
FIGURE 2.
OLDER PEOPLE ARE MORE LIKELY TO VIEW THE DECISION SOLELY AS THE DOCTOR'S



Those currently on short-term medications were more likely than the population average to support a collaborative model, with 45% of those on short-term medications choosing: "I would like the doctor to decide, informed by my preferences" compared to 40% for the population as a whole,

those on long-term medications were similarly likely to (42%) see Figure 4. Those on long-term medications, in comparison, were more likely to want to decide themselves (24%) than those on short-term medication (16%).

In general, which of the following statements best represents your view regarding decisions about types of medicines or medical treatments?



...BUT THOSE WHO VALUE THEIR RIGHTS TO CHOOSE DO SO STRONGLY

In order to try and expose who should have the final say when it came to deciding on the most appropriate medicine, we asked a hypothetical trade-off question where people were forced to choose between two statements; one of which gave the ultimate power to the doctor, and the other to the patient. For each option, participants could also indicate how strongly they held their view.

The statements were:

Option A: Patients should have the right to any medicine that is available on the NHS that they consider might help their condition

Option B: Doctors should be able to deny patients a medicine that is available on the NHS if they think there is something else that is more suitable

The results gave an even split between the final say lying with the patient (option A, 51%) and the final say lying with the doctor (option B, 49%) again supporting the view that the population as a whole think that decisions should be made jointly.

Nonetheless, as Figure 5 demonstrates, it is also notable that those people choosing option A (the patient's right to choose) held their opinions more strongly than people choosing option B (the doctor's right to deny).

When faced with this forced choice, almost a third (29%) of the population felt strongly that patients should have a right to any NHS medication that they felt could help their condition, around twice the proportion who felt strongly that a doctor should be able to deny patients an NHS medication if they felt there was a better alternative (15%). We also found that patients on short-term medication were more likely to feel that the final decision lay

Option A: Patients should have the right to any medicine that is available on the NHS that they consider might help their condition

Option B: Doctors should be able to deny patients a medicine that is available on the NHS if they think there is something else that is more suitable

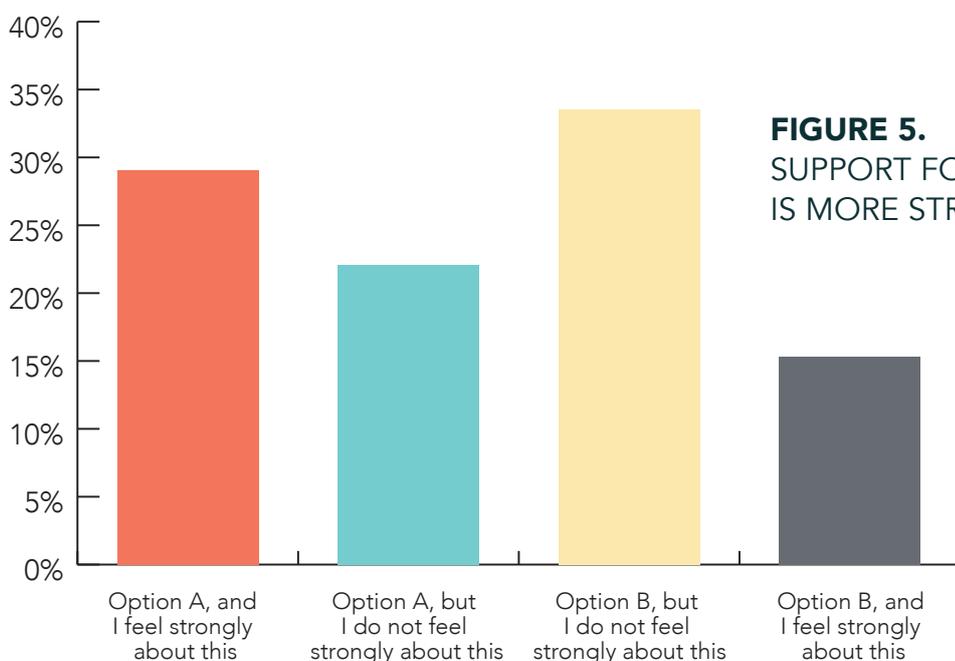


FIGURE 5.
SUPPORT FOR OPTION A IS MORE STRONGLY HELD

with the patient (70%) than those on long term medication (49%). This could be driven by age - as those on short-term medication are more likely to be younger than those on long-term medication.⁴²

This strength of feeling came through in some of our qualitative work too. While many patients demonstrated great faith in the judgements of their doctors, some believed that there were occasions when it was important to challenge their doctors, using strong language to make their case:

You know, gone are the days where the doctor is always right...just because they have 'Doctor' in front of their name, does not mean they are God, believe you me. You should challenge, challenge, challenge.

Male focus group participant, 53

Others felt passionately that they were in a unique position to understand the trade-offs in terms of what they were experiencing and the risks of certain treatments and therefore should get the ultimate say. As one female focus group participant explained, she is best placed to assess the risks because only she can quantify the level of pain:

I should be allowed to make that choice myself where the risk outweighs where I was suffering with it.

Female focus group participant, 50

In summary, there appears to be a strong theoretical case for patients participating fully in decisions around which medications they are prescribed, and at a high level we found a consensus between practitioners and patients that decisions should indeed be joint.

However where official policy suggests that the ultimate decision should lie with the patient, the population as a whole demonstrates a high level of comfort with the idea that the final decision lies with the doctor - suggesting a lack of policy implementation in addition to a lack of desirability among patients. We also found a significant minority - who were more likely to be younger and/or on short-term medication - who felt strongly that the balance of power over the final decision should lie firmly with the patient.

In the next section we consider arguments against patient choice of medication, as expressed by experts and patients alike.

...patients having too much choice could mean patients facing the 'tyranny of choice', with far too many options and too much responsibility causing them psychological stress when they are already in a vulnerable position.

DISADVANTAGES OF GREATER PATIENT CHOICE

As a starting point, there is some evidence in the literature that attitudes of practitioners may act as a brake on choice in some areas, suggesting that paternalistic attitudes may run both ways. Qualitative research undertaken by Eurobarometer in 2012 found a view amongst doctors that "patients would be confused if given alternatives or would have less faith in the treatment proposed". Concerns were raised that more input from the patient – potentially based on inaccurate information gleaned from the internet – could mean patients disagreeing with the healthcare expert and refusing the best treatment.⁴³

In our own expert interviews, we occasionally sensed a degree of scepticism around the value of patient choice, rooted in a fear that it could bring more harm than good. Primarily, these practitioners saw the doctor's role as one of providing care, a concept which included doctors taking on responsibility for their patients' healthcare decisions. A number of people we spoke to expressed the concern that if patients were presented with too many options then they ran the risk of being overwhelmed.

Choice paralyses people, more than five choices paralyzes people.

Expert interviewee

For them, patients having too much choice could mean patients facing the 'tyranny of choice', with far too many options and too much responsibility causing them psychological stress when they are already in a vulnerable position.⁴⁴ As one expert interviewee explained, when patients are seeing a doctor, they are going there to be cared for - it is therefore unfair to expect them to take on the responsibility for their treatments, with the associated risks.

42. For example, in our poll 70% of those aged 60+ said that they were on a long-term medication, compared with 21% of those aged 18-24.

43. Eurobarometer Qualitative Study on patient involvement in healthcare. European Commission, 2012. p4, Available at https://ec.europa.eu/eip/ageing/library/eurobarometer-qualitative-study-patient-involvement-healthcare_en

44. Renata Salecl, *The Tyranny of Choice*, Profile Books, London, 2010.

...shared decision might be useful, but it is not a priority[...]the whole point of healthcare is you need someone to look after you.

Expert interviewee

Previous research by the Health Foundation (2012) identified other concerns, such as around equity and fairness: patients who are better educated and/or from a higher socioeconomic background have been found more likely to exercise their choice right and therefore obtain the benefits.⁴⁵ However, because those patients who are less educated tend to be less confident to get involved, they also stand the most to gain from more deeply embedding shared decision making in the prescription process, by ensuring that they are involved.⁴⁶

It seems possible therefore that the policy of shared decision making is an example of a “polyvalent” idea, a sociological concept which describes an idea commanding superficial but not deep agreement between different stakeholders.⁴⁷

Similarly, our qualitative work also exposed some reservations amongst the public around patients being involved in decisions about their medical treatment. While many could see an intrinsic value, others felt that the risks could outweigh the advantages. In particular concerns were expressed that having too much choice at a time when people were already vulnerable could negatively affect health and wellbeing. As one male participant explained, having a lot of options could be anxiety-inducing, especially when you are first presented with a diagnosis:

[it is] probably a bad thing to have a lot of choice because you are overwhelmed and you are in a very vulnerable situation when you are first diagnosed.

Male interviewee, 24

Similarly, some were able to put themselves in other people’s shoes, imagining that the strain of taking on responsibility for healthcare decisions would not always be appealing to people:

Now, some people are not going to be able to take that sort of information in and understand these trade-offs, so I accept there are some people where the only option is to tell them what to do.

Male focus group participant, 53

The notion of having too many options was controversial among participants. Indeed, for some, the idea that patients choose medications from a list of options felt wrong in principle: patients would not necessarily be able to pick the best option for treatment, and there could be resourcing issues for the system as a whole.

What I don’t necessarily think it should mean is that you get to pick and choose exactly what drugs you want.

Male interviewee, 28

...if they just gave them out to everyone then that would just put so much strain on the whole system.

Male focus group participant, 39

CONCLUSIONS

Those patients who do not want to be involved in their choice of medication are primarily concerned that they would make the wrong choice. They worry that they would not be able to understand the information or that their opinions are not valid when compared to the superior knowledge of the doctor. As a result, it seems that patients who do not want to be involved feel that this is a rational decision on their own part. This begs the question that if they felt more confident, would they perhaps want greater involvement - we address this question of empowerment in Chapter 8.

Nonetheless, while many did not want to make the final decision or final ‘choice’, there is strong support for something more nuanced: being informed agents throughout the process, with the option to make the final decision if they want to. This suggests that government policies to promote shared decision making including an assessment of how much involvement a patient wants to have are ones that the public support and feel are important to protect. Within this, certain groups, such as those who are younger or on short-term medication, are particularly supportive of patient choice, and for this

Those patients who do not want to be involved in their choice of medication are primarily concerned that they would make the wrong choice.

45. Helping people share decision making: A review of the evidence considering whether shared decision making is worthwhile, The Health Foundation, (2012). Available at <https://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf>; Boyle, D. The barriers to choice review. How are people using choice in public services? Cabinet Office, 2013. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/80070/Barriers_to_choice_review_0.pdf

46. Coulter A & Collins A, Making Shared Decision-Making a Reality. King’s Fund, 2011, p.34. Available at: https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

47. Slade, M. Implementing Shared-Decision Making in routine mental healthcare. UoN, 2017. P150, Available at: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/wps.20412>

cohort the right within the NHS Constitution to any appropriate medication is particularly important.

More difficult for policymakers is the fact that so many people in England want their doctor to decide their treatments, with a significant proportion preferring not to be involved in this decision. This is a complex challenge if we start from the premise that greater patient involvement supports both clinical outcomes and efficiency, and suggests the need for concerted efforts to boost patient empowerment.

Before we consider how this could be done, we first of all explore whether patients have in practice felt involved in decisions around medication (regardless of whether they view it as objectively desirable) and, separately, whether they view their level of involvement as sufficient.

CHAPTER 3: WHAT CHOICE DO PATIENTS CURRENTLY HAVE OVER MEDICATION?

KEY FINDINGS

- There is little formal data collection around the extent to which patients routinely feel they have had a conversation with their doctor about options for medication treatment.
- Our survey showed that out of people who visited the doctor and were prescribed medication at least once in the last year around a third stated that they were **always** presented with options but nearly a quarter stated they **never** were, with a mixed picture for the remainder.
- Younger people are slightly more likely to be presented with options than older people.
- Even when choices are presented, in practice they may not be meaningful.

We know that a decade ago, shared decision making was not widespread: a study of GP prescription processes undertaken, in 2010, found, for example, that shared decision making was limited.

It seems that a strong argument can be made for the benefits of involving patients in the choice of their medicines and treatments. The extent to which they are involved however is a different question, and one which this research project aims to address, not least because existing evidence is patchy.

We know that a decade ago, shared decision making was not widespread: a study of GP prescription processes undertaken, in 2010, found, for example, that shared decision making was limited.⁴⁸ A consultation from the Department of Health in 2012 pointed out that policy reforms thus far had failed to effectively involve patients in decisions about their healthcare, arguing that “providing greater patient choice, be it over a clinical team, setting, location or provider” did not equate to the widespread adoption of shared decision making.⁴⁹ In the same year, the Health

48. Stevenson, F. and others. Doctor–patient communication about drugs: the evidence for shared decision making. *Social Science & Medicine*, 2000, 50(6), 829–840.

49. Liberating the NHS: No decision about me, without me. The Department for Health, 2012, p.1. Available at 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

Foundation suggested that patient choice over their medication had not happened in practice.⁵⁰

Around the same time, evidence was collected from patient groups that demonstrated people do not always have access to NICE-approved medication. A survey conducted by National Voices in 2013 of patient groups found “a minimum of 1,116 cases of patients reported being unable to access NICE-approved treatments. Adding the national to the regionally reported instances, that is a minimum of 4,928 affected patients.”⁵¹

More recently a survey of 645 people with Rheumatoid Arthritis (RA), conducted by the National Rheumatoid Arthritis Society (NRAS), found that out only 7% were given a choice at the first consultation over the way they ingest the treatment - in this case it was between weekly injections or weekly tablets.⁵²

There is no mechanism to monitor whether CCGs comply with NICE guidelines in terms of making all approved medications available to

Did your doctor have a conversation with you about the different options for medical treatment that might be appropriate for you?

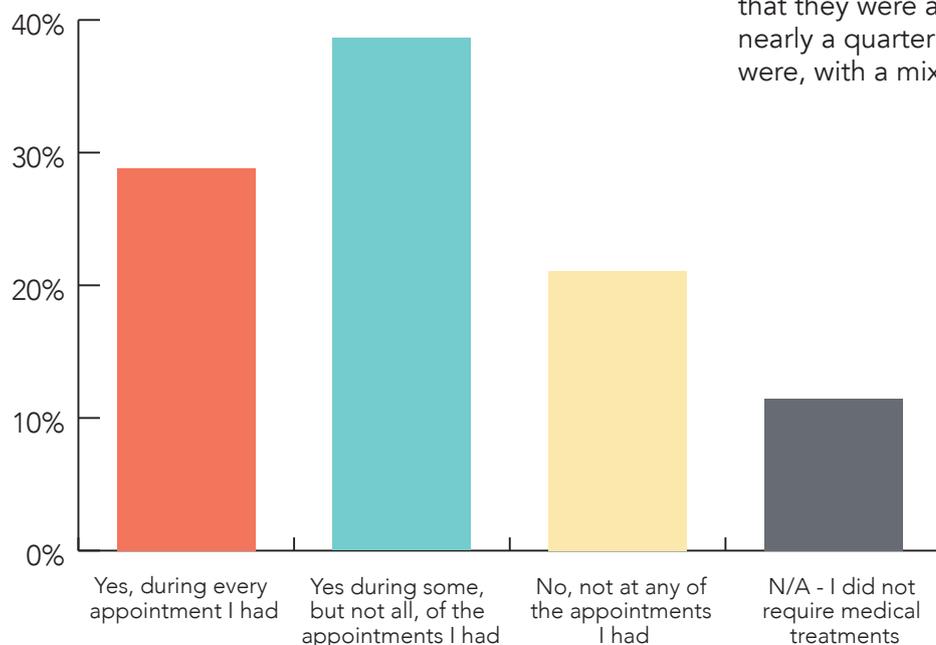


FIGURE 6. THERE IS WIDE VARIATION IN WHETHER PATIENTS FEEL THEY HAVE OPTIONS

Base: Sample of 1,550 adults who said they had seen a doctor in the last year drawn from a nationally representative sample of 2019 adults in England interviewed online 29 July 2020 - 7 August 2020.

patients in practice. The nearest we get to this is the NHS Innovation Scorecard that monitors the difference between the volume of common medicines that would be expected to be prescribed if the NICE recommendations are followed, and actual prescription levels for each one. The most recent report, covering 2018-19 indicates some divergence, which could be due either to patients exercising choice or conversely by clinicians not following NICE recommendations for a variety of different reasons.^{53,54} That there may be some way to go is evidenced by a 2016 report published jointly by NHS England and Health Improvement, which stated that “improving the information available for patients, ensuring that they are consistently offered a choice, and raising their awareness - particularly of their legal rights - are ...high priority.”⁵⁵

In our poll, we asked people who had had at least one doctor’s appointment in the previous year (76% of the total sample) whether that doctor had had a conversation with them about the different options for medical treatments that might be appropriate. We found around three in ten (29%) had on every occasion, around two in ten (21%) never had, and around four in ten (39%) sometimes had (see Figure 6). Alternatively, of those who were prescribed medication on at least one visit to the doctor in the last year, around a third (29% out of 89%) stated that they were always presented with options but nearly a quarter (21% out of 89%) stated they never were, with a mixed picture for the remainder.

