Better medicines: public and professional views on the lifecycle from discovery to taking medicines

Medicines Lifecycle Engagement Report

Hopkins Van Mil
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Bringing people together to inform the future

Contents

Foreword by Professor Alison Pilnick & Professor Reecha Sofat

Over recent decades, the way we develop and use medicines has been transformed: from research and development of new products to their regulation, the ways they are prescribed, and the experiences patients have of taking them. By exploring this entire medicines lifecycle through a deliberative process with patients, caregivers, and professionals, we have gathered their views and experiences about the challenges and opportunities that are already arising and those that lie ahead. Through a deliberative processes engaging with the whole of the medicines lifecycle, rather than isolated components of it, we have been able to create a bird's eye view which can inform prioritisation for future actions and interventions.

One of the clearest messages from this work is the expectation that patients should have a more active role. From opportunities to participate in medicines research to discussions over medication choices through to reporting side effects, people want to be involved and heard. Current systems are seen as presenting geographical, financial and informational barriers to this involvement. These barriers further compound system pressures and lead to poorer preventative approaches.

Equally important is the need to address disparities in medicines access and provision, and the ways these are perceived. What is seen by professionals as valuable flexibility for place-specific targeting can be seen by patients as a 'postcode lottery,' which they find unfair and hard to understand. A more consistent, data-driven approach could help mitigate these differences while maintaining flexibility for personalised care.

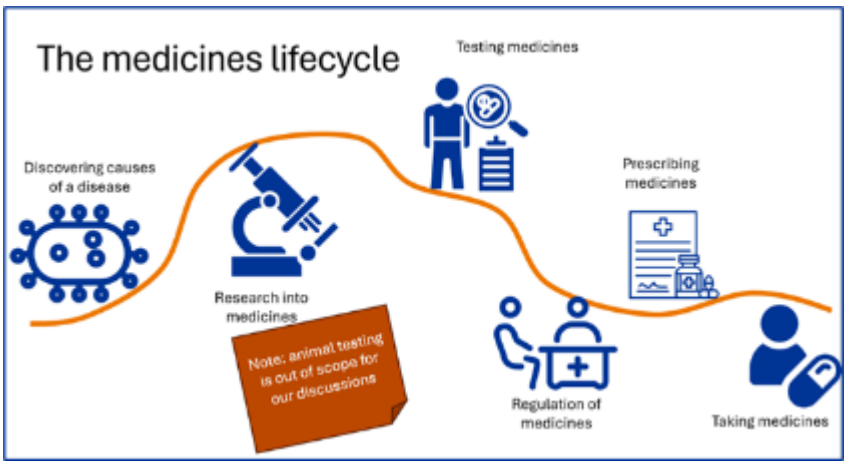
All of the participants recognise the importance of technology, but are also clear it is not a panacea. Enabling the flow of information and continuity of care across NHS settings is seen as a fundamental need. However, patients and professionals alike stress the importance of maintaining a balance between digital innovation and human expertise, so that the professional judgment of healthcare providers is not sidelined.

Healthcare infrastructure also plays a critical role in medicines policy, and the changing nature of the GP/patient relationship is significant here. As healthcare delivery shifts to a wider range of community-based settings, there is an opportunity to reconsider how medicines are managed, prescribed, and reviewed. Patients' primary ongoing relationships may now be with pharmacists and specialist nurses, for example. These relationships offer opportunities for these professionals to play an expanded role in medicines management, easing the burden on GPs as well as acute services while improving access to expert advice.

The future of medicines policy must be shaped by evidence, inclusivity, and collaboration. The themes outlined in this report bring together the views of stakeholders from throughout the medicines lifecycle. They present opportunities for further research and reform, ensuring that the way we develop and use medicines meets the evolving needs of patients and healthcare professionals alike. As a result of this work, we can inform the embedding of the medicines lifecycle in the NHS plan's 'three shifts' of embracing digital advances, strengthening community-based care, and prioritising prevention. We hope to use our findings to build a medicines system that is more responsive, efficient, and person-centred.

Executive Summary

In September 2023, Hopkins Van Mil (HVM) was commissioned by the University of Liverpool to carry out engagement with public and professional stakeholders on the medicines lifecycle.