50. Da Silva, D. Helping people share decision making: A review of the evidence considering whether shared decision making is worthwhile. The Health Foundation, 2012. Available at <https://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf> [accessed 01/10/2020]
 51. Don Redding, Teeth in the NHS Constitution: the case of the right to NICE approved treatments, National Voices, 2013, p.26. Available at <https://www.nationalvoices.org.uk/sites/default/files/public/publications/teeth-in-the-nhs-constitution.pdf>
 52. The National Rheumatoid Arthritis Society, Medicines in Rheumatoid Arthritis, 2017, p.10. Available at <https://www.nras.org.uk/data/files/Publications/RAAW%2017/30108%20Medicines%20in%20RA%20Booklet%20A5%20%28PrF5%29.pdf>
 53. Don Redding, Teeth in the NHS Constitution: the case of the right to NICE approved treatments, National Voices, 2013, p.26. Available at <https://www.nationalvoices.org.uk/sites/default/files/public/publications/teeth-in-the-nhs-constitution.pdf>
 54. NICE Technology Appraisals in the NHS in England (Innovation Scorecard) - To September 2019, GOV.UK. 2020. Available at <https://www.gov.uk/government/statistics/nice-technology-appraisals-in-the-nhs-in-england-innovation-scorecard-to-september-2019>
 55. Securing meaningful choice for patients: CCG planning and improvement guide, NHS England and NHS Improvement. NHS England, 2016, p.2. Available at <https://www.england.nhs.uk/wp-content/uploads/2017/01/choice-planning-guidance.pdf>

We then explored the same questions in our qualitative research, to better understand how patient choice is experienced on the ground and how close it matches up with expectations and desires. Participants described a vast range of experiences, from those who had felt that they were completely involved in decisions and able to choose the right medication to those who had felt exasperated that their personal preferences had not been taken into account by their doctor.

Yes, they are very much taken into account... when I go into my consultant appointments, he'll basically say, "Right, where are we at? What has been happening?" and he will take any conversations I have had with him in between, any WhatsApp messages I have sent him, and he'll have a think about it.

Male interviewee, 38

..at the time, it was very much, "This is what you have to do." Obviously, being someone who had no idea about the disease, it was very much a, "Okay, yes, I'll take your word for it."

Male interviewee, 23

Of course, a simple polling question cannot reflect the complexity of reasons why people visit their GP, but given that we also provided an option for people to indicate if no medication was required (11% of total), the results do suggest that people do not always feel that they were presented with real choices around treatment options.

We did find however that younger people were slightly more likely to have had a conversation with their doctor about the different options for medical treatment than older people (see Figure 7 below) and separately that graduates were slightly more likely to have had a conversation with their doctor (73%) about the different options for medical treatment (some or all of the time) than non-graduates (65%).

"No, not any of the appointments I had."

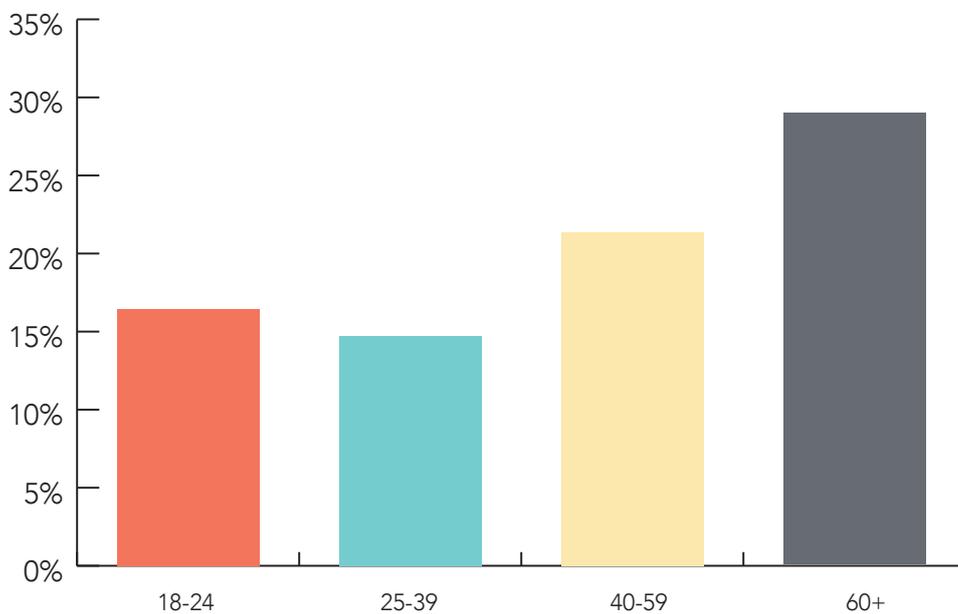


FIGURE 7.
YOUNGER PEOPLE WERE MORE LIKELY TO HAVE HAD A CONVERSATION ABOUT OPTIONS

The contextual nature of the ability of patients to be involved in decisions around their health came through clearly in our qualitative research. Participants regularly explained the nature of their condition and the state of their health set the terms, and often meant that they were unable to go through a decision-making process in the normal sense of the phrase. We picked up a sense that although people believed that in principle the final decision was theirs, in practice they couldn't exercise it. One of our experts suggested that this was essentially a 'Hobson's Choice', where although the patient has the legal prerogative to make the decision, in reality, they can only take the doctor-recommended route.

Sometimes the options presented feel like 'Hobson's Choice' between accepting doctor-recommended treatment or worsening condition. Choice is not just about listing options - doctors must put things into perspective for the individual patient and help them categorise risk.

Expert interviewee

I wouldn't really call them decisions, because I was told 'take this medicine, it should help'. It's not a decision, because you want to do anything to not be ill.

Female interviewee, 48

He gave me two options basically to either take it in advance before the actual pain has happened or whilst the pain is happening take those pills. But those were the only options that I really had, to be honest.

Male focus group participant, 36

"He gave me two options basically to either take it in advance before the actual pain has happened or whilst the pain is happening take those pills. But those were the only options that I really had, to be honest."

Male focus group participant, 36

We conclude that there is a mixed picture across the population as to whether people feel they are presented with different options for medical treatment when they visit their doctor, with younger people slightly more likely to be presented with options than older people and even when choices are presented, in practice, they may not be meaningful.

CHAPTER 4: DO PATIENTS WANT MORE CHOICE THAN THEY CURRENTLY HAVE?

KEY FINDINGS

- There is strong evidence that many people are as involved in the decisions about their medication as they want to be, but there is also a significant minority of predominantly younger individuals who want to be more involved.
- More than 3 in 5 (62%) of the population are content with their level of involvement in the decision-making process around the prescribing of their most recent medication.
- 3 in 10 would have liked to be more involved, rising to 4 in 10 for those under the age of 40.
- A majority (58%) of those currently on short-term medication wanted to be more involved.
- People under 40 (50%) and those on short-term medication (66%) are more likely to disagree with their doctor than the general population (35%).
- While obtaining a second medical opinion is rare, it was also more common amongst younger cohorts.
- We also found that most patients (65%) routinely engage in a soft informal process of checking the advice they get from their doctor, indicating a generalised desire to feel more informed about the decisions that are made.

One of the key parts of the emerging picture is that some patients - albeit a minority - are seeking a greater sense of agency and control over the final decision around the medications they are prescribed than others. As we saw in previous chapters, younger people and those people with higher levels of education appear more likely to believe that the final decision lies with the patient,

and older people are less likely to feel that they have been offered choices when they visit their doctor.

Given that, as we saw in the introduction, the NICE guidance states that doctors should "establish what level of involvement in decision making the patient would like" it may therefore be that the system is

working well, with patients making a conscious and rational decision to engage at the level that they deem appropriate given their self-assessment of their ability to contribute.

To explore whether this is indeed the case, we asked a series of questions in our poll as follows:

- Thinking of the most recent time you were prescribed medication or treatment, would you have preferred to be more or less involved in the decision about which medication was chosen, or was your level of involvement about right?

- When you get advice from your doctor, how frequently, if ever, do you disagree with their advice?
- When you get advice from your doctor, how frequently, if ever, do you obtain a second medical opinion from another doctor?

On first impressions, our survey suggests that for the majority the system works pretty well. The majority (62%) stated they were adequately involved in decisions about which medication was chosen (see Figure 8); the same proportion (62%) stated they rarely or never disagreed with their doctor (see Figure 9); and we also found that most people (72%) rarely or never obtain a second medical opinion from another doctor.

Would you have preferred to be more or less involved in the decision about which medicine was chosen?

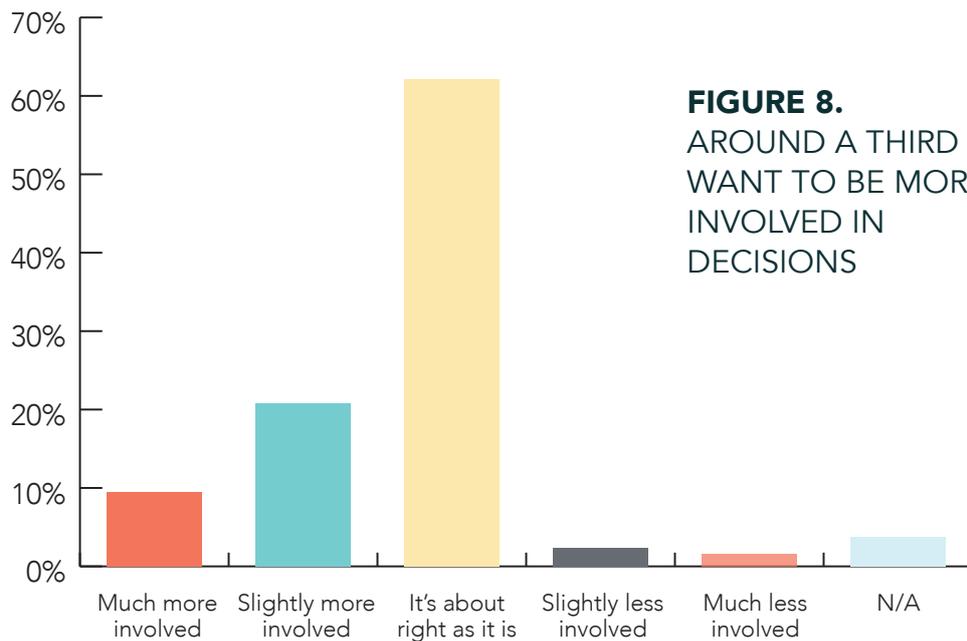


FIGURE 8.
AROUND A THIRD
WANT TO BE MORE
INVOLVED IN
DECISIONS

How frequently, if ever, do you disagree with the doctor's advice?

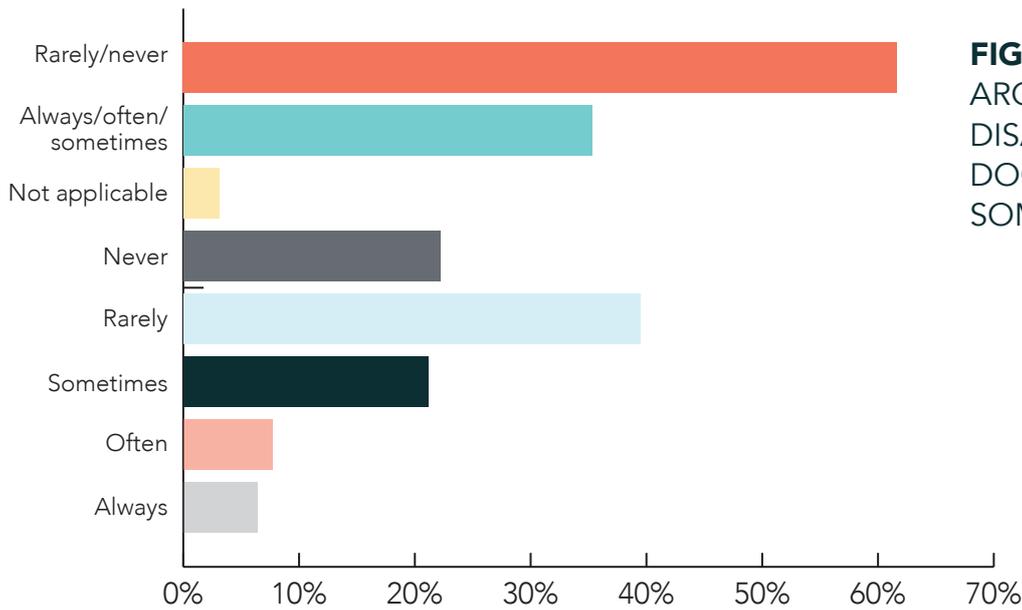


FIGURE 9.
AROUND A THIRD
DISAGREE WITH THEIR
DOCTOR AT LEAST
SOMETIMES

THERE IS A SIGNIFICANT MINORITY - MAINLY YOUNGER - WHO WANT TO BE MORE INVOLVED

However, for a significant minority, in particular younger cohorts and those on short-term medication, a different picture emerges. While three in ten of the population said they wanted to be more involved in the most recent decision about their medication or treatment, this rises to four in ten of the population under the age of 40 (see Figure 10).

I would like to be more involved in decisions about what medication or treatment was chosen (combined).

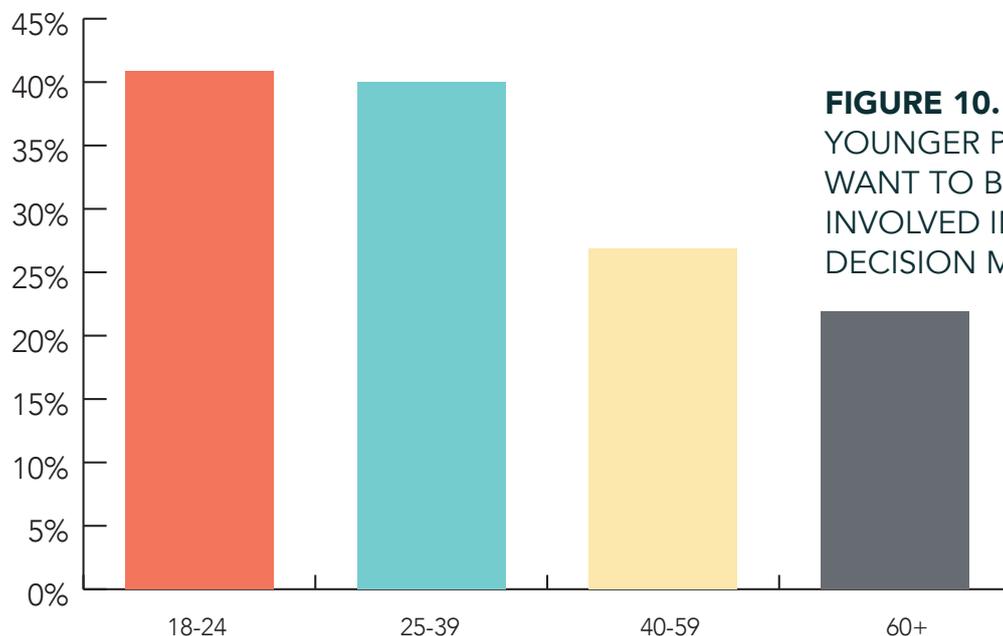


FIGURE 10.
YOUNGER PEOPLE
WANT TO BE MORE
INVOLVED IN
DECISION MAKING

Similarly, younger people were significantly more likely to disagree with their doctor's advice at least sometimes (see Figure 11).

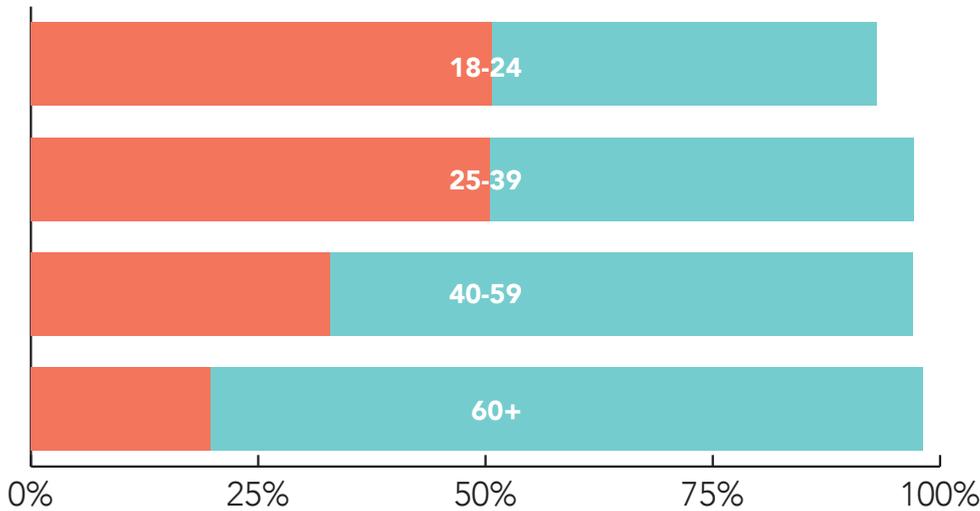


FIGURE 11. PROPORTION OF THOSE WHO HAVE DISAGREED WITH THEIR DOCTOR'S ADVICE (ACROSS AGE GROUPS)

Always/often/sometimes
Rarely or never disagreed

We also found a dramatic difference by age when we looked at the propensity for people to obtain a second medical opinion. Nearly half (48%) of 18-24 year olds obtained a second medical opinion at least sometimes (with 1 in 5 doing so "often"), compared to only 6% of over 60s (see Figure 12).

When you get advice from your doctor, how frequently, if ever, do you obtain a second medical opinion from another doctor?

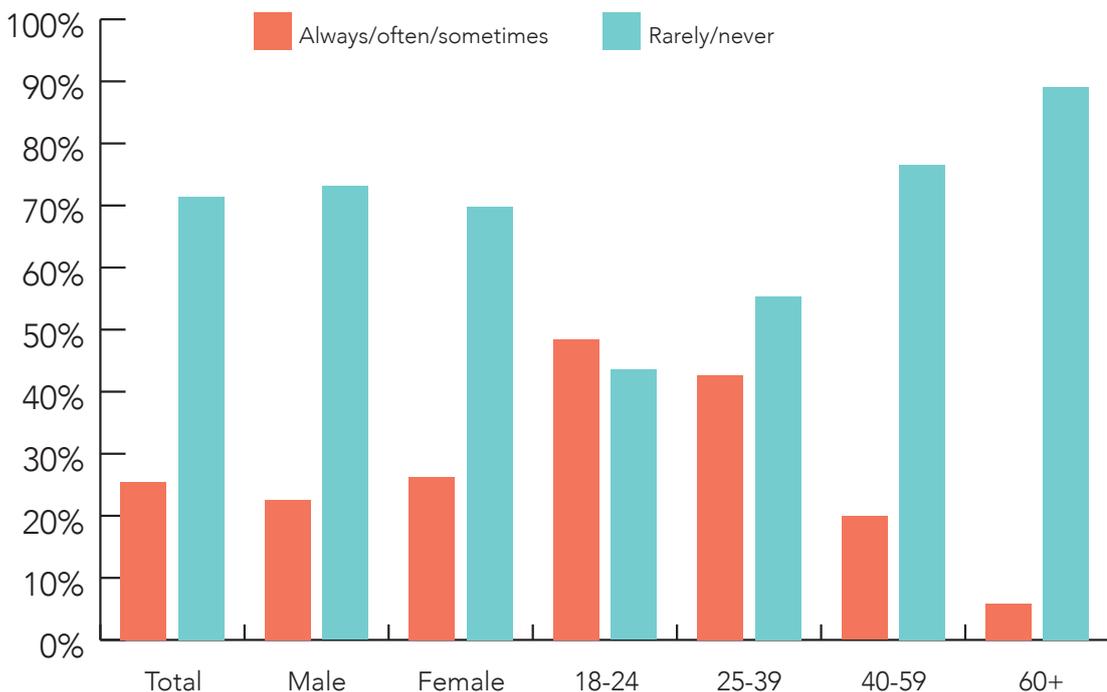


FIGURE 12. YOUNGER PEOPLE ARE MORE LIKELY TO SEEK A SECOND OPINION

Perhaps reflecting the fact that younger people are less likely to be on long-term medication, we also found that people on short-term medication are more likely to be seeking greater control over their medication decisions. We found that a majority (58%) of people on short-term medication wanted to be more involved in the decision over which medication was prescribed whereas just under a quarter (23%) of those on long-term medication wanted to be more involved. Similarly, around two-thirds (66%) of people on short-term medication said that they disagreed with their doctor at least sometimes, this is more than double those on long-term medication (31%). Two-thirds of people on short-term medication (66%) also obtained a second opinion from another doctor at least sometimes, compared to a mere 18% of people on long-term medication.

Although our headline satisfaction metrics around patient involvement are strong, they are weaker than the equivalent satisfaction scores that come from NHS-commissioned GP survey data (2019), which showed that 93% of patients were “involved as much as they wanted to be in decisions about their care and treatment”.⁵⁶ However previous qualitative research conducted by Eurobarometer did pick up a desire by patients for more information and options with regard to treatment, and a more open dialogue with health professionals.⁵⁷

Our results are also different to previous research around whether the nature of a person’s condition affects their level of involvement. A Cabinet Office paper in 2013, for example, reported that patients with long-term conditions wanted to be more involved than others, whereas our results point to the opposite conclusion, and are more in line with GP patient survey results that demonstrate only 4 out of 10 patients with long term conditions said that they have had a conversation with a healthcare professional about what is important to them when managing their condition(s).^{58,59} This could be related to the age of people with long-term and short conditions in our survey, with the latter being more likely to be younger - suggesting that age is more of a factor in driving patient’s desire for involvement than their type of condition.⁶⁰ It is also worth noting that although we found that

people with shorter-term conditions wanted to be more involved in decisions, they also were more likely to think the final decision lay with the doctor. Alternatively, people on short-term medication may have been disproportionately affected by the changes in the ways that GPs were working during the first phase of the pandemic (see Appendix 1).

Our focus groups picked up some examples of individuals who, despite wanting to be involved, and making the effort to inform themselves about other treatment options, had felt that they had not been given access to certain treatments that they felt they should have been. Given the small sample sizes of qualitative research, the fact that we found examples of people not being as involved as they would like, suggests that the headline figures in the GP survey data may not reflect the lived reality of patient experiences.

We found some difficult cases of patients reporting that their own life decisions and important personal preferences had not been part of the discussion about what their medication and treatment plans would be. For example, one 39-year-old male explained that he had been recommended a treatment that had meant that him trying for a baby had to go on hold:

He put me on it anyway, which meant that then we had to delay [having a baby] for a year...I felt like I wasn't actually particularly given a lot of choice at that point, because that was the cheapest... it was quite frustrating that that was the one they started me on given the scenario.

Male focus group participant, 39

He went on to explain that he had felt very much that this life-changing decision had been a unilateral one taken by the doctor despite him being aware of many other options that were more suited to his lifestyle:

I don't think I had a lot of choice on that one and knowing that there are 20 other types of drugs, it was quite frustrating that that was the one they started me on given the scenario.

Male focus group participant, 39

56. GP - Patient Survey. IPSOS MORI, 2019. Available at: https://www.gp-patient.co.uk/downloads/2019/GPPS_2019_National_infographic_PUBLIC.pdf. Conversely inpatient survey data conducted by the Care Quality Commission reports that 40% want to be more involved in decisions about their care. Available at: https://www.cqc.org.uk/sites/default/files/20150822_ip15_statistical_release_corrected.pdf

57. Eurobarometer Qualitative Study on patient involvement in healthcare. European Commission, 2012. Available at https://ec.europa.eu/eip/ageing/library/eurobarometer-qualitative-study-patient-involvement-healthcare_en

58. For more, see: D. The barriers to choice review. How are people using choice in public services? London: Cabinet Office. (2013), p.23. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/80070/Barriers_to_choice_review_0.pdf

59. GP Patient Survey 2020. Available at <https://www.england.nhs.uk/statistics/2020/07/09/gp-patient-survey-2020/>

60. In our survey, 31% of those aged 18-24 were on a short-term medication compared to 4% of those aged 60+.

PATIENTS ROUTINELY CHECK THEIR DOCTOR'S ADVICE INFORMALLY

Finally, we asked a question around whether people researched the advice that they were given informally, for example by asking family and friends or using the internet. Two-thirds of the population (65%) said that they did so at least sometimes, with women more likely to do so (71%) than men (59%). Although younger people are also more likely to do so, half of those over the age of 60 still said they

did so "sometimes". People with degrees were more likely to research the advice they are given at least sometimes (73%), but most people without degrees (62%) also did so (Figure 13).

The high levels of independent research suggest a generalised level of concern, engagement (with their treatment) and a desire to obtain independent information as reassurance that the doctor's advice is appropriate.

When you get advice from your doctor, how frequently, if ever, do you research the advice you are given, for example by asking family and friends or using the internet?

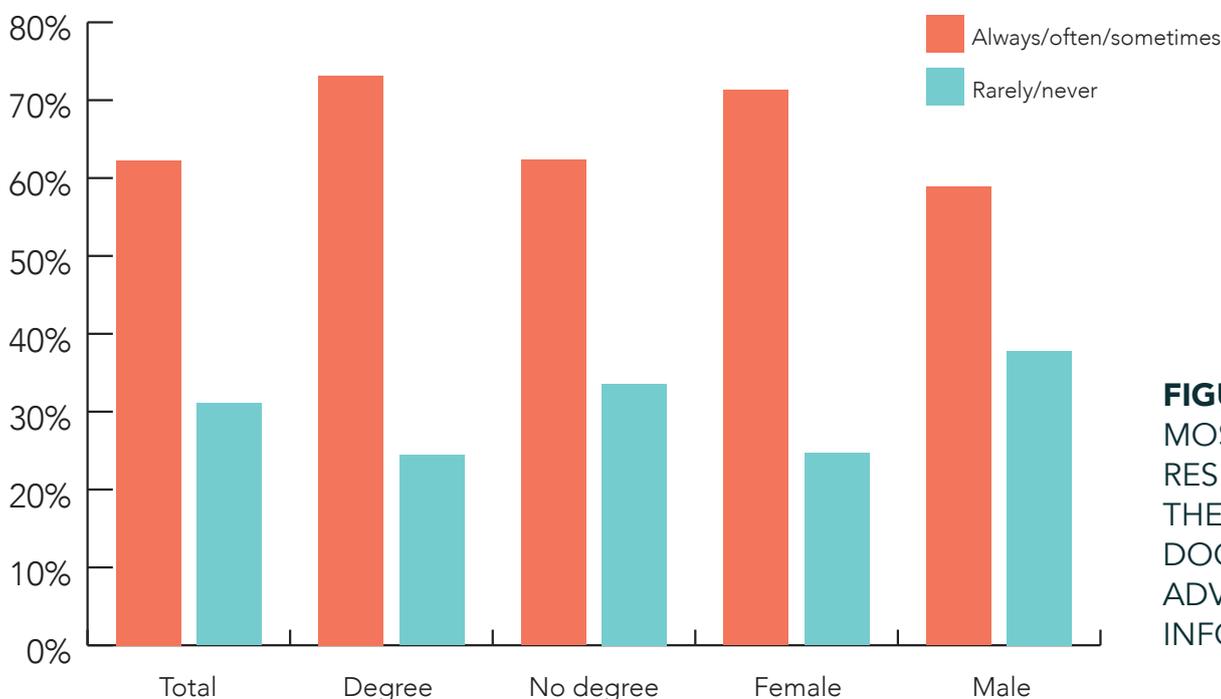


FIGURE 13. MOST PEOPLE RESEARCH THEIR DOCTOR'S ADVICE INFORMALLY

CONCLUSION

While there is strong evidence that many people are as involved in the decisions about their own medication as they want to be, there is also a significant minority of predominantly younger individuals who want to be more involved. We found that most patients routinely engage in a soft informal process of checking the advice they get from their doctor, indicating a desire to feel more informed about the decisions that are made. The next section explores the barriers to greater patient

choice over their own prescription medications with a view to exploring if policy changes could overcome them.

The conversations that we conducted during our interviews and focus groups enabled us to group these barriers - and corresponding enablers - into four main themes, that are explored in the subsequent chapters. These are time and structures; availability of information; cost; and patient empowerment.

SECTION 2

CHAPTER 5: TIME AND STRUCTURAL BARRIERS

KEY FINDINGS

- Patients are sympathetic to the pressures that doctors are under but nevertheless perceive that a lack of time with their doctor is a barrier to choice, alongside the fact they can't always get an appointment with the same doctor.
- Other healthcare professionals such as clinical nurses and pharmacists are seen as more accessible.
- Our evidence review also suggests that structural capacity issues within CCGs, alongside legislative complexity, may act as a barrier to patient choice over medication.

In this section we explore the main supply-side issues that we found acted as barriers to patients feeling they can exercise a meaningful choice around the medications and treatments they are prescribed: time with their doctor, the relationship with their doctor and wider structural constraints within the NHS.

It's almost like so many barriers are being put in place for the discussion itself, let alone then actually getting the medication changed.

Male interviewee, 23

TIME WITH THE DOCTOR

In 2019, the Royal College of General Practitioners declared that the standard 10-minute consultation was "not fit for purpose" and that resourcing should be available to enable GPs to have more time consider the all the "physical, psychological and social factors" potentially impacting on a patient's health in a more holistic manner.⁶¹

Previous qualitative research with patients and doctors conducted by Eurobarometer concluded that:

The main barrier to effective communication was the time available for doctors to spend with patients. Both patients and practitioners described how doctors had insufficient time to explain treatment options.⁶²

Our own results point to a similar conclusion. When patients noted that they had felt uninvolved in decisions about their healthcare many of them

61. 15-minute minimum consultations, continuity of care through 'micro-teams', and an end to isolated working: this is the future of general practice. RCGP, 2019. Available at: <https://www.rcgp.org.uk/about-us/news/2019/may/15-minute-minimum-consultations-continuity-of-care.aspx>

62. Eurobarometer Qualitative Study on patient involvement in healthcare. European Commission, 2012. p4, Available at https://ec.europa.eu/eip/ageing/library/eurobarometer-qualitative-study-patient-involvement-healthcare_en

attributed it to lack of time, which made it hard for doctors to explain the options available to them. Participants also reported that the limited time meant that they felt undervalued, either directly as a result of not being given enough time, or because they felt dehumanised by the experience of such a short appointment, as one participant explained:

Now they do not have the time. You are just basically a name on the books, and that is it.

Female focus group participant, 55

...it is time-boxed appointments versus clinical need, and I think that is wrong. That is why people are feeling like they are feeling, because I think GPs do not have the time for that personal touch anymore.

Male focus group participant, 53

I do not think our GPs, generally, just have the time anymore to cultivate those relationships with patients. You get your 10-minute slot for an appointment

Male focus group participant, 29

A dominant point of view across most participants was that time constraints were overwhelmingly a result of tight resources and the considerable amount of pressure that doctors were put under. As a result, they were generally sympathetic toward the doctors themselves, showing more concern about the lack of resources available within the healthcare system:

I personally feel that because the NHS is so stressed...a lot of the time they just try and cut corners...I just feel, sometimes, as if the doctors just do not have time for you.

Male focus group participant, 28

They will find out what is wrong with you, prescribe the medication, and then leave it to someone else to deal with that secondary bit, which I mean is fair enough.

Male interviewee, 24

I couldn't expect her to know every patient really well, and have a friendly relationship with everybody.

Male focus group participant, 53

"I would speak to my clinical nurse specialist just to confirm, 'Did I understand this correctly?' Because they are, kind of, a bit more human and also know me better."
Female interviewee, 29

It is harder to get more time with your doctor and get more information with your doctor...you can see what is happening to the health service in real time. So, I think it has been underfunded, it does not have as many resources, and you see massive differences between services, I feel.

Male focus group participant, 29

Though many patients were sympathetic to the reasons for limited time slots with their doctors, it hadn't stopped them from feeling frustrated. However, we did find patients reporting that other healthcare professionals have had more time available to properly explain treatment options to patients.

In particular, people reported that nurses and pharmacists had been able to offer that time and attentiveness which they believed doctors simply weren't able to do. Often, participants spoke about the relationships that they developed with their specialist nursing team, and how this had allowed them to feel more involved in their treatment.

I think the person who was very helpful was my IBD nurse, who is the contact inflammatory bowel disease nurse at the hospital who had a bit more time [than the doctors] to explain things to you.

Male interviewee, 24

I think the best one, and I think of her and her team as, kind of, NHS angels, which would be the diabetic specialist nurse, who really knows her stuff and who's really on tap for me when I need her. She's really caring, highly informative, very professional.

Male interviewee, 66

I would speak to my clinical nurse specialist just to confirm, "Did I understand this correctly?" Because they are, kind of, a bit more human and also know me better.

Female interviewee, 29

This was something that was likewise picked up in our expert interviews, in particular that pharmacists are 'under-utilised' and well placed to empower patients to take a more active role in their own healthcare.

[Pharmacies] have a good 'footprint' in the local community with their place on the high streets and are well placed to provide information.[... but] They're currently too focussed on 'box-pushing' when we need to reduce the amount of drugs people are on.

Expert interviewee

"Pharmacists I feel are specialists in pharmacology, they also have more time with their patients, they can go through spending quality time with them."

Expert interviewee

This view has informed our recommendation around greater involvement of pharmacists in the prescribing process.

THE RELATIONSHIP WITH THEIR DOCTOR

Over and above the issue of time, many participants perceived the ability to have a relationship with their doctor as crucial to them getting involved in decisions about their healthcare. Patients and experts agreed that a successful doctor-patient relationship was not a single moment in time, but an ongoing interaction between the two parties. Hence, experts, as well as patients, stressed the importance of the continuity of care in improving healthcare outcomes and bolstering patient choice.

"I think the relationship that I had many years ago, up until probably my thirties, worked brilliantly. I would say you do not have a relationship with your doctor nowadays."

Male focus group participant, 53

Patient choice is not a one-off exercise. It's about being supported long-term throughout your treatments.

Expert interviewee, private sector

For many patients, familiarity and a longer-term connection with their doctor is something that they believed would have improved the decision-making process. Those who said they'd seen the same doctor for many years reported having a constructive relationship with them that had enabled them to make the most of their appointments:

I find it quite important because I feel like if I see the same doctor regularly, I don't have to recap everything every single time.

Female focus group participant, 27

The trust that we have in him [enables us to have good choice over our medication] and that he gives a range of options, and also that other members of my family would have been on the other drugs which I know broadly the side effects and the good things as well.

Male interviewee, 21

Conversely, many other participants reported seeing multiple different doctors for the same condition. Many older patients in particular showed frustration about not having regular contact with the same doctor, nostalgic about a time when they could have a single doctor for themselves and their family. In their eyes, this had led to a far greater understanding of patient needs.