Our aim was to explore public views and attitudes towards medicines from discovery, through regulation and policy to prescribing and taking medicines. We wanted to understand the medicines lifecycle from different views. Firstly, those that take medicines, where we explored their views on how the system works to deliver medicines for them and those they care for. Secondly, we explored the views of those working within the system, across the domains of drug discovery, both academic and pharmaceutical research, regulation and guidelines and health care professionals who are responsible for prescribing.

By spending time discussing the medicines lifecycle with both public and professional stakeholders, we sought to understand the similarities and differences in perceptions and practices. We believe that if these similarities and differences are addressed, it could help to improve the experience of those that take medicines and streamline the pipeline that sits behind the delivery of medicines to the population.

The engagement process and questions

Between June and August 2024, we involved a diverse group of people taking medication or caring for people with a range of long term health conditions: 31 took part in a webinar, three online workshops and a dedicated online space for sharing information and perspectives. An additional ten people taking medication took part in two one-to-one interviews. We also interviewed 13 people working in the medicines sector. Table 1 below summarises the main questions discussed.

Table 1 Summary of main questions

Main Questions	
To public stakeholders	**To professional stakeholders**
1. What do the parts of the medicines lifecycle mean to you/ your family/ those you care for? 2. Drawing on your experience and perspectives, what works well/ less well in your experience?	1. What issues in the medicines lifecycle do you think have the most impact on how patients and the public experience the medicines system? 2. What do you perceive to be key challenges or issues that need addressing within the system of

3. Taking medicines: what works well/ less well and why? Role of health care professionals (HCPs) Medicines reviews? 4. Reviewing professional and public stakeholder summaries of issues and opportunities for the medicines lifecycle – what's missing?	delivering medicines to those that need them? 3. What opportunities or solutions would you like to see to help address the issues we have discussed?

Key Findings

Both public and professional stakeholders share the view that medicines have transformed the health of the population and the science behind these discoveries is, as several participants said, "amazing". The process of ensuring the safety of medicines is largely trusted. Participants also acknowledge how thankful they are to live in a country with a publicly funded health system that enables access to most of the medicines they need.

But whilst the medicines lifecycle is seen in a largely positive light, there are still significant opportunities to optimise it. The report that follows focuses on the issues and opportunities raised by those we spoke with, highlighting the similarities and differences between public and professionals.

Medicines Research

An overarching ambition all participants share is for a greater diversity in the types of people who take part in medicines research studies, and in the types of issues and conditions researched. Both public and professional participants raised these hopes for change in the future:

- Research taking place in a wider range of settings: beyond major hospitals to more community settings
- Research design and recruitment that includes those traditionally excluded: older people, women, minoritised ethnicities, children
- More research into medicines use among people with multiple health conditions and the impact of polypharmacy
- Better communication of opportunities to be involved in research

Hopes and concerns more often voiced by public participants include:

- More research into the long term effectiveness and harms of medicines
- Better incentives and support for taking part in research

Points raised more by professional participants include:

- The structural barriers to research taking place in community settings
- International barriers and enablers to improving medicines research, such as global research practices sometimes limiting research settings to hospitals

Medicines Policy and Regulation

During the public stakeholder workshops what is seen as “the postcode lottery” of medicines availability was raised by participants’ own accord. This topic gained traction as several participants shared their own or family members’ experiences of differences in access to some treatments. The key difference in perspective to highlight between public and professional stakeholders is on the postcode lottery and the differences in care across the UK:

- Public stakeholders see these differences as an example of inequality, and many are surprised that discrepancies depending on location existed. There is a prevailing view that care should be consistent no matter where in the country someone is.
- Professional stakeholders are more accepting of the differences by location and many see the regional differences as a strength, enabling care to be tailored more to the needs of the region.

By regulation we mean the ways in which medicines are made available in the UK, for example how they are licenced and approved for use. There is a general feeling amongst both groups that, whilst there are many things that the UK can be proud of, there are opportunities for improvement when it comes to regulation. These include increasing awareness for the Yellow Card reporting scheme and reviewing and revising the medicines information available to the public.