I think the relationship that I had many years ago, up until probably my thirties, worked brilliantly. I would say you do not have a relationship with your doctor nowadays.

Male focus group participant, 53

You used to get to know your doctor very well, you would feel at ease, and you were able to speak to them. Now I very rarely see the same doctor twice, and they have always got locums and all sorts standing in.

Female focus group participant, 75

Participants' perspectives on the significance of having longevity in their relationship with their doctors depended on their condition. For example, they were less likely to feel aggrieved about not

seeing a familiar doctor if the condition was minor, but for longer-term conditions, patients wanted to be able to build a personal relationship.

With haematological diseases, I think there's a lot more longevity in the relationships... you continue to know them for the rest of your life.

Female interviewee, 29

If I am going for a continuing problem I always try to see my same doctor. But if it's just an ad-hoc thing then I'll probably just go and see the first doctor I can get.

Female focus group participant, 27

This perhaps provides context to our finding that those on short-term medical treatments are less likely to feel satisfied by the decision-making process, and perhaps also suggests that part of the problem might be that the patient themselves is less invested in ensuring that they have the right treatment, as the stakes are not as high.

Once again, patients were sympathetic to the high pressure that doctors faced, that could explain why they are less available.

I don't see him regularly because he is quite busy himself and I'd rather see someone as soon as possible.

Male focus group participant, 36

Some respondents believed that their pharmacists, by contrast, were more consistently present and understanding, with more time to be attentive to the patient's needs, and with the added benefit of having a 'footprint' in the local community which makes them more accessible.

[pharmacists] remember you, they remember your family, they remember where you live, and they remember what medication you are getting. It is pretty cool, to be honest with you. You can have a chat with them and they will recommend alternatives, if it works.

Male focus group participant, 53

CAPACITY ISSUES WITHIN CLINICAL COMMISSIONING GROUP

Our evidence review suggested other structural reasons why patient choice in medicines may be limited that might not be as observable to the public or patients. A round-up of the evidence around variation in prescribing practices, conducted by National Voices in 2013, concluded, for example, that barriers to patients receiving the most up-to-date medicines as recommended by NICE were the result of: "differing interpretations of NICE guidance by primary care trusts; differing interpretations of NICE guidance by clinicians; bureaucratic delays; prescriber policy of favouring cheaper alternatives; the fact that the therapy is unconventional; clinicians unaware of NICE guidance; lack of infrastructure/resources at a local level and; lack of staff".⁶³

The interpretation of NICE's medical recommendations is something that has been publicly disputed - reinforcing National Voice's findings. A court ruling in 2014 over a CCG that refused a patient a NICE-recommended treatment concluded "the CCG was wrong to refuse the patient access to the treatment that she needed because the CCG simply disagreed with the recommendation made by NICE", but indicated that in some cases it might be possible for a CCG to go against NICE recommendations.⁶⁴ Other evidence suggests that complexity in the system, in part derived from legislation, is possibly a contributory factor in this regard.^{65,66,67}

In addition, there have been wider resourcing and leadership failures at the commissioning level that may distract from their legal obligation to promote the duty of patient choice. A review by the NAO in 2019 found, for example, that 42% of CCGs were rated either 'requires improvement' or 'inadequate' - a measurement based mainly on financial sustainability and the quality of leadership.⁶⁸ There is also inequity in funding: an earlier NAO report in 2017 found a £63 difference in funding per person between local areas with the lowest and highest allocations after adjusting for need.⁶⁹

63. Don Redding, Teeth in the NHS Constitution: the case of the right to NICE approved treatments, National Voices, 2013. Available at <https://www.nationalvoices.org.uk/sites/default/files/public/publications/teeth-in-the-nhs-constitution.pdf>

64. Court Judgement: what it means for commissioners and providers. NICE, 2014. Available at: <https://www.nice.org.uk/news/feature/court-judgement-what-it-means-for-commissioners-and-providers-and-using-nice-guidance-and-standards>

65. Data-driven Healthcare: Regulation & Regulators, Reform, 2019. Available at <https://reform.uk/research/data-driven-healthcare-regulation-regulators>

66. Nick Timmins, 'The World's Biggest Quango' The First Five Years of NHS England, The Institute for Government and The King's Fund, 2017. Available at <https://www.kingsfund.org.uk/publications/worlds-biggest-quango-nhs-england>

67. O'Connor, A. and others. Toward the 'tipping point': decision aids and informed patient choice. Health affairs, 2008, 26(3), 716-725. Available at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.26.3.716>

68. A review of the role and costs of clinical commissioning groups (Summary). NAO, 2019, p.6. Available at: <https://www.nao.org.uk/wp-content/uploads/2018/12/Review-of-the-role-and-costs-of-clinical-commissioning-groups-Summary.pdf>

69. Comptroller and Auditor General. Improving patient access to general practice. NAO, 2017. Available at: <https://www.nao.org.uk/wp-content/uploads/2017/01/Improving-patient-access-general-practice.pdf>

Separately we found concerns that CCGs are not involving patients collectively in decisions about which treatments should be made available: each CCG has a formulary group to build such lists of available treatments, and each is supposed to include patients in drawing these up. Despite guidance from NICE to involve patients collectively in this process, it seems that a significant number do not: research published by the healthcare media and marketing company Cogora in 2016 reported that between one-fifth and two-fifths (22% to 41%) of surveyed CCGs' formulary groups included patients in the process of drawing up formulary lists.⁷⁰

In the concluding section of this report, we make a number of recommendations designed to formalise the role of patient groups and pharmacists in the decision-making process, in order to take the pressure off the ten-minute doctor appointments.

70. Murphy, E. How do CCGs decide what drugs to include on their local formulary? Cogora, 2016. Available at: <https://www.cogora.com/ccgs-decide-drugs-include-local-formulary/#:~:text=CCGs%20are%2C%20among%20other%20things,CCGs%20and%20For%20acute%20trusts.>

CHAPTER 6: INFORMATION BARRIERS

KEY FINDINGS

- Most people (62%) are content with the amount of independent information they receive about which medication would suit them best.
- Younger people, however, were most likely to think there was too much independent information.
- This suggests that younger people perhaps feel overwhelmed by the sheer amount of uncurated information that they need to wade through to obtain the control and agency that they seek.
- Our focus groups suggested a greater demand for curated information from trusted sources - be it online or from other patients.

As we saw in Chapter 1, having access to appropriate information is viewed by patients as an essential part of having a choice. If there is too little information, or if the information is inappropriate or overwhelming, it acts as a barrier to choice.

To get a sense of how people viewed the information they were given about the medicines they are prescribed, we asked a series of questions in our poll around whether people felt they had too little or too much information, and the actions they took to check the information they were given.

At a high level, there is a sense of contentment about the amount of information that is provided. When asked whether there was “too much or too little independent information provided about which medication would suit you best, or if the level currently about right’ around two thirds of the population as a whole (64%) agreed it was about right, with equal proportions (19%) thinking it was too much or too little. Those with a more educational qualifications were slightly more likely to be searching for information: 23% of people with degrees thought there was too little information, compared to 17% of people without degrees.

However, there was also evidence of greater information overload amongst younger people: 28% of 18-24 year olds and 29% of 25-39 year olds thought there was too much independent information, compared to 19% of the population as a whole. This result is striking given that, as we have seen, younger people are also more likely to want greater choice, and more likely to disagree with their doctor, suggesting perhaps that younger

people feel overwhelmed by the sheer amount of uncurated information that they need to wade through to obtain the control and agency that they seek.

We also saw in Chapter 4 that most people do engage in a form of informal checking of the advice they receive from their doctor, for example with family and friends and online. The fact that younger people also feel that there is too much independent information possibly suggests that those people who want to be more involved and informed in decision making find the independent information they obtain from other sources - such as online - difficult to comprehend.

Our qualitative work supported these poll results: a number of patients we spoke to noted that they had felt unable to access information from their doctor and so had looked elsewhere, including online, for additional information. For some online resources were useful when considered alongside official information:

In the hospital, usually, when they put you on a new med, they give you a leaflet or a booklet in the hospital there and then. Then, they would direct you to something on the website, if you wanted to read through. To be honest, with the internet, obviously, you can find anything out about a drug these days.

Male interviewee, 38

However, most participants, while being pleased that they were able to go online to obtain information or check their doctor's advice, felt cautious of doing so. In particular, participants were concerned about receiving too much information, or the wrong type of information online, an insight which supports the poll finding that younger people feel there is too much information available.

There was a sense that an overwhelming amount of information online could make patients feel more anxious about their own condition, thinking that it might be far worse than it was in reality:

...especially Google...by the time I have read it I have gone, "Oh no, I have got this, I have got that." It is too handy...I have got quite a good imagination and by the time I finish reading I go, "Oh God, I have not got long left to live."

Female focus group participant, 75

"...especially Google...by the time I have read it I have gone, 'Oh no, I have got this, I have got that.' It is too handy...I have got quite a good imagination and by the time I finish reading I go, 'Oh God, I have not got long left to live.'"

Female focus group participant, 75

If you go round the wrong corner or just go into the wrong website you get all sorts of scary information. It is hard, sometimes, knowing where to look.

Male focus group participant, 29

There was therefore a high premium placed on the reputation of the source providing the information when patients were considering whether to pursue the results of their own research.

...if it looks like it's a proper news article that speaks to a scientist from a certain university, then that would give me more confidence.

Female interviewee, 23

Many patients suggested that official NHS pages, as well as NICE and British National Formulary (BNF) websites, were trustworthy and even empowering sources of information. Indeed, as we shall see in Chapter 8 we found relatively high awareness of the technical role that NICE plays in the healthcare system, suggesting that they could be a credible partner to provide curated information to the public alongside the NHS brand. However, for those that did cite using trusted websites, some felt that these could be improved by better linking them with other trusted sites.

Or even if your reputable patient access site had links to stuff like the NHS website or the BNF. So, they are not giving you the information themselves, but they can at least tell you where to find good quality, good standard info, with your standard disclaimers that they are not responsible for what you find and all that sort of stuff. Just a means to find that information a little bit easier. I think it would help a lot of people that might not be as confident to do that in person.

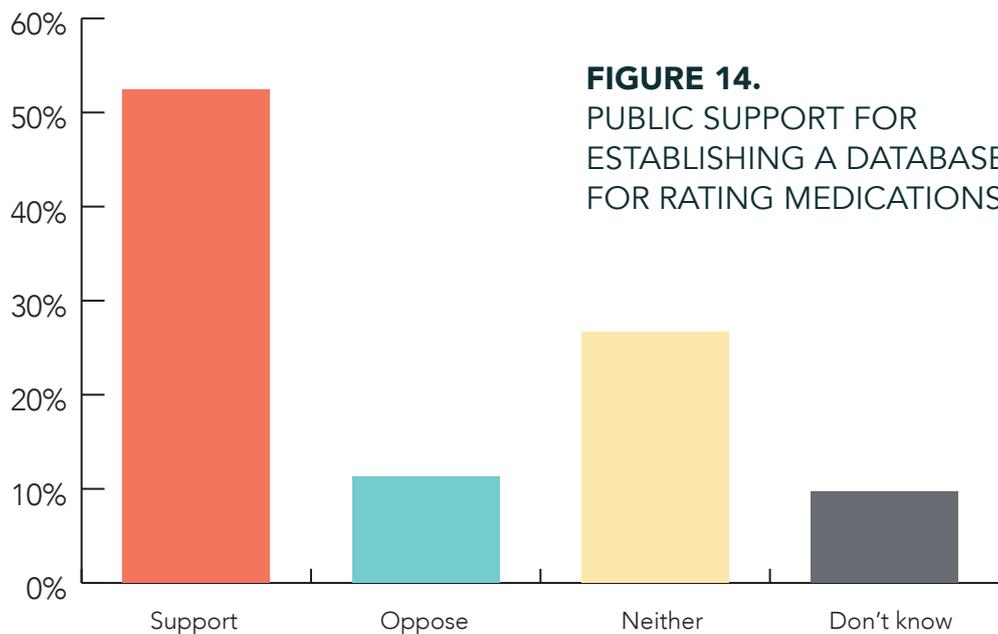
Male focus group participant, 29

ADVICE FROM OTHER PATIENTS

Another possible avenue of advice and information comes from other patients who are facing the same choices. We explored in principle whether people would trust the views of other patients by inserting a hypothetical question in the poll around a 'Tripadvisor'-style rating system for different medicines. To be clear: this is not a policy recommendation, and there are a number of reasons why it may not be suitable in practice that we did not explore, such as manipulation by pharmaceutical companies or the risk to an individual of taking crowd-sourced advice that was inappropriate to their condition. Rather we were interested whether patients would be well disposed of in principle to taking collective advice from other patients who they did not know on the advantages and disadvantages of certain medications, just as they did for other choices in their lives.

We found relatively strong support for such a system. Just over half (53%) the population would support the creation of additional information resources for patients to use to rate medicines with only 11% opposed to the idea (see Figure 14).

Would you oppose or support a database that allowed patients to rate the medicines and treatments they have been prescribed, which would be accessible to other patients?



This suggests that although people on the whole felt the amount of information they had was appropriate, they would still find it useful to have access to different sources of information, particularly those that are accessible and included patient-led evaluations of the advantages and disadvantages of different healthcare treatments and medications.

Rather than a Tripadvisor style website, this might indicate a greater role for organised patient support groups to provide curated information on medicines.

“I think it is incredibly important that patients and users are involved in helping us. But at the moment evidence based healthcare is the medium.[...] we need to curate information in a less clinically oriented way.”

Expert interviewee

One participant explained, after speaking with a relevant patient group, she had felt able to challenge her doctor to provide a greater understanding of her situation and their recommended decision:

I spoke to the people at the Aplastic Anaemia Trust who were really helpful. When I was diagnosed, I got given quite a lot of information, from various charities that I think provided the information. I looked at the, kind of, guidelines for treatments because I know there has to be guidelines for treatment. I had to be, to the clinicians, like, “You need to explain that better. Can you idiot proof that please? Can you turn that into an idiot’s guide because I don’t understand how white blood cells work.”

Female interviewee, 29

In summary, our research has demonstrated that although most people are content with the independent information provided, some people, particularly those segments of the population who are seeking greater agency and control, have a need for higher quality curated independent information around different medications that may suit them.

CHAPTER 7: COST BARRIERS

KEY FINDINGS

- A key part of decision making is cost-effectiveness, that is whether a medical treatment presents good value for money as well as good clinical outcomes.
- Primarily, NICE is responsible for cost-effectiveness - it is one of the primary criteria that it uses to decide if a new medicine is made available on the NHS - but in practice, CCGs also put additional pressure on prescribing doctors to advocate the cheapest alternatives, in ways that patients are not necessarily aware of.
- Meanwhile, patients themselves are broadly supportive of cheaper alternatives being prescribed where they are equivalent or for low stakes conditions but express concern at the idea of knowing high costs if it deters people from agreeing to the medication.

In this section, we look at cost-related reasons that may restrict a patient's choice of medicine, including whether patients themselves think that the cost to the NHS of their prescription should be something that they are made aware of.

As described in the introduction to this research, consideration of the cost-effectiveness of medical treatments is, as a matter of explicit government policy, taken into account at the point that it is decided whether to make a medicine available to NHS patients at all. Indeed, one of the primary purposes of NICE is precisely to make that judgement based on established criteria designed to take into account both the effect on the taxpayer and the clinical impact of the drug or treatment. At one level, that could be considered the end of the story, because the NHS Constitution then gives patients the right to any NICE-approved medicine or treatment that doctors consider appropriate.

However, in practice, there are a number of ways in which cost considerations re-emerge in the system that affect the options that patients either have or are presented to them. The first is that CCGs can decide how to use their budgets to purchase treatments including medication in the locations in which they operate which can, in practice, limit availability in some areas. This is hugely unpopular amongst the general population who feel strongly that such "postcode lottery" considerations run contrary to the ethos of the NHS: in our poll when presented with a choice between uniformity of availability and devolution of decision making, 86% of the population preferred the geographic uniformity, with the strength of this result applying across all subsections of the population (see Figure 15 below).