The key difference in perspective to highlight in this section between public stakeholders and professional stakeholders is in the perceptions of how medicines regulation compares with other countries, particularly the United States.

- Some public stakeholders view the US as having more choice in medicines, particularly when it comes to medication for mental health conditions. This is a point of frustration as they cannot access the same medication in the UK through the NHS.
- Professional stakeholders feel that there are not many differences between the Federal Drug Administration (FDA) and Medicines Healthcare products Regulatory Agency (MHRA) and that any increased scrutiny is in fact a strength: many point to the damaging societal and economic impact of the US opioid crisis as evidence for this.

Medicines Prescribing and Information

For public participants a particular area of concern is the lack of time available to discuss prescribed medicines with a GP and the absence of continuity of care with a single GP. For professional stakeholders, concerns with prescribing generally focus on the issue that existing systems have not been designed to involve and combine the contributions of multiple professionals.

Key issues in prescribing raised by both professional and public stakeholders include the navigating between specialist and GP care, use of branded and generic medicines, and polypharmacy and deprescribing.

Medicines Taking and Reviewing

Public participants raised issues with medicines taking, focussing on experiences of unreliable medicines availability because of shortages and for some, a lack of support when you/ the person you care for are having difficulty taking a new

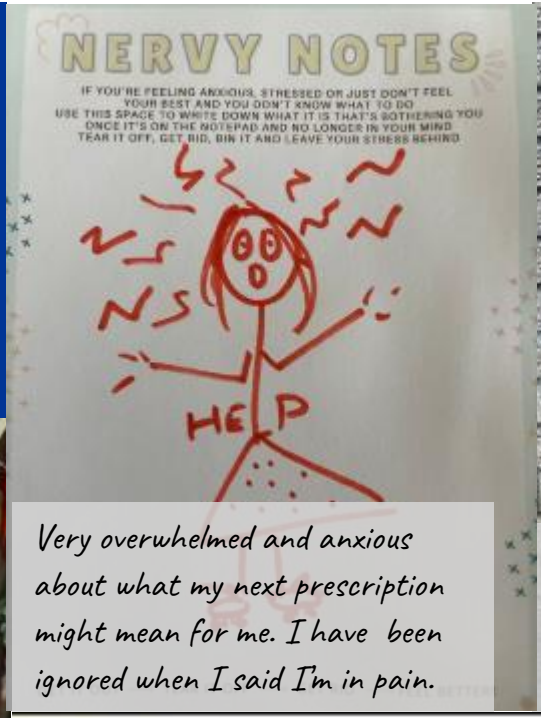
medicine. Alternatives to medicines, or ways to take fewer medicines and improve health, is another priority.

Issues that garner more professional stakeholder attention include the disruption of medicines routines caused by transitions between care settings.

Both public and professional participant cohorts think it is important to explore the role of patients in deciding which medicines to take and how they take them i.e. how to encourage a partnership between patient and healthcare professional, and how to reduce medicine wastage.

Part 1
Setting the scene

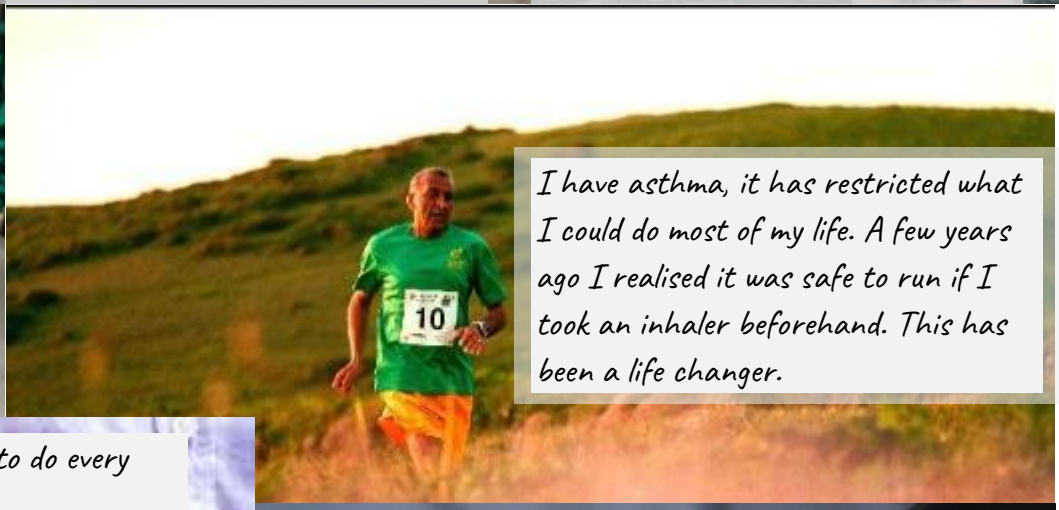
Before our public workshops began, we asked participants to share an image that represents their connection to medicines. These are some of their images.