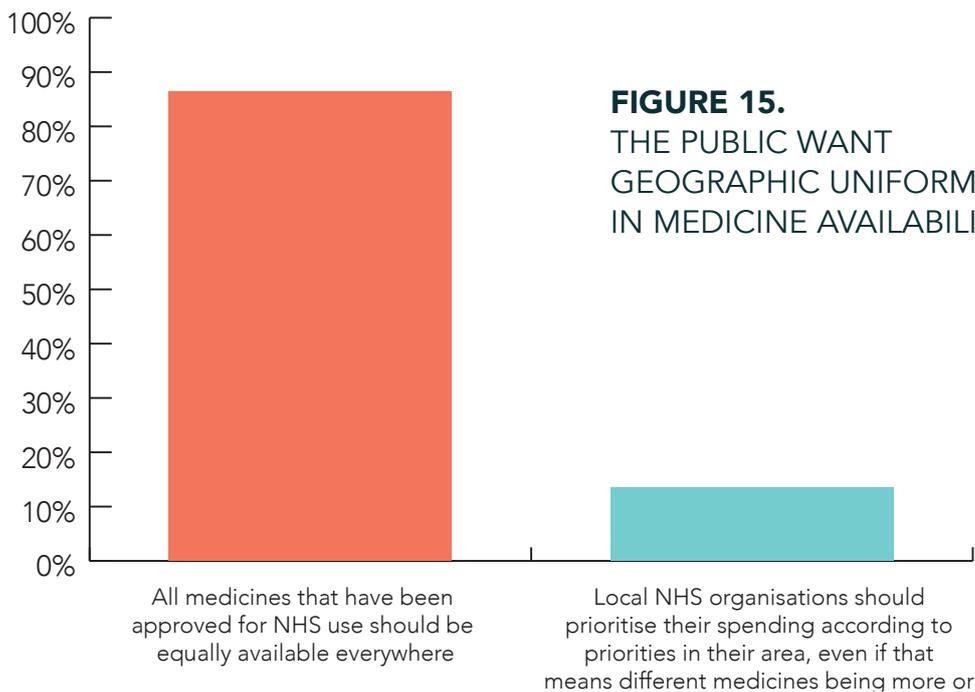


FIGURE 15.
THE PUBLIC WANT
GEOGRAPHIC UNIFORMITY
IN MEDICINE AVAILABILITY

Some of our expert interviewees who are doctors did warn of the monetary pressures placed on them by CCGs, limiting the spectrum of drugs available to them to prescribe their patients. This does to seem to be a reality: while CCGs must legally consider the preferences of the patients, they are able to reject applications from GPs for certain treatments if they do not believe them to have clinical value or if they are over budget.⁷¹ In this way GPs in the UK experience pressure from both the demand side - the need to care for patients - and the supply side - the need to ration resources - causing stress that is high by international standards.⁷²

It's too much about money [...] and GPs don't get enough choice over what is prescribed.

Expert interviewee

In fact, there are a number of live initiatives designed to encourage prescribing doctors to prescribe the cheapest alternative, thereby reducing choice for patients without them necessarily being aware of it. For example, the NHS

Five-Year Review published in 2017 contained a "ten-point efficiency plan" that included amongst other initiatives a greater centralisation of formulary decisions, and embedding clinical pharmacists in GP practices to "optimise medicines usage". The review published ratings of the progress made by hospital trusts of their progress in moving towards cheaper prescription options; new regional "Medicines Optimisation Committees" to reduce wastage and advance the use of cheaper alternatives including in care homes, and reduce the number of prescriptions of low clinical value or where products are available cheaply over-the-counter.⁷³ Another example is a workstream within the NHS entitled Choose Wisely which aims to raise awareness amongst clinicians and patients alike of the benefits of not pursuing treatment, where the potential costs and benefits are finely balanced, following a similar initiative in the US.^{74,75}

Meanwhile, at an institutional level, NHS England has established a commercial medicines team to negotiate directly with pharmaceutical companies to drive down the cost of new medicines.⁷⁶

71. Robertson, R. Six Ways in Which NHS Financial Pressures Can Affect Patient Care. King's Fund, 2016. Available at: <https://www.kingsfund.org.uk/publications/six-ways> [accessed 28/09/2020]

72. Baird, B and others. Understanding pressures in general practice. King's Fund, 2016, p3. Available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Understanding-GP-pressures-Kings-Fund-May-2016.pdf [accessed 01/10/2020]

73. GPs are free to prescribe "any drugs, medicines or appliances which are needed for the treatment of any patient" (subject to a few 'blacklisted' exceptions) which must then be reimbursed by the CCG, the only caveat being that they should not be of excessive cost, usually defined as not prescribing a branded version when a generic is available. See A Guide To The Law On Patient Choice. Landmark Chambers, 2018, p13. Available at: <https://www.landmarkchambers.co.uk/wp-content/uploads/2018/07/Guide-to-Patient-Choice-Rights.pdf> and National Health Service (General Medical Services Contracts)

74. About Choosing Wisely UK. Choosing Wisely, 2020. Available at: <https://www.choosingwisely.co.uk/about-choosing-wisely-uk/>

75. Vogel, L Choosing Wisely around the world, Canadian Medical Association Journal . 2015 Aug 11; 187(11). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4527925/>

76. Next steps on the NHS five year forward view. NHS, 2017. Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf>

This includes the possibility that if a drug has already been approved by NICE as being cost effective, if it nevertheless will be expensive (over £20m in three years for the NHS), then NHS England will attempt to negotiate the price down further, and if that is not successful, access can be restricted with the approval of NICE. In the words of the King's Fund what this means is that:

Some patients will be denied access, at least for a time, purely on the grounds of affordability, to a new technology that has already been judged to be cost-effective.⁷⁷

With the NHS spending upwards of £18 billion on procuring medicines on behalf of patients, it is understandable that there will be efforts to contain costs, however it does feel jarring that this should take place when cost effectiveness is, in theory, already taken into account by NICE when deciding whether to make a medicine available.^{78,79}

One way of squaring that circle is to consider that a treatment that may be appropriate for one person is not appropriate for another, such that both should be available for consideration by doctors and patients. However if doctors are feeling under pressure to prescribe the cheaper options - as our evidence suggests - then this has knock-on effects for the patient-doctor relationship, with patients either being guided towards a cheaper option without their knowledge or losing faith in their doctor's commitment to what is best for them regardless of cost, undermining trust.

Doctors say 'my hands are tied' and that really diminishes the trusts that patients should have with their doctors. Patients want to feel as though the consultants should have the power to make those decisions.

Expert interviewee

This is a point that is not lost on patients. We picked up an awareness in our interviews that doctors had started patients on one drug without mentioning that any others existed that might come in different forms or suit them better, raising questions in the minds of some as to whether cost and/or other structural issues were to blame. For example one 53-year-old participant with Chrons explained he had a strong sense that something involving regulation and financial pressures from

higher up in the food chain had limited his - and his doctor's - choices:

"if a doctor could make that judgement call and have the power to do that, to take away those six months, it would have helped me, for sure. But, I mean, I do understand where they are at in terms of funding and things like that.[...]I feel like it is a structural problem. I don't feel like it is a problem of the doctors not recommending it."

Male interviewee, 53

We asked some specific questions during our qualitative research around whether patients should have the same information as doctors about the cost of the medicines that were potentially being prescribed to them. We found that people engaged with this question with some intellectual curiosity, possibly because it in a sense goes to the heart of one of the founding principles of the NHS, that the cost of care and treatment should be irrelevant at the point of use.

There was a general acceptance that if a patient was aware of the cost to the NHS of what they were being prescribed, it put the moral burden onto them as individuals to decide whether the cost to the taxpayer of choosing a more expensive treatment is justified. Whether this would be a positive or a negative thing was, however, more contested.

On the one hand, some people thought that knowledge of the cost would make them appreciate the value of the drug more, and in some cases give them the choice - if they wished - to make a decision that eased the burdens on the NHS.

I think people value it more if they know the...price that is paid for it.

Male focus group participant, 53

...when I found out how expensive the drug was my aunt was on, and the one that I wanted to go on, I did kind of think, "Well, maybe it is a good thing I am going through this process [of taking the cheapest drugs first]."

Male focus group participant, 24

77. Timmins, N. Ministers, not NHS England, should decide on the affordability of cost-effective new treatments. King's Fund, 2017. Available at: <https://www.kingsfund.org.uk/publications/articles/ministers-not-nhs-england-should-decide-affordability-of-treatments>

78. NHS procurement, The Institute for Government, April 22, 2020. Available at <https://www.instituteforgovernment.org.uk/explainers/nhs-procurement>

79. Calovski, V., & Calnan, M. Chapter Seven: Creeping Privatisation? Examining Procurement Choices in the 'New NHS in England. In Navigating Private and Public Healthcare, 2020, pp. 131-154. Palgrave Macmillan, Singapore

"I think one of the downsides of printing the cost of things is people might start feeling bad about that."

Male focus group participant, 28

And some just thought it was common sense to save money where it was possible to do so.

Yes, of course, if it is going to save you £8,000 a year. Brilliant. It's exactly the same thing and it won't affect me in any way, I would much rather you do that.

Male focus group participant, 39

On the other hand, there was also a view that it was the outcomes that were important rather than the cost, and so knowing the cost would place an unnecessary moral burden on the patients.

I think one of the downsides of printing the cost of things is people might start feeling bad about that.

Male focus group participant, 28

I don't think that is fair to put someone, present them with that moral dilemma... a lot of us might be influenced wrongly.

Male interviewee, 53

Depending on the views of the individual, this could cause people either to choose the more expensive option in the presumption that it was better, or to choose the cheapest in order to not be a burden.

...some people may then assume that the more expensive drugs are better. It is not always the case. It is just what the pharmaceutical companies are charging for them.

Female focus group participant, 50

I think I would then go for the cheapest one because... I don't want to be a burden.

Male focus group participant, 23

There was a sense that it might be most appropriate to know the cost of medication when the stakes were lower: the more serious the condition, the more likely people are to prioritise the health outcomes rather than the cost. One woman with

an immune condition, for example, was very happy to be explained that her prescription for hayfever was being made on cost grounds:

I have been in an appointment with a GP for hay-fever medicine, and they said to me, "I can prescribe you this, which is a brand name. Or, if you're willing to take this generic one, which is just a slightly different volume, you're saving us £20 a month. Are you happy to take it?" I went, "Yes, of course."

Female focus group participant, 48

Similarly, another of our interviewees made a distinction between general cost saving measures and ensuring that patients had sufficient support in the case of an emergency:

It's a bit of a moral dilemma because obviously, that's a fair point, putting a bigger strain on the NHS but equally, it is important to have {in the example of allergies} a number of Epipens in case one fails.

Male focus group participant, 21

As a side point, we also found frustration amongst some people who paid for prescriptions if they later found out there was a non-prescription alternative that would have been cheaper for them to buy over the counter:

...there have been times where the doctors give me medication and it has cost a fortune for me, then you can literally buy it over the counter for cheaper than a prescription.

Male focus group participant, 28

Taken together, we are of the view that having asymmetric information around cost pressures reduces trust between patients and doctors. Given our earlier result that the vast majority of the population is (currently) comfortable with the doctor making the final decision we feel that if the doctor is considering cost as a factor without the patient being aware of that, that is a problem for the relationship between them.

This informs our recommendation that more information about cost-effectiveness should be available online to ensure patients are able to access information about cost when relevant to decisions about their medication.

CHAPTER 8: PATIENT EMPOWERMENT

KEY FINDINGS

- Lack of patient confidence was a barrier preventing people from being more involved in their treatment choices, which in turn could be influenced by a large number of factors including the patient's own life stage.
- We found little knowledge of existing patient rights but agreement amongst many participants that an awareness of such rights could be empowering for patients.
- Our poll suggested a reasonable public understanding of the technical role of NICE, and our qualitative discussions suggested people would find the agency a credible source of information about their choices and rights.

"A lot of patients don't have the confidence to challenge their doctors - this is cultural."

Expert interviewee

For a patient to have a real choice over their medications, they need to have sufficient confidence to be able to do so. There is then a deep connection between confidence and a patient's own perceived levels of expertise which in turn is closely linked to knowledge, and the availability of information, all of which are discussed above. In this section, we consider the issue of confidence head-on, focusing on whether having the knowledge of their right to choose affects the level of confidence that patients have to be more assertive and exert greater ownership over the decision of which medicines and treatments were most appropriate for them.

Our expert interviews suggested that, in general, patients lack the necessary confidence to fully participate in shared decision making.

A lot of patients don't have the confidence to challenge their doctors - this is cultural.

Expert interviewee

In the focus groups and interviews, we asked patients what the factors were that affected the confidence that people might have to challenge their doctor's decisions and have more say over their treatment. Patients reported a varying degree of responses, suggesting that it was ultimately depended on the individual situation and the result of a multitude of factors from age to medical condition:

I think it depends on your surgery. I think it depends on your GP. I think it depends on the patient's age. I think it depends on the doctor's age. I think it depends on what kind of practice. I think it depends on the area of illness.

Female interviewee, 48

We asked participants what might make them feel more confident when approaching their doctor and seeking more influence over their own treatments. Again, the importance of having relevant information was key, whether that be from online resources, other doctors or other family members, giving patients more confidence to push back on their doctor's decisions and obtain a greater say in their own treatments.

The doctor can't always just be right...if the doctor you feel isn't providing you the right service or the right information there, or there is some research you have done there that you think is worthwhile that the doctor isn't considering, that is something that you can potentially maybe address.

Male focus group participant, 36

Many patients also believed that this ultimately depended on the character or life stage of the patient. Patients who had less experience with their condition or were diagnosed before they reached adulthood could recall not feeling capable of challenging their doctors:

I think just having the confidence to ask for more information in the right way... I do not think everyone has the confidence to do that, because it is hard, especially if you have spent years and years struggling to ask questions of anyone in any authority.

Male focus group participant, 29

I was quite young, as well, like I was 16, 17 when I was first being given all this information, so I don't necessarily know if I even really cared to air my opinions, because they weren't that informed.

Female interviewee, 23

I was still being treated a bit like a child...I felt a little bit disabled from having a say.

Male interviewee, 28

Older participants in our sample seemed to report having less confidence to challenge their doctor and ask questions. When we explored this with older participants, one explained that they believed that it was their age made them be seen as less valuable:

I would really like to feel that I could spend just a few more minutes just to ask questions, but I always seem to be rushed out the door. I think maybe because I am old and I really do not matter as much at all, because I do not question anything.

Female focus group participant, 75

We also explored how participants' perceptions of their rights affected their confidence to be actively involved in decisions about their healthcare, and in particular the right to choose.⁸⁰ It is explicit government policy that patients should be aware of their rights and the scenarios in which they may be able to utilise them, in order to encourage more patients to become involved in decisions about their healthcare.⁸¹

With regards to the right to choose their treatment or medication, our qualitative research participants had a mix of views. Some patients had discovered that if they were more assertive they could get the medication that they wanted:

... because I have gone through the system so many times and I have been doing it for so long, I will just sit there and say, "I am not leaving until you give me the hospital one. I am not trekking to another pharmacy. I am getting it from here." But people aren't aware that that is even the case, so they will just accept when they are given the blue slip and go.

Male interviewee, 24

Alongside this we found limited *a priori* knowledge of the general concept that patients might be entitled to a range of treatments.

One of our interviewees did, however, use the language of rights and responsibilities in describing his approach to patient choice. In this instance, patient choice was something that they had the right to, and also responsibility to achieve through ensuring that they are informed and involved in decisions about their health:

80. Department for Health and Social Care. The NHS Constitution for England. GOV.UK, 2015. Available at: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england#patients-and-the-public-your-rights-and-the-nhs-pledges-to-you>

81. Department for Health and Social Care. New Rights for NHS patients. Gov.uk, 2012. Available at: <https://www.gov.uk/government/news/new-rights-for-nhs-patients#:~:text=The%20rights%20set%20out%20in,may%20include%20taking%20legal%20action.> [accessed 22/09/2020]

Taken together, this suggests a relatively high understanding of the role of NICE amongst around half the population, including their role around drug approval, value for money and medical advice, with a neutral - technical, even - reputation overall. This suggests NICE could have a greater role in helping patients to understand their treatment choices, providing high-value curated content that could improve patient confidence.

In our focus groups however, most patients were not initially aware of NICE's existence, nor about the range of medication that NICE guidelines might entitle them to.

I don't fully know what they do. I know they produce some guidelines, but beyond that I am not really sure.

Female focus group participant, 27

Among the few that had heard of NICE, one participant explained that they had only thought of it as a barrier, rather than something they could use to exercise their choice-right.

No, I would not have gone to NICE, no.[...] I do not associate NICE with choice. I associate NICE with being bad boys, because you tend not to find the good things that NICE has done, it is always when we have got this wonder drug that can really affect people's lives, but NICE has declined it.

Male focus group participant, 53

We therefore specifically asked participants if information from NICE about their entitlements is something that they would be interested in viewing prior to a meeting with their doctor. The respondents were largely in favour of having such information, viewing it as a useful tool.

If there was something specific you actually wanted you could look on there first to know before you go in whether you were legally entitled to it should they refuse you.

Female focus group participant, 50

it would be nice to actually have a look beforehand and at least have an idea of what is available.

Male focus group participant,, 39

"...it would be nice to actually have a look beforehand and at least have an idea of what is available."

Male focus group participant, 39

When we introduced the idea of patients having rights, many (but not all) of the respondents suggested that knowing more about their rights would make them more likely to obtain their own information and use it to challenge their doctors, particularly if they didn't agree with their initial proposal.

It gives you a bit more authority in that sense, to be honest. You feel a bit more empowered, i.e. the doctor can't always just be right, and you have some sort of privileges and rights to be honest, so you would probably want to action those rights in a sense if the doctor you feel isn't providing you the right service or the right information there.

Male focus group participant, 36

I probably would only look at it if I disagreed with something.

Female focus group participant, 50

We found one particularly interesting example of empowerment in our focus group work involving a 75-year-old female participant with a heart condition who explained that she had never considered trying to be involved in decisions about her healthcare. A big part of this, for her, was because she doubted whether she would be able to understand her condition as well as the doctor could.

However, once other participants in the focus group had shared their experience of being involved, and argued that it was in fact their right to be, the participant began to change their mind about whether they should be involved and her right to question the doctor's judgement.

Well, I have never considered a choice and I am going to do so now. I think I am just a little bit too quiet when I go to the doctor, obviously, listening to everyone else. I think I am going to be a little bit more assertive next time.