Very overwhelmed and anxious about what my next prescription might mean for me. I have been ignored when I said I'm in pain.

Allows my son to have a mainstream education & attend school

The medicine I take enables me to wear whatever shoes I want, something I couldn't do for years!



I have asthma, it has restricted what I could do most of my life. A few years ago I realised it was safe to run if I took an inhaler beforehand. This has been a life changer.

This is what I have to do every morning.

My weekly medicine box. While it might seem a boring old photo, it symbolises the way in which medicines have become part of my daily routine; they are a habitual part of my life.

Our medicine cabinet at home. A huge mess!

1. Introduction

1.1 How did this engagement project come about?

Medicines are a major public health intervention. They are used in the treatment, prevention and cure of thousands of conditions. Scientific progress underpinned by technological advancement means that more conditions can be cured or prevented.

These advances do come with some cost, system and individual challenges. In the UK the National Health Service (NHS) spends approximately £40billion a year[1] on medicines (pharmaceuticals specifically). This is a cost second only to the workforce. However, within the system there are some major challenges which contribute to this cost, but also mean that we don't realise the full benefits of this cost. For example:

- The length of time to develop new drugs is approximately 13 years+ with additional delays in regulation
- [2]16.5% of UK hospital admissions are due to adverse drug reactions
- There is a significant lack of data around how new drugs perform when compared to medicines already available[3]
- Medicines data are not routinely linked to health outcome data, so we don't know if medicines are used as intended, if they are having the intended benefit and if they are value for money.

The Covid-19 pandemic disrupted usual systems of both healthcare delivery and drug discovery. Discovery and development of new treatments and vaccines for Covid-19 underpinned our exit from a society in lockdown. They also demonstrated that drug discovery, regulation and implementation can happen in time frames that were previously unrealised.

Now is an opportune time to review the medicines system, learn from the pandemic and explore changes that will potentially streamline the development of medicines, encourage more personalised medicines and improve medicines access and adherence.

In September 2023, Hopkins Van Mil (HVM) was commissioned by the University of Liverpool to carry out engagement with public and professional stakeholders on the medicines lifecycle. The Principal Investigator is Professor Reecha Sofat, Breckenridge Chair of Clinical Pharmacology and Therapeutics and NIHR Research Professor and the research was conducted in a collaborative partnership with Professor Alison Pilnick, Manchester Metropolitan University and Professor Aroon Hingorani, University College London.

1.2 What did the engagement project aim to do?

Our aim was to explore public views and attitudes towards medicines, from discovery, through regulation and policy, to prescribing and taking medicines. We

[1] Office for National Statistics
[2] University of Liverpool
[3] London School of Economics, 2021

wanted to garner people's understanding of this lifecycle of medicines and explore their views on how the system works to deliver medicines for them and those they care for.

We also explored the views of those working in the system. We interviewed health care professionals, regulators, academics, those working in the pharmaceutical industry and those who are involved in medicines policy and the implementation of it, including regulation, guidelines and access to medicines. We wanted to understand their views in developing and delivering medicines.

By spending time discussing the medicines lifecycle with both public and professional stakeholders, we sought to understand the similarities and differences in what they believe is important and what needs to change. Understanding these similarities and differences will hopefully help to show where research, policy or communication efforts are needed to improve the medicines systems and the health outcomes of the nation.

2. Methodology

2.1 How the project was designed and managed

HVM worked with the University of Liverpool, Manchester Metropolitan University & University College London research collaborative partnership to design an engagement project that involved people who take medicines and people who work in the sector. Our work was funded by the Medical Research Council (MRC) Health Data Research UK (HDRUK) and the National Institute for Health and Care Research (NIHR). The original design involved public and professional stakeholders in a series of cohort-based workshops. The process would culminate in a joint public and professional stakeholder workshop. However, finding dates to bring together the wide range of clinicians, academics, regulators, researchers and those working in industry proved to be impossible in our time frame. The engagement was re-designed to involve public stakeholders in a webinar and three online workshops. Between the second and third workshops we interviewed 13 professional stakeholders. We shared key findings from these interviews with public participants for their views at their third and final workshop.

Before the project went to fieldwork, the project team submitted details of the project aims, process and recruitment for review by the University of Liverpool Central University Research Ethics Committee A. The design received ethical approval from the Committee (reference: 13799) in June 2024.

The engagement process took place in three phases:

- Planning, recruitment, design and ethics review: October 2023-April 2024
- Fieldwork: June-August 2024
- Analysis and report writing: September-December 2024

2.2 Participants and recruitment

Public Cohort

For the recruitment of public stakeholders, HVM worked with the research collaborative to develop a recruitment specification. This specification sought to involve a diverse group of people taking medication or caring for people with a range of long term health conditions. 31 adults were recruited to take part in the online workshops. A further 10 adults were recruited to take part in one to one interviews. This is because we recognised that online workshops may not be accessible for some people on long term medication and that 1-2-1 interviews would be a more comfortable setting for our conversations.

HVM worked with the recruitment specialists Acumen. For the 31 adults with a connection to long term health conditions, two thirds had long term health conditions themselves, and one third were carers and family members, including parents of children with long term health conditions. The participants were selected to achieve a range of age, sex, gender, ethnicities and locations.

Full details of the recruitment can be found in appendix 1.

Stakeholder Cohort

13 stakeholders involved in medicines discovery, approval, regulation or administration in a professional capacity were invited to take part in 1-2-1 interviews, to discuss their experiences and views on the UK medicines lifecycle and how it could be improved. They are listed in the acknowledgements section on page 72.

2.3 What did participants do?

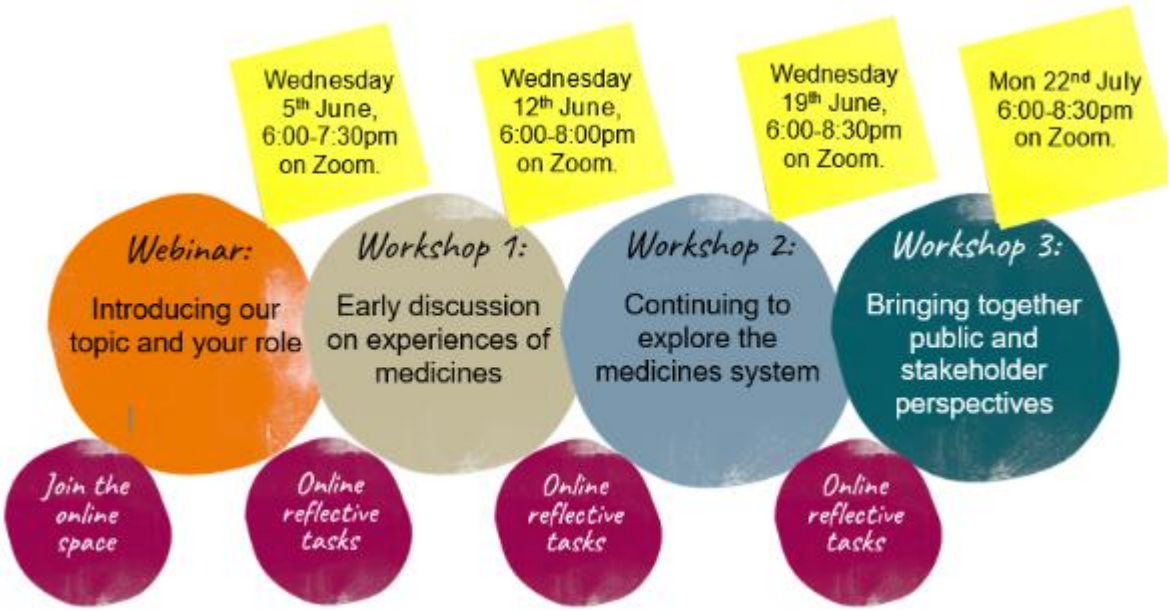
For the public online workshop process we used Zoom video-conferencing and a dedicated online space (Recollective). A webinar and three workshops took place between June 5th and July 22nd, 2024.