Female focus group participant, 75

If as a result of taking part in a discussion about patient rights, an older participant was able to feel sufficiently empowered to be “a little bit more assertive” for the first time in their life, we feel that with the right tools, it may be possible to alter the dynamic of the doctor-patient relationship across the board. In the next, concluding section, we bring together the results of our work so far and explain our associated policy recommendations.

CONCLUSIONS AND RECOMMENDATIONS

Patients remain an untapped resource in the health and care system, one that - often without them knowing it - brings additional expertise to the table and drives better outcomes.⁸² However, despite the clear value of their involvement and numerous policy statements lauding the benefits of patient choice, our research has found a significant proportion (just under a third, 30%) of people across England have not felt as involved in decisions about their medical treatments as they would have liked to, and a similar number (just over a third 36%) have disagreed with their doctor. Further, we found one fifth (21%) of people who had doctor's appointments in the last year did not have different treatment options explained to them. Those on short-term medication and those under 40 felt particularly disempowered in conversations about treatments with their doctor.

Before making recommendations for change, it is important to reflect for a moment about what these numbers mean. On the one hand, there is a clear majority who are broadly satisfied. This perhaps explains why there isn't a huge political clamour for change in the way that prescribing decisions take place between doctors and patients. However, the proportion of the population who are less satisfied, although a minority, is nevertheless substantial: three in ten adults (30%) wanting to be more involved in the choice of medicine they are prescribed equates to over 12 million people in England. Moreover, the fact these are younger people suggests future generations of patients may not share the same paternalistic defaults of their grandparents' generation. There is also a question about outcomes: if we wish, as a policy priority, to achieve greater patient choice, having a third of the

Patients remain an untapped resource in the health and care system, one that - often without them knowing it - brings additional expertise to the table and drives better outcomes.

population wanting the same thing is a very good place to start. The question then becomes how to do it.

Our research suggests that the challenges to shared decision making go deeper than NHS structures, although they are relevant, to the psyche of the population and culture of our NHS. We have found that many across the country still hold onto a paternalistic view that doctors know best and patients have little to bring to the table when it comes to decision making. That so many subscribe to a paternalistic view of their healthcare additionally suggests that policy aims are not being followed through and more needs to be done to change hearts and minds on the ground.

This is not to say that the NHS has not come on leaps and bounds over the past 30 years (see Appendix 2 for reforms since the 1990s). Many (but not all) of our expert interviewees and research participants said that the days of paternalism are behind us, and the insights from our poll suggest that some views are changing. However, there clearly remain challenges for shared decision making and the associated concept of patient choice to become part of everyday practice in the NHS.

82. Coulter A & Collins A, Making Shared Decision-Making a Reality. King's Fund, 2011. Available at: https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

As our NHS makes plans to grow and develop in the wake of the pandemic, policies that put patients at the heart of decision making and ensure that their expertise is maximised should be at the forefront of policy, in the interests both of efficiency and efficacy, as well as from a population resilience perspective.

In the context of Covid-19, we have made a series of recommendations that focus on making NHS resources count - while our research suggests that there are clearly resourcing pressures in the NHS today, these are questions that go beyond one single policy area.

Within this, we have highlighted three key strands for policymakers' next steps in making patient choice and shared decision making everyday practice: boosting the role of other healthcare professionals; ensuring patients have access to the right type of information; and protecting and promoting patient rights.

The key insight that informs our recommendations is that shared decision making is a process that takes place over time, as information is gathered and processed, advice is taken and different options are weighed up, and particularly so for decisions about one's health. Just as many people often take a bit of time to decide to seek medical help after they notice symptoms, it is also normal, if not desirable, to take a bit of time to decide on the most appropriate treatment path to alleviate those symptoms. Patient choice over medication cannot be real in one 10 minute appointment: it needs to be nurtured before and after that appointment takes place.

BOOSTING THE ROLE OF OTHER HEALTHCARE PROFESSIONALS

We know that a core part of patients being able to choose their medications is having enough time with their doctor to discuss their own treatment options. Research suggests that the UK has one of the shortest appointment times among "economically-advanced" nations, with the average appointment time being 9.2 minutes.⁸³ The Royal College of GPs argues that the lack of patient-doctor time is a core driver in our disproportionately poor healthcare outcomes. Certainly, our qualitative research reinforces the point that patients struggle to feel involved in

We know that a core part of patients being able to choose their medications is having enough time with their doctor to discuss their own treatment options.

decisions about medical treatment because of time. We found that a number of patients felt that they did not have enough time to talk things through with their doctor and, as a result, sometimes left with the wrong prescription or took drugs that failed to treat them effectively.

Irrespective of time, it seems that patients are not getting the most out of conversations with their doctor. To reiterate: we found only 29% of the population had felt that they had had conversations with their doctor about the different options for medical treatments that might be appropriate in all their doctor's appointments in the past year, and one fifth (21%) said that they had never had such a conversation in any of their appointments. Evidently, we are some way off where the NHS wants to be, indeed, the NHS states on its website "In the near future, NHS England wants all patients to be able to say: I have discussed with my GP or healthcare professional the different options available to me, including the pros and cons and, where appropriate, whether to choose to not have treatment."⁸⁴

However, we also heard from patients how other healthcare professionals such as pharmacists and clinical nurses or patient groups had been able to step in and provide them with the detail and the type of conversation they needed to make a well-informed decision. Indeed, these healthcare professionals played invaluable roles to patients making long-term or life-changing decisions. It seems, therefore, that more can be done to better maximise the resources already available to patients to ensure that all patients have the options of going to other healthcare professionals to have important conversations about their healthcare. Expanding and supporting these options will not only make those 9.2 minutes with their GP count, but also so ensure that the NHS is using its human resources most efficiently. We, therefore, recommend that these sources of medical advice are more formally integrated with the prescription process:

83. 15-minute minimum consultations, continuity of care through 'micro-teams', and an end to isolated working: this is the future of general practice, The Royal College of General Practitioners, Press Release, May 2019, Available at <https://www.rcgp.org.uk/about-us/news/2019/may/15-minute-minimum-consultations-continuity-of-care.aspx>

84. Your NHS, The NHS, Webpage, 2020. Available at <https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/>

Recommendation 1: NHS England and Clinical Commissioning Groups should make sure patients are able to access support from their pharmacist and/or clinical nurse as they consider their options throughout their care pathway [this should be reflected in pharmacists contracts].

The relationship between GPs and pharmacies have been growing over time, with pharmacists increasingly playing a more active role in the prescription process.⁸⁵ NHS England has already committed to better drawing on the talent held by pharmacists, aiming to employ more clinical pharmacists to support GPs.⁸⁶ This however could be built on, enabling pharmacists to play a more active role in community healthcare. Furthermore, ensuring that pharmacists are not only able to help patients make the decision but also speed up the process of their prescription would add extra incentives for patients to draw on additional help, and therefore ease the strain on GP time. Consequently, we recommend that:

Recommendation 2: Pharmacists should be recognised as an integral part of the patient care pathway. The discussions that pharmacists have with patients should be recorded on their files alongside those with other healthcare professionals in both primary and secondary care, such as GPs, clinical nurses and consultants. This could include the opportunity for pharmacists to recommend prescriptions for GPs to consider or sign off.

ENSURING PATIENTS HAVE ACCESS TO WELL-CURATED INFORMATION

The need to be informed to make a good decision is a truism, and decisions about medical treatments are no exception. Informed patients are crucial to achieving better clinical outcomes;⁸⁷ and to reiterate National Voices in 2017 “the strongest correlation to ill-health... is health literacy”.⁸⁸ Indeed, a big part of shared decision making is patients feeling empowered to ask their doctor questions and confident to engage in decision making about their treatments - and this often requires additional information tools.⁸⁹

Having access to good healthcare information is important to patients too. The majority of

The need to be informed to make a good decision is a truism, and decisions about medical treatments are no exception.

participants in our interviews and focus groups said that having the necessary information to understand their condition and treatment options was the first principle in achieving patient choice. Fortunately, the majority of people (63%) said that the amount of independent information was about right. This, however, was less for younger generations. Nearly a third of younger people are finding too much information online, suggesting that uncurated independent information online might be overwhelming those who use it most.

We know that we have culture amongst the population of going online to get more information: over two-thirds (66%) of the population already do extra research on the medical advice their doctor gives them. There is a danger in patients going online to make decisions about their healthcare. One thing that Covid-19 has highlighted has been the danger of health misinformation online.⁹⁰ It is therefore more important than ever that the NHS ensures that where possible it can provide patients with trusted, accessible information on their conditions to avoid them going to less trusted sites.

As some of our participants highlighted, patient groups often provided invaluable sources of information to patients, enabling them to go and make positive decisions about their healthcare. We therefore recommend that the role of such groups is formally recognised to give patients a space to discuss their treatment options closer to the way that suits them, to take some of the pressure off the more structured doctor appointments. In order to ensure that quality of advice is maintained, patient groups could receive accreditation to provide such advice and support services. This could be linked to funding if the benefits to the NHS can be demonstrated such as if, for example, patient groups can demonstrate that the decision making support they provide patients can help reduce the costs of non-adherence of medical prescriptions.

85. Bradley, C. P, The future role of pharmacists in primary care, 2009, 891-892. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2784524/>

86. <https://www.england.nhs.uk/gp/expanding-our-workforce/cp-gp/>

87. Alf Collins and Angela Coulter, Making shared decision making a reality, The King's Fund, July 2011. Available at https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

88. <https://www.nationalvoices.org.uk/publications/our-publications/new-relationship-people-and-communities>

89. Debra de Silva, Helping people share decision making: A review of evidence considering whether shared decision making is worthwhile, The Health Foundation, 2012. Available at <https://www.health.org.uk/publications/helping-people-share-decision-making>

90. Talha Burki, The online anti-vaccine movement in the age of COVID-19, The Lancet, 2020. Available at [https://www.thelancet.com/journals/landig/article/PIIS2589-7500\(20\)30227-2/fulltext](https://www.thelancet.com/journals/landig/article/PIIS2589-7500(20)30227-2/fulltext)

Recommendation 3: NHS England should formalise the relationship between the NHS and patient groups to provide more structured support to patients making decisions about their healthcare, subject to the groups themselves wanting to do so. This could include procuring appropriate services from charities to support patient decision making.

There also seems to be a gap in the types of information available to patients on the NHS websites and NICE website. The fact that a larger proportion of the public is doing research independently on their doctor's advice (66%) than have heard of NICE (53%) suggests that the resources currently available to patients on NICE website might not be cutting through - especially as out of those who had heard of it, few thought of it as a source of information. Currently, information and advice on NICE guidelines are split by medical treatments, rather than conditions - this might make it difficult for the patient to situate themselves on their pathway.

The NHS Comprehensive model of personalised care, published in 2019, has made shared decision making a priority, including working with NICE to make in-consultation shared decision making tools.⁹¹ However, more should be done to ensure that that information is available to the patient before visiting healthcare professionals so that patients might be able to prepare questions before their doctor's appointment and be more health-literate in the trade-offs they might need to make as part of their decision about their healthcare. We therefore recommend:

Recommendation 4: NHS England and NICE should extend NHS online content to provide patients with interactive tools to explain different treatment pathways and options using language that is accessible to patients. These should include explainers of the types of medical professionals they can consult to discuss options and their patient rights to NICE-approved medications under the NHS Constitution.

Crucially, we recommend that the information goes on the NHS' website, where patients and the public are far more likely to go for healthcare information. We imagine this is the type of thing the public would support, as the majority (53%) of people said that would support the curation of additional patient-led information.⁹² Ideally, there should be

little difference in substantive content between the NICE pathway information that is promoted to patients and that used by healthcare professionals. The main change, therefore, is around accessibility, and inclusive language.

PROTECTING AND PROMOTING PATIENT RIGHTS

That patients remain an untapped resource in the health and care system seems to go much deeper than the NHS structures and clinicians and into patient perceptions of themselves. Our research suggests that a significant proportion of the public remain paternalistic - with roughly a third of survey respondents (36%) preferring the doctor to make prescription decisions alone.

When exploring the reasons for and against patient choice with patients themselves, we found the key reasons patients did not want to be involved revolved around their confidence and their perceived lack of medical expertise. Too many of the patients we spoke to during our research did not feel it was their place to be involved in their healthcare treatment; this is not good for patients nor the health service. The stark generation divide between those who are older than 40 and those who are younger than 40 reinforces the notion that there remains a cultural assumption that the doctor's orders are infallible. With the younger generations taking a different approach, long-term the NHS might have a challenge on its plate: keeping up with the younger generations as they inevitably interact with the health system more and desire greater autonomy over their healthcare. We, therefore, recommend that the NHS and the Department for Health and Social Care use policymaking to change the culture in the NHS, to ensure that empowered patients are at the heart of all of its next steps. Indeed, if the NHS is to realise its goals set out in the NHS Long-term Plan - to ensure patients have "control over their own health and more personalised care when they need it" - it seems a cultural revolution is needed.

...we found the key reasons patients did not want to be involved revolved around their confidence and their perceived lack of medical expertise.

91. Shared decision making, NICE, Webpage, 2020, Available at <https://www.england.nhs.uk/shared-decision-making/>; No decision about me, without me: shared decision making in the UK's National Health Service, All.Can, Jul 4, 2020. Available at: <https://www.all-can.org/efficiency-hub/no-decision-about-me-without-me-shared-decision-making-in-the-uks-national-health-service/>

92. We asked "Would you support or oppose a database that allowed patients to rate the medicines and treatments they have been prescribed for certain conditions, which would be accessible to other patients?"

We know from other examples that involving patients more in healthcare - beyond the services they receive - can encourage them to feel ownership over the healthcare system and improve outcomes.

Structural changes could go some way to shift these cultural norms in favour of more patient involvement in the health and care system. We know from other examples that involving patients more in healthcare - beyond the services they receive - can encourage them to feel ownership over the healthcare system and improve outcomes.⁹³

The beginnings of such changes are already in action: during Covid-19 we have seen over a million people step forward to support the health service; many of these people were from a diverse background, and many would like to continue to support the healthcare service.⁹⁴ It therefore seems that, if a cultural change is needed to tap into patient power and expertise, one of the first steps should be recognising patients' value as people as well as patients.⁹⁵ To these ends, we recommend that:

Recommendation 5: NHS Improvement should conduct a review of how best to include patients as a resource in the health and social care service. This should include building additional opportunities for patients to get involved in the healthcare service more generally, for example, through additional or more varied volunteering opportunities.

In addition, it is clear that more needs to be done to ensure that patient rights are realised in the NHS. To ensure that as the NHS takes its next steps that patient rights are exercised we recommend that:

Recommendation 6: The Department for Health and Social Care (DHSC) and the NHS should ensure patient rights in the NHS Constitution are enforced and implemented through healthcare policy and delivery.

There are already a number of rights in the NHS Constitution that protect patients and maximise their experience. However, the importance of the continuity of care seems to be overlooked in the constitution, despite its benefits being well-known.⁹⁶ Our participants regularly pointed to the importance of being able to build strong personal relationships with their doctor in order to feel comfortable and confident to get involved in decision making. And with new digital mediums to stay in touch with doctors that have been magnified during Covid-19, it is important that the NHS continues to build its offer in-line with digital capabilities.

Specifically, we now see no reason beyond one of internal NHS structures why the idea of a 'family doctor' could not be recreated regardless of where members of the family now live, and no reason why an individual should not be able to keep the same doctor when they move to a different catchment area. We understand that this would require a change to the current contractual framework, but we feel that the benefits - particularly when some family members need the support of others, when members of the same family have the same medical needs, or when an individual values their ongoing relationship - outweigh the costs of change. In recognition that this is a big organisational issue, we suggest it should be introduced as a pilot to start with - for example by advertising for volunteers.

Recommendation 7: The Department for Health and Social Care (DHSC) should pilot including 'the right to the continuity of care' in the NHS Constitution.

Shared decision making and patient choice have been in the policy agenda for a time with little change.⁹⁷ And while this for a host of reasons, it seems that there is a real gap between policymakers and accountability for delivery of policies. A key challenge has been a lack of data collection on patient choice, and the impact it might be having on the services itself,⁹⁸ we therefore recommend:

93. Katherine Gottlieb, The Nuka System of Care: improving health through ownership and relationships, *International Journal of Circumpolar Health*, 72:1,2013. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3752290/>

94. What's Next: Priorities for Britain, Demos, 2020, p.15. Available at <https://demos.co.uk/wp-content/uploads/2020/09/What-Next-Priorities-for-Britain.pdf>

95. Batalden M, Batalden P, Margolis P, et al Coproduction of healthcare service *BMJ Quality & Safety* 2016; 25:509-517. Available at <https://qualitysafety.bmj.com/content/25/7/509>

96. George Freeman and Jane Hughes, Continuity of care and the patient experience, The King's Fund, 2010. Available at https://www.kingsfund.org.uk/sites/default/files/field/field_document/continuity-care-patient-experience-gp-inquiry-research-paper-mar11.pdf

97. Maskrey N. Shared decision making: why the slow progress? An essay by Neal Maskrey. *BMJ : British Medical Journal*, 2019;367. Available at <https://www.bmj.com/content/367/bmj.l6762>

98. No decision about me, without me: shared decision making in the UK's National Health Service, All.Can, Jul 4, 2020. Available at: <https://www.all-can.org/efficiency-hub/no-decision-about-me-without-me-shared-decision-making-in-the-uks-national-health-service/>

Recommendation 8: The GP Patient Survey should routinely include a question on (1) whether patients would like to have been presented with more choices in decisions about their medication and (2) whether they adhered to the treatment plan or course of medication that their doctor prescribed.