The initial 90 minute webinar introduced participants to the topic of the medicines lifecycle and more specifically what it looks like in the context of the UK. At the end of the webinar we showed an animation inspired by the art installation 'Cradle to Grave'. This showed some of the medicines which might be taken at different stages throughout a person's lifetime.[4]

The three workshops that followed totalled seven hours of discussion, presentations and Q&As, and visual voting using the tool Menti. In workshop 1, participants shared their first impressions and existing connections to the medicines lifecycle. For workshop 2, participants discussed the factors that influence decisions about medicines and their own experiences of how medicines are reviewed. For the final workshop, participants reviewed summaries of public and stakeholder views on the challenges and opportunities facing different parts of the medicines lifecycle and

[4] The animation was made by Hopkins Van Mil specifically for this project and drew inspiration from a previous project called 'Cradle to Grave' by Susie Freeman, Dr Liz Lee and David Critchley.

identified which of those mattered most to them.



Before and between the workshops, public participants used the online space to take part in activities such as uploading images that represented a connection to medicines[5], watching presentations, reviewing workshop notes and sharing views on discussion boards.

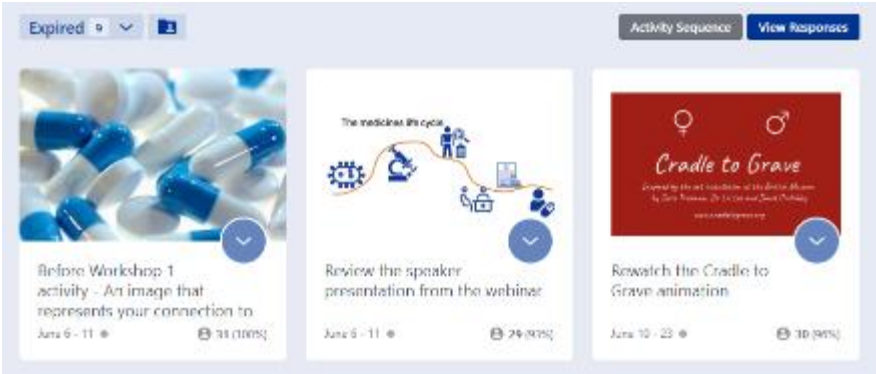


Figure 1 Online space Recollective

For the interviews with members of the public, participants were asked to answer questions on their own personal experiences of the medicines lifecycle i.e. what their day of taking or managing medicines looks like and their opinions of the medicines lifecycle more broadly[6]. The second interview focused on the wider context and participants answered questions on medicines research, medicines policy and regulation, prescribing, medicine information and the process of taking and reviewing medicines.

Professional stakeholders were interviewed about what they perceived to be the key issues within the medicines system and its structures, which issues have the most impact and if they had potential solutions for the problems that they identified.

2.4 How we developed the findings in this report

The medicines lifecycle is a vast topic. Our approach to discussion was to share the lifecycle as illustrated in Figure 2 with participants and ask for their views on what

[5] A sample of these are shared on Page 10. The complete set of images are included in appendix 2
[6] Interview questionnaire is in appendix 3

works well and less well for each component. At the start we did not share a pre-prepared list of issues or opportunities. Rather we wanted participants to identify, explore and share their own perspectives, based on their lived and professional experience.