However, simply collecting data will not necessarily mean that organisations responsible for implementation will be held accountable. To push patient choice over medication up the agenda, we recommend:

Recommendation 9: Annual data from NHS Patient surveys should be laid before Parliament to ensure that CCG performance in delivering patients rights in the NHS is scrutinised and held to account.

Further, it is also important from a patient rights and empowerment perspective that patients have the opportunity to engage with all elements of decision making over medications, even when they include cost. Indeed, cost and fairness have been recurrent themes in our discussions with patients with immunology conditions. As Chapter 7 explored, patients often feared that they would be denied medications because of cost and assumed that their doctors were under pressure from above to recommend them the cheaper options. As our evidence review and expert interviewees

clarified, this is indeed a core part of running the NHS in a sustainable and fair way. However, that cost considerations are important does not mean that the current prescription process cannot be reformed to ensure that a) the patient-doctor relationship is not eroded by patients feeling that the doctor is not on their side and b) that the patient do not feel pushed into taking the wrong drug because of cost.

We, therefore, advise that if the doctor is restricting options or making a recommendation based on cost to the NHS, this information should be shared with the patient so that it can be on the table alongside other considerations that the patient may consider relevant. The evidence from our focus groups suggests that if the doctor is genuinely of the view that there is little difference in terms of effectiveness, having this information may well be welcome to patients. In general, however, we feel that decisions on cost-effectiveness should lie primarily with NICE, and that when cost, or cost effectiveness, is a consideration, that the information should be shared with the patient as a point of principle.

Recommendation 10: Additional online content created by NICE and NHS England (see Recommendation 4) should include information about the cost-effectiveness of medications.

APPENDIX 1

METHODOLOGY

As described in the introductory chapter, our primary research methods for this project consisted of: a nationally representative poll of 2,025 adults living in England, two focus groups, 12 patient interviews and 10 interviews with expert practitioners. This project was initially conceived prior to the Covid-19 pandemic but was then shifted online as the crisis took hold; our primary research ended up taking place from late July to early September 2020. In terms of the methods employed we do not feel that the pandemic influenced the integrity of the project: we routinely undertake polling online and the sample was representative of the England population. Neither did we feel that shifting the focus groups online constrained the discussion: in fact, given that we were recruiting participants with long-term medical conditions there was some indication that being able to take part remotely made recruitment to the groups easier.

Having said that, it is worth noting that because data were collected during the time of lockdown, when the NHS was under considerable pressure, it is possible that this would have influenced some of the responses, in particular for those on short-term medications (defined as those who answered “yes- but only for a certain period of time” to whether they were currently taking a prescription) and therefore might have been prescribed their medication under extremely adverse circumstances.

We carried out 12 semi-structured interviews with patients during the period between August-September 2020. The interviews were conducted by phone or video call, and lasted around 1 hour each. The participants were recruited by adverts on Twitter and paid £40 to participate. All patients we spoke with were being treated for immunological

conditions, and were sampled to include a range of different conditions. To achieve balance, we sampled patients with varying experiences in how much choice they reported to have had over their own medication, varying experiences in their relationship with their doctors as well as age, gender and region. Four of the interviewees were part of the same family and shared the same doctor. We conducted these interviews individually, and used the opportunity to explore how the background, lifestyle and personal preferences of the individuals would impact their experience of the same practitioner.

We conducted two focus groups in the week beginning the 17th of August 2020. The participants were recruited by a recruitment agency (MRFGR) and paid £40 to participate. The first focus group consisted of 6 participants and consisted of people on medication for any long term condition. As a minimum, the group consisted of 2 people aged over 45, and 2 aged under 45 to explore different experiences across age groups. The second focus group featured people on medication for an immunology condition, such as type 1 diabetes, rheumatoid arthritis, lupus, crohn’s disease or psoriatic arthritis with no other restrictions.

We undertook qualitative research with people on long-term conditions because we wanted to be sure that people had had numerous interactions with doctors over a period of time so that there was sufficient content to explore. We specifically chose immunology because it is a category of diseases which aren’t usually acute but are long-term, without the complexities of other conditions, such as cancer or mental health. Although we explicitly excluded discussions around particular

brands of products according to pharmacovigilance regulations we were also aware that our funding partner had a particular expertise in this area, which was available for us to draw on if needed during the research.

We did not seek to balance the sample for the interviews or the focus groups to make it representative of the wider population; instead, we sought to obtain participants with a diverse range of views and circumstances, with a specific focus on people with experiences of medicine choice. When analysing the data we were not seeking to understand prevalence – as with the survey – rather a deeper understanding of the reasons why people did or did not experience good choice over their own treatments. In practice our qualitative samples ended up with a reasonable geographic, age, socioeconomic and gender spread but non-white participants were possibly under-represented. (see tables 1 and 2 below).

AGE	GENDER	ETHNICITY (self-identified)	IMMUNE CONDITION
53	Male	White British	Ulcerative colitis
29	Male	Jewish	Crohn's Disease
23	Female	White British	Aplastic Anaemia
53	Male	White British	Type 1 Diabetes
49	Female	Jewish	Granulomatosis with polyangiitis
23	Female	White British	Inflammatory Bowel Disease
21	Female	White British	Crohn's Disease
24	Male	Jewish	Crohn's
52	Male	White British	Crohn's disease and Ankylosing Spondylitis
21	Male	White British	Crohns
53	Male	American-Irish	Juvenile onset Type-1 diabetes
38	Male	White or White British	Neurosarcoidosis (An immunology condition)

TABLE 1.
PARTICIPANTS IN ONE-ON-ONE PATIENT INTERVIEWS

AGE	GENDER	ETHNICITY (from standard list)	CONDITION	OCCUPATION
58	Female	White or White British	Depression (a long-term health condition)	Higher managerial, administrative or professional
55	Female	White or White British	Respiratory condition (a long-term health condition)	Semi-skilled and unskilled manual worker
53	Male	White or White British	High or low blood pressure (a long-term health condition)	Supervisory or clerical and junior managerial, administrative or professional
75	Female	White or White British	A heart condition such as heart failure or angina (a long-term health condition)	State pensioner, casual worker, or unemployed with state benefits only
29	Male	White or White British	Anxiety - Medication to lower blood pressure (a long-term health condition)	Higher managerial, administrative or professional
28	Male	White or White British	Hiatal Hernia (Acid Reflux) and often painkillers for back. (Slipped disk) (a long-term health condition)	Skilled manual worker
36	Male	Asian or Asian British: Pakistani	IBS (an immunology condition)	Supervisory or clerical and junior managerial, administrative or professional
50	Female	White or White British	Lupus (an immunology condition)	Higher managerial, administrative or professional
27	Female	White or White British	Sjogren's syndrome (an immunology condition)	Supervisory or clerical and junior managerial, administrative or professional
39	Male	White or White British	Rheumatoid Arthritis (an immunology condition)	Intermediate managerial, administrative or professional
45	Female	White or White British	Asthma (an immunology condition)	Intermediate managerial, administrative or professional

TABLE 2.
PARTICIPANTS IN FOCUS GROUPS

Throughout our qualitative research, we adhered to the BHbIA pharmacovigilance guidelines and recorded any mentions of adverse events: any unintended consequences associated with taking medication.^{99,100} As part of the screening process with participants, we gained consent to be able to share the contact details of any participant who reported adverse effects with our funding partners.

99. BHbIA. Guidelines and Legislation. BHbIA, 2020. Available at: <https://www.bhbria.org.uk/guidelines-and-legislation>

100. The ABPI Pharmacovigilance Expert Network and the BHbIA. Guidance notes on collecting adverse events, product complaints and special reporting situations during market research. BHbIA, 2018, p3. Available at: https://www.bhbria.org.uk/assets/Downloads/Guidelines/abpi_and_bhbria_guidance_notes_on_collecting_ae_pc_and_srs_during_market_research_final_20aug2018.pdf

POLLING QUESTIONNAIRE

Question 1

How many times in the last year have you had an appointment with a doctor?

By doctor, we mean a GP or a hospital doctor that you have had an appointment with. Do not include visits to emergency (A&E) care, appointments to take a test or when you have an operation.

*More than ten times; Between 6-9 times; Between 2-5 times; Once or twice; Not in the last year
If at least once...*

When you had appointment(s) with a doctor in the last year, did they have a conversation with you about the different options for medical treatments that might be appropriate for you?

*Yes during every appointment I had; Yes during some, but not all, of the appointments I had;
No, not at any of the appointments I had; N/A - I did not require medical treatments*

Question 2

Are you currently taking prescription medication?

Yes, but only for a certain period of time; Yes, for a long-term condition; No

These questions are about what happens when, or if, you are prescribed a medicine or other type of medical treatment by a doctor, such as your GP or a hospital doctor.

Do not include treatments you receive during emergency (A&E) care or during or immediately after an operation.

Question 3

In general, which of the following statements best represents your view regarding decisions about types of medicines or medical treatments? (select one)

*I would like the doctor to decide; I would like the doctor to decide, informed by my preferences;
I would like to decide myself, informed by the doctor's advice; I would like to decide myself*

Question 4

Thinking of the most recent time you were prescribed a medication or treatment, would you have preferred to be more or less involved in the decision about which medication was chosen, or was your level of involvement about right?

*Much more involved; Slightly more involved; It's about right as it is; Slightly less involved;
Much less involved; I have never been prescribed a medication or treatment*

Question 5

When you get advice from your doctor, how frequently, if ever, do you:

- disagree with their advice?
- obtain a second medical opinion from another doctor?
- research the advice you are given, for example by asking family and friends or using the internet?

Always; Often; Sometimes; Rarely; Never; Not applicable

Question 6

Do you think there is too much or too little independent information provided about which medication would suit you best, or is the level currently about right as it is?

Far too much; Slightly too much; About right as it is; Slightly too little; Far too little

Question 7

Would you support or oppose a database that allowed patients to rate the medicines and treatments they have been prescribed for certain conditions, which would be accessible to other patients?

Strongly support; Support; Neither; Oppose; Strongly oppose; Don't know

In the following questions, we are exploring how you feel about certain trade-offs. Please select the option which you would give higher priority to, even if you would prefer to select 'both' or 'neither'.

For each of the following pairs of statements, which comes closest to your views?

Option A, and I feel strongly about this

Option A, but I do not feel strongly about this

Option B, but I do not feel strongly about this

Option B, and I feel strongly about this

Question 8

A) All medicines that have been approved for NHS use should be equally available everywhere

B) Local NHS organisations should prioritise their spending according to priorities in their area, even if that means different medicines being more or less available in different parts of the country

Question 9

A) Patients should have the right to any medicine that is available on the NHS that they consider might help their condition

B) Doctors should be able to deny patients a medicine that is available on the NHS if they think there is something else that is more suitable

Question 10

Have you heard of the National Institute for Clinical Excellence (NICE)¹⁰¹? Yes-No

If yes...

You said you had heard of the National Institute for Clinical Excellence (NICE). In your own words, tell us what you think it does. You can write as much or as little as you want. [freeform]

DISCUSSION GUIDE

5 mins	<p>Introduction</p> <p>Welcome to the focus group. My name is X and this is X, we work for Demos, a research organisation based in London. We are an independent charity.</p> <p>We are conducting a research project to understand people's attitudes towards the choice of medicines in the NHS. We are interested in your own perspective and personal experiences.</p> <p>Housekeeping</p> <p>Our research is independent but we receive funding from the pharmaceutical company Abbvie to enable it to take place. We will not pass any of your details to them.</p> <p>This research is not about specific brands of treatments or medicines, and we do not ask any questions about this aspect of your experiences. However, we are required to remind you that if during the course of this focus group, you mention a side effect or a product complaint when you, or someone you know, became ill after taking a specific medicine, we will need to report this and it may be that the manufacturer will follow up with you for more detail. You have already consented to this but you are free to leave the session now if you change your mind.</p> <p>The session will be voice recorded to ensure I have an accurate record of what you say. It will be accessed only by people working on this project and contributions will be kept anonymous. There are six members of the public on this call, and two Demos researchers, myself and X. You can have your video switched on, or off, and you are free to leave at any time without having to give a reason.</p> <p>This session will take a maximum of 90 minutes and you will be paid £40 by the recruiters for taking part. There will be an opportunity for a very short break just after half way through if you need it.</p> <p>If anyone gets shut out of the group, please call my colleague X on X.</p> <p>[Check everyone has their normal name.]</p> <p>Is everyone happy to go ahead? Are there any questions before we start? If you have questions during the session, please do ask them or put them in the chat if you prefer.</p>
5 mins	<p>Icebreaker</p> <p>In our research we are particularly interested in the conversations that take place in the GP's surgery or during a routine appointment you might have with a hospital consultant.</p> <p>Perhaps we could start with some introductions. Please can you each tell the group your name and on a scale of one to ten how well you know your doctor.</p> <p>Do you always see the same GP or hospital doctor, for example? Do you feel that they know you well?</p> <p>[discussion]</p> <p>Are you happy with any of the conversations you have had with your GP or hospital doctor(s)?</p>

101. Sadly there is an error here: the correct name is the National Institute for Health and Care Excellence

<p>10 mins</p>	<p>What does 'patient choice' mean?</p> <p>Thank you. I'm now going to tell you a phrase and I want to know what it means to you. The phrase is 'patient choice'.</p> <p>[discussion]</p> <p>(Prompts if not mentioned: choice of doctors, hospitals, appointments, treatment plan, medicines?)</p> <p>What should 'good' patient choice look like? How do you know if it is working well?</p> <p>We've touched on a number of different aspects of patient choice [doctors, hospitals, appointments, treatment plan, medicines...others if mentioned]</p> <p>Which is the most important?</p> <p>And which is the least important?</p>
<p>15 mins</p>	<p>General desirability of medicine choice</p> <p>We are now going to talk in more detail about the general principle of patient choice when it comes to medication and medical treatments.</p> <p>Often it's the case that there is more than one medicine or treatment that could be helpful for a particular health condition.</p> <p>In general, when doctors prescribe medicines and treatments for patients, how important is it that the patients are able to choose which option is best for them? You can answer in general terms, or from your own experience.</p> <p>[if relevant: steer conversation towards conversations in GP surgery or routine appointment with hospital consultant, away from acute/A&E situations, during or post-operations, end of life care, ethics of refusing treatment]</p> <p>Speaking generally, what types of issues do you think doctors should discuss with patients when considering different medicines or treatments? (Prompts if needed - ease of formulation eg. pill/injection; side-effects; cost to NHS; effectiveness; effect of doing nothing)</p> <p>Should they tell patients about the cost to the NHS of the different options? For example if there are two options and one is more expensive for the taxpayer than the other, should the patient know that?</p> <p>Out of all things we've mentioned [list] Which issues are the most important to you personally? And the least?</p> <p>Thinking generally, who should make the final decision as to the best medicine to try?</p>
<p>10 mins</p>	<p>Personal experience of medicine choice</p> <p>We're now going to turn to your personal experiences of how these types of conversations have worked in practice.</p> <p>In general, do you feel your views are taken into account during the process of deciding which medicines should be prescribed to you?</p> <p>Thinking about a recent time when you had a conversation with a doctor about them prescribing medication for you, were you given a choice between different options? Do you feel you were told about all the options from your doctor? Have you since heard or come across any others?</p> <p>Did you fully understand all the options?</p> <p>Were you given enough information to choose?</p> <p>Who made the final decision of which option was prescribed?</p> <p>Were you happy with how the decision about your treatment was made?</p> <p>Could it have been better?</p> <p>How?</p>

<p>5 mins</p>	<p>Barriers to choice</p> <p>In your view, what is it that prevents patients getting more involved in the decision about which medicines might be best suited to them personally.</p> <p>[Prompts: patient-doctor relationship, lack of confidence, feeling of tight resources, inability to research the options, lack of time with doctor]</p>
<p>10 mins</p>	<p>Enablers of choice</p> <p>What would make you more confident in telling your doctor which medicine you wanted to try?</p> <p>[Prompts: more information as to what was available, how effective each was and any side effects, more time, second professional opinion, talking to family and friends, patient self-help groups, online trip-advisor type ratings for particular products]</p>
<p>10 mins</p>	<p>Break</p> <p>Let's take a quick break before the final section of the focus group. You can go on mute and pause your video but please don't close zoom down. Shall we come back at [5 mins time]</p>
<p>15 mins</p>	<p>Patient rights</p> <p>Welcome back.</p> <p>In this final section we are going to talk about which medicines are available to patients and why.</p> <p>As far as you are aware, are there any legal entitlements for patients when it comes to making a choice about the medicines you receive?</p> <p>[Prompts: Which individuals or organisations make that decision? Can you challenge it? Clarify whether their answer is something they knew already or if they've just realised it in these discussions?]</p> <p>Have you ever considered taking legal action?</p> <p>[If you wanted a medication that your doctor had refused, what would you do?]</p> <p>Has anyone heard of NICE?</p> <p>NICE is a government agency that approves treatments for use on the NHS, based on their effectiveness and their cost to the taxpayer. You, as a patient, actually have a right to any medicine that has been approved by NICE, as long as a doctor says it's clinically appropriate for you.</p> <p>In principle, if you had a health condition that needed treatment, would you want to know about all the different medicines that are NICE-approved that might work for you?</p> <p>[discussion]</p> <p>What if it's a long list?</p> <p>[discussion]</p> <p>Does knowing that you have this right as a patient - to any NICE approved medicine that might help you - affect how you feel about conversations you have had in the past with your doctor? How? Why?</p> <p>Now that you know you have this right as a patient - to any NICE approved medicine that might help you - do you think you will change your behaviour in future in any way? How? Why?</p>
<p>5 mins</p>	<p>Conclusions</p> <p>We're very near the end of the focus group now. Thank you for a really interesting and insightful discussion.</p> <p>I just have one final question.</p> <p>When thinking about all the issues we've touched on, if there's one thing you could change about the way that medicines are prescribed at the moment, what would it be?</p> <p>Finally, do any of you want to say anything else before we finish?</p> <p>Thank participants, remind that payment will be on its way.</p>

APPENDIX 2

A HISTORY OF PATIENT CHOICE IN ENGLAND

That patient choice is a core part of the NHS Constitution is the result of over a century of liberal philosophy and academic research. This section sketches out some of the key historical developments in the patient-doctor relationship and how these have informed the current model.