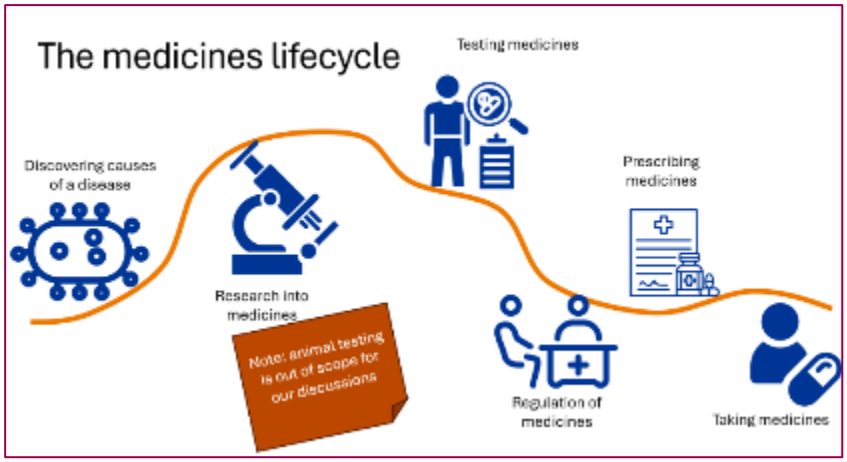


Figure 2 Lifecycle graphic shared in webinar

All the workshop discussions and interviews were recorded with the permission of the participants. The audio recordings were used to create transcripts. These transcripts and the responses on the online space were thematically coded using the analysis software NVivo.

The HVM analysis and reporting team met regularly to reflect on emerging themes and to develop our analysis approach. After each participant session, facilitators reflected on emerging views from their group discussions. Emerging findings from participant discussions and stakeholder interviews were explored and validated with participants in later workshops to test and refine our understanding.

Report structure

The findings section of this report follows the course of the medicines lifecycle. It begins with views on the how medicines are discovered and researched. We then explore medicines policy and regulation. This is followed by how medicines are prescribed and the information associated with this. The lifecycle findings end with views on how medicines are taken and how usage is reviewed. Because we involved more public stakeholders than those working in the medicines sector, we have more findings on the lifecycle topics that are more familiar to the public, notably the prescribing, information and taking of medicines. To conclude our findings, we share our reflections on where there seems to be greatest interest in future research to address the better use of medicines.

Language in this report

This research project is qualitative in nature. As such we do not report on the number of times something was said, but rather the strength of feeling expressed by participants across the methods used. Strength is determined by the kind of language used and the extent to which participants raise, review and return to an issue. We use the term **professional stakeholder** for the 10 participants who work in the medicines sector and the term **public stakeholder** for those who take medicines for long term health conditions or care for someone with a health condition. We refer to participant opinions and beliefs in the present and verbatim and paraphrased quotes in the past, to reflect how our discussions developed into current findings.

Interpreting and extrapolating findings

As with any research method, it is important to consider what the qualitative approach means for interpreting or extrapolating findings.

- People interested in a topic are more likely to sign up and attend. While our recruitment process was designed to reduce potential bias, participants may have been more interested in medicines than the general public.
- This report is a snapshot in time and people's views may change in the future.
- The dialogue was a qualitative exercise, which did not aim to be representative of the UK population. As such, findings are not intended to be statistically representative or generalisable across the wider public.
- The range of individuals involved and their personal experiences means that this report includes contrasting and contradictory findings. The aim is to share this range of experience rather than seek to always find consistency and consensus.

Part 2
The findings

3. Medicines in research

Calls for more real-world research: settings, people and multiple conditions

What you will find in this chapter

In this first chapter you will learn more about public and professional stakeholder views on medicines research as part of the medicines lifecycle.

Even though our discussions on the who, what and how of medicines research took place largely separately, there is a lot of common ground in what public and professional stakeholders think needs to change to improve outcomes from the medicines lifecycle.

An overarching ambition all participants share is for a greater diversity in the types of people who take part in medicines research studies, and in the types of issues and conditions researched. Both public and professional participants raised these hopes for change in the future:

- Research taking place in a wider range of settings: beyond major hospitals to more community settings
- Research design and recruitment that includes those traditionally excluded: older people, women, minoritised ethnicities, children
- More research into medicines use among people with multiple health conditions and the impact of polypharmacy
- Better communication of opportunities to be involved in research

Hopes and concerns more often voiced by public participants includes:

- More research into the long term effectiveness and impact of medicines
- Better incentives and conditions for taking part in research
- A more considered approach to media coverage of medicines research: balancing the coverage of sensational breakthroughs with better follow up over time to understand real impact and availability.