The role of the patient and doctors in healthcare has changed over thousands of years, taking multiple forms. In Ancient Egypt, a distinct priest-suppliant relationship existed, where the healer was responsible both for healing sufferers with magic and mysticism and representing them before god.¹⁰² The Ancient Greek model, by comparison, encouraged a more cooperative relationship, underpinned by Hippocratic Oath: “a code of attitudes that physicians must assume in relation to their patients”.¹⁰³ The oath continues to be relevant today - and is demonstrative of the patient’s rights and the doctors’ obligations.¹⁰⁴

In more recent European history - between the 18th and 19th century - the patient-doctor relationship has been a more paternalistic one. Symptoms

were understood as a consequence of internal pathologies that only doctors could comprehend, and as a result, the doctor’s assessments were final.¹⁰⁵

The dominance of the paternalistic doctor-patient model was challenged in the mid- 20th by the introduction of psychology. Psychology placed more emphasis on the patient as distinct individuals who respond differently to treatments. This meant that patient feedback became a valuable barometer of success for doctors.^{106,107} This paved the way for a more communicative relationship in which doctors and patients work together to tackle illnesses.

The result of these historic shifts is a modern emphasis on a shared decision making model in the 21st century, founded on the belief that the values, beliefs and responses of patients are a useful input in improving the provision of medical care.¹⁰⁸ The last decade of reforms in the NHS have been committed to this model, focused on a mantra of ‘no decision about me, without me’.^{109,110}

102. Harbisetar V, Krishna K, Srinivasa P, Gowda M. The Enigma of Doctor-Patient Relationship. NCBI, 2019. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482679/>

103. Osorio, J. H. (2011). Evolution and changes in the physician-patient relationship. *Colombia Médica*, 42(3), 400-405.

104. Oxtoby, K. (2016). Is the Hippocratic oath still relevant to practising doctors today?. *BMJ*, 355, i6629.

105. McKinstry B, Paternalism and the doctor-patient relationship in general practice. NCBI, 1992. Vol 42P340, *British Journal of Medical Practice*. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1372178/>

106. The Health Foundation, Person-centred care made simple What everyone should know about person-centred care, The Health Foundation, 2016. P14 Available at: <https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf>

107. Kaba R & Sooriakumaran K, The Evolution of the Doctor-Patient Relationship. *International Journal Of Surgery*, 2007. p59 Available at: <https://reader.elsevier.com/reader/sd/pii/S1743919106000094?token=1C719902DDAE1CEE479E8BE4F9E554E03442FC36CEBD4D52B9333462918153DCDE4D49126E4AF8E4765EB3D53C3E8988>

108. Coulter A & Collins A, Making Shared Decision-Making a Reality. King’s Fund, 2011. Available at: https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

109. Department of Health. Equity and Excellence: Liberating the NHS. 2010. p3, Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf

110. Department of Health. Liberating the NHS: No Decision About Me, Without Me, 2012. Available at: 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

In theory, this means that doctors and patients work together to generate a consensus about the best course of treatment.¹¹¹ Doctors offer their expert medical knowledge on a given medicine, while patients can offer accounts of their experiences with different treatments and indicate which they think is beneficial to their condition.¹¹²

REFORMS SINCE THE 1990S

Since the 1990s, successive governments have committed to achieving greater patient autonomy and expanding patient choice in the NHS. As this section will outline, policies have focused on patient choice regarding NHS suppliers, in particular GPs, and the hospital where a procedure is undertaken; only recently has policy attention begun to explore the potential of a shared decision making model over choice in medicines. Instead, reforms have aimed to reduce the reliance on top-down targets and centralised interventions, and place a greater emphasis on the impact on quality that comes from having a wider pool of healthcare services providers - including private companies and charities alongside the NHS - from which services can be commissioned and ultimately chosen by patients. This focus on provider choice has not been without its controversy: there are arguments that this type of provider choice is not what patients value¹¹³ and claims that it has had limited impact on the quality or efficiency of healthcare provision nationwide.¹¹⁴

The Internal Market

Reforms began establishing an 'internal market' in the NHS in the 1990s.¹¹⁵ This was based on the idea that competition in a closed market of newly formed NHS trusts would enable more choice for NHS patients between services, and this ability to choose would boost the quality and efficiency

of NHS services overall. On the demand side, GP Fundholding was introduced to give GPs more choice over which treatments they procured from hospitals and trusts.¹¹⁶

Throughout the decade, increased focus was placed on the significance of patient choice.¹¹⁷ However, there is little evidence that the increased choice given to GPs over providers resulted in the more direct choice of any sort for the patient.^{118,119}

New Labour and the expansion of choice

Upon winning the election in 1997, the incoming Labour government scrapped GP fundholding but maintained the separation between providers and purchasers of healthcare.¹²⁰ The NHS Plan of 2000 signalled a commitment to a shared-decision making model and improving the patient choice of treatment in principle: "NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works".¹²¹ The Plan stated that the government would enhance patient choice by expanding information about the options available to patients, as well as offering greater choice over local GPs.¹²²

The period 2000-2005 saw increased devolution from the NHS, as private providers were encouraged to offer more choices to NHS patients.¹²³ In part, the policies pursued practical benefits such as decreased waiting times and improved quality of care, but they also aimed at improving the availability of providers for patients.¹²⁴ Patients were given a handful of elective services to choose from, one of which was in the private sector. Primary care groups involving all GPs paid providers based on the number of patients

111. Edwards A & Elwyn G, Shared Decision Making in Healthcare: Achieving Evidence Based Patient Choice. OUP, 2009. p4

112. Coulter A & Collins A, Making Shared Decision-Making a Reality. King's Fund, 2011. p2 Available at: <https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality>

113. Alex Mold (2015), Making the Patient Consumer: Patient organisations and health consumerism in Britain, Manchester University Press. Available at <https://manchesteruniversitypress.co.uk/9780719095313/>

114. Marianna Fotaki (2014), What market-based patient choice can't do for the NHS: The theory and evidence of how choice works in health care. Centre for Health and Public Interest. Available at <https://chpi.org.uk/wp-content/uploads/2014/03/What-market-based-patient-choice-cant-do-for-the-NHS-CHPI.pdf>

115. Robinson R. The Impact of the NHS Reforms 1991-1995: A Review of Research Evidence. Journal of Public Health Medicine, 1996. p339 Vol 18 No. 3

116. Mays N, Dixon A & Jones L, Chapter 1: Return to the market: objectives and evolution of New Labour's Market Reforms. 2011. King's Fund, p4, available at: <https://www.kingsfund.org.uk/sites/default/files/chapter-1-Return-to-the-market-objectives-evolution-new-labours-market-reforms-sept11.pdf>

117. Brereton L & Vasoodaven V, The Impact of the NHS Market: A Review of the Literature. Civitas, 2010. P7, Available at: https://www.civitas.org.uk/content/files/Civitas_LiteratureReview_NHS_market_Feb10.pdf

118. Fotaki M, What Market-Based Choices Can't Do for the NHS. CHPI, 2014. p6 Available at: <https://chpi.org.uk/wp-content/uploads/2014/03/What-market-based-patient-choice-cant-do-for-the-NHS-CHPI.pdf>

119. Mays N, Dixon A & Jones L, Chapter 1: Return to the market: objectives and evolution of New Labour's Market Reforms. 2011. King's Fund, p10, available at: <https://www.kingsfund.org.uk/sites/default/files/chapter-1-Return-to-the-market-objectives-evolution-new-labours-market-reforms-sept11.pdf>

120. Brereton L & Vasoodaven V, The Impact of the NHS Market: A Review of the Literature. Civitas, 2010. P12, Available at: https://www.civitas.org.uk/content/files/Civitas_LiteratureReview_NHS_market_Feb10.pdf

121. NHS. The NHS Plan: A Plan For Investment, A Plan For Reform. NHS, 2000. p88 Available at: https://webarchive.nationalarchives.gov.uk/20121102184216/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002960

122. NHS. The NHS Plan: A Plan For Investment, A Plan For Reform. NHS, 2000. p89 Available at: https://webarchive.nationalarchives.gov.uk/20121102184216/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002960

123. King's Fund. An Independent Audit of the NHS under Labour (1997-2005). Kings Fund, 2005 https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/independent-audit-nhs-under-labour-1997%E2%80%932005-sunday-times-march-2005.pdf

124. Brereton L & Vasoodaven V, The Impact of the NHS Market: A Review of the Literature. Civitas, 2010. P7, Available at: https://www.civitas.org.uk/content/files/Civitas_LiteratureReview_NHS_market_Feb10.pdf

they treated ('payment by results'¹²⁵ rather than in block contracts.¹²⁶

Choose and Book, introduced in 2005, was a platform which intended to help execute the uptake of patient choice over hospitals and providers. The platform enabled choice at referral, allowing clinicians to give patients better access to treatments and hospitals which better suited their clinical needs.¹²⁷ The scheme has had mixed results, but some studies have suggested that patients believed they were not actually given a meaningful choice on appointment dates, times or hospitals: only a third of patients were given a choice of referral at their first outpatient appointment.¹²⁸ In addition, research by the King's Fund found that while 60% of patients were offered a choice through Choose and Book, the scheme was less popular with GPs who were less likely to offer choice to patients who needed more complicated treatments.¹²⁹

A 2007 government white paper named 'Choice Matters' marked the launch of the Extended Choice Network (ECN) - an initiative to extend patient choice from healthcare providers to a national level as opposed to just four or five locally. As long as the health providers were able to meet NHS standards and costs, then a patient could theoretically choose to pursue treatment provided by any public or private provider.¹³⁰

In this way, most of the focus was on the choice of provider. However, in his review of the NHS, Professor Lord Darzi recommended the introduction of personalised health budgets as an option for some people with long-term conditions and/or who required health support best provided in a nursing home setting. Building on the experience

of personalised budgets in the care sector, these enabled patients and their representatives greater autonomy to design their own treatment package within a given financial envelope.¹³¹

The Coalition Government's Health and Social Care Act 2012

In 2010, the Coalition Government stated their intention to extend the principle of shared decision making to their NHS in a number of white papers.^{132,133,134} This came to life through the Health and Social Care Act (HSCA) 2012, which signalled a drastic restructuring of the NHS. It placed duties on the NHS to promote the involvement of patients in choice of treatment,¹³⁵ and renewed its priorities for improving patient choice of providers by devolving responsibility for commissioning healthcare services to local CCGs and NHS England.¹³⁶

Through the creation of CCGs, the HSCA formalised the relationship between healthcare commissioners and private providers by dictating that no provider should be treated in an anti-competitive way¹³⁷ - thus allowing greater choice over providers for patients.¹³⁸ The result has been the increased role of external providers in healthcare. As of 2014, 30 out of a total of 195 contracts awarded by competitive tender have moved to non-NHS providers.¹³⁹

CCGs must engage their localities by gathering their perspectives and incorporating them into local healthcare commissioning. This is intended to improve the effectiveness of commissioning as well as the patient experience by allowing staff to better understand the population's needs.¹⁴⁰ CCGs can therefore make decentralised decisions about the provision of medicine which reflect the needs of the community they serve.

125. Mays N, Dixon A & Jones L, Chapter 1: Return to the market: objectives and evolution of New Labour's Market Reforms. 2011. King's Fund, p9, available at: <https://www.kingsfund.org.uk/sites/default/files/chapter-1-Return-to-the-market-objectives-evolution-new-labours-market-reforms-sept11.pdf>

126. Brereton L & Vasoodaven V, The Impact of the NHS Market: A Review of the Literature. Civitas, 2010. P13, Available at: https://www.civitas.org.uk/content/files/Civitas_LiteratureReview_NHS_market_Feb10.pdf

127. Green J, McDowall Z & Potts H. Does Choose and Book fail to deliver the expected choice of patients? A survey of patients' experience of outpatient booking. NCBI, 2008. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2529277/>

128. *ibid.*

129. Patient Choice: How patients choose and how providers respond. King's Fund, 2010. pp2-3 Available at: https://www.kingsfund.org.uk/sites/default/files/field_publication_summary/Patient-choice-summary-Kings-Fund-Anna-Dixon-Ruth-Robertson-John-Appleby-Peter-Purge-Nancy-Devlin-Helen-Magee-June-2010.pdf

130. Wallace A & Taylor Gooby P. New Labour and Reform of the English NHS: User Views and Attitudes. NCBI, 2010. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060529/>

131. Professor Lord Darzi KBE. High Quality Health Care For All 2008. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825?ldcService=GET_FILE&dID=168197&Rendition=Web

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134. DHSC. The Government's Mandate to NHS England for 2016-17. DHSC, 2017. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/600604/NHSE_Mandate_2016-17.pdf

135. Da Silva, D. Helping People Share Decision Making, 2012. p(i), available at <https://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf>

136. Glover-Thomas, N. The Health and Social Care Act 2012, 2013. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4523576/>

137. The Health and Social Care Act, Section 75. 2012 <http://www.legislation.gov.uk/ukpga/2012/7/section/75/enacted>

138. NHS Procurement, Patient Choice and Competition Regulations, 2013. Regulations 3(4). <https://www.gov.uk/government/publications/procurement-patient-choice-and-competition-regulations-guidance>

139. Iacobucci G, A third of NHS contracts awarded since care act have been awarded to the private sector, finds BMJ investigation. British Medical Journal, 2014. P1, Available at: <https://www.jstor.org/stable/pdf/26518964.pdf?refreqid=excelsior%3Af6742eeb28820d65ed9efe694900e55f>

140. <https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf> pp9-13

Following the creation of CCGs and localised healthcare commissioning, the NHS Involvement hub was launched to engage local populations about healthcare decisions. They provide information about methods for citizens and stakeholders seeking more active involvement in the running of the NHS, including stakeholder forums, elected representatives and formal consultations. The creation of the hub was based on the understanding that by engaging citizens in decisions about local healthcare, awareness of choice would be increased, and more citizens would be encouraged to utilise available options.¹⁴¹

While these engagement processes have created a more bespoke provision of healthcare to localities, there is no indication that these changes were motivated by providing specific medicine choice to individual patients.

The NHS Long Term Plan

By the end of the decade, however, that emphasis was changing. The NHS Long Term Plan 2019 included a commitment that “people will get more control over their own health and more personalised care when they need it” with a “fundamental shift in how we work alongside patients and individuals to deliver more person-centred care”.¹⁴²

There are two main actions to flow from this. First a commitment to “support and help train staff to have the conversations which help patients make the decisions that are right for them”, including the development of toolkits to support shared decision making in practice, and specific workstreams designed to promote patient choice as a whole through improved health literacy.¹⁴³ At the same time, following from a US initiative, a workstream entitled *Choose Wisely* aims to raise awareness amongst clinicians and patients alike of the benefits of not pursuing treatment, where potential costs and benefits are finely balanced. This too places greater emphasis on the content of the conversation between patient and doctor.^{144,145}

Second, a massive expansion of personal health budgeting to encompass a projected 2.5 million people in 2023-24. This *Comprehensive Model for Personalised Care*, which was constructed through public involvement with relevant stakeholders, will be particularly relevant for those with long-term health conditions and crucially links community and primary care providers through a patient-centric approach. It includes the choice of treatment, implying choice over the type of medication for long-term conditions but is also far wider, encompassing non-clinical ‘social prescribing’ community referral interventions as well as pharmaceutical solutions.^{146,147,148}

141. The NHS Involvement Hub. NHS. Available at: <https://www.england.nhs.uk/participation/involvementguidance/>

142. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

143. <https://www.england.nhs.uk/ourwork/patient-participation/health-decisions/>

144. <https://www.choosingwisely.co.uk/about-choosing-wisely-uk/>

145. Vogel, L Choosing Wisely around the world, *Canadian Medical Association Journal*, 2015 Aug 11; 187(11). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4527925/>

146. NHS England Comprehensive Model of Personalised Care. NHS England, 2020 <https://www.england.nhs.uk/personalisedcare/comprehensive-model-of-personal>

147. NHS England, NHS Long Term Plan, NHS, 2019. p25 Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf>

148. What is personalised care? NHS. Available at: <https://www.england.nhs.uk/personalisedcare/what-is-personalised-care/>

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