Points raised more by professional participants includes:

- The structural barriers to research taking place in community settings
- International barriers and enablers to improving medicines research

Levers for change in medicines research raised by public and professional participants includes:

- Changing the financial model of health research
- The application of Artificial Intelligence (AI) and technology

3.1 Perceptions of medicines research: from amazing to time-consuming

At the start of the workshop discussions public participants ranked medicines research as the second most important part of the medicines lifecycle, after "the effects of medicines on a person's health and wellbeing".

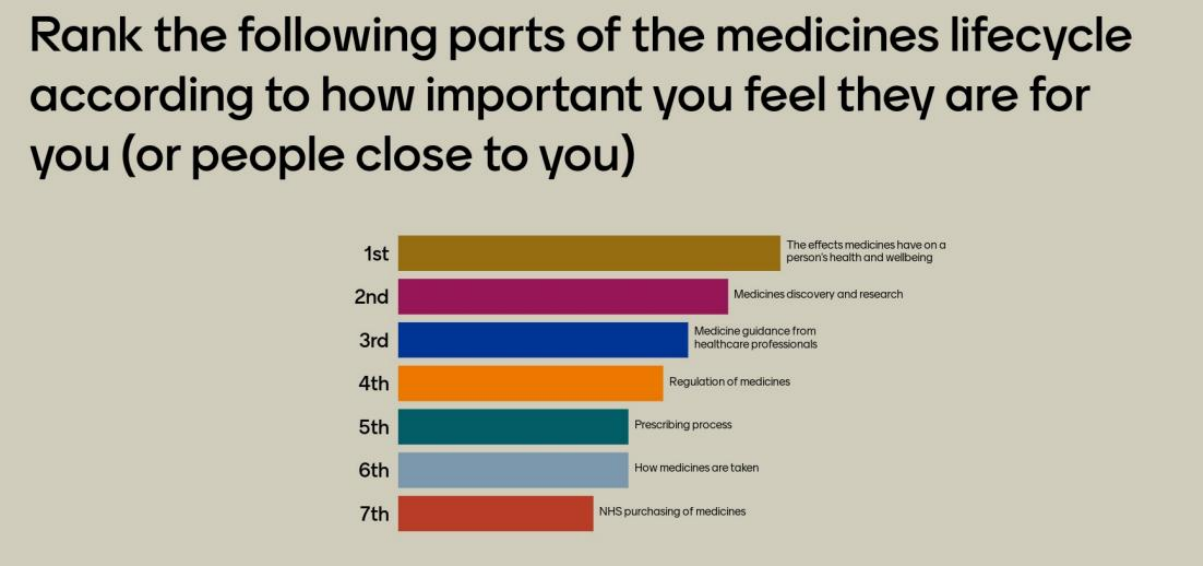


Figure 3 Menti response workshop 1

The importance of medicines discovery and research is underpinned by both positive and negative associations.

Positive perceptions are informed by personal experiences of how research has led to big improvements in public participants' or their family's health and care. Common conditions such as diabetes and rarer conditions such as Turner Syndrome were mentioned in this context. However many public stakeholders feel they have "no idea" how medicines discovery and research actually happens.

> *"It's amazing, the work that the scientists do when they're researching...a lot goes on behind the scenes that we just have no idea about."* ***Public stakeholder, workshop***

This amazement around the achievements of research is caveated by dissatisfaction with how long it can take for research to lead to medicines availability. Participants understand the tensions between speed of research and the safety of medicines, with COVID-19 vaccines the most cited example of this tension and potential benefits.

Another strong perception among participants is that large pharmaceutical companies decide what is and is not researched and that this is driven by what is likely to be profitable rather than what society needs.

3.2 Shared ambition 1: greater diversity in who takes part in medicines research studies

Research to find new treatments often excludes many people most in need of new medication. Both public and professional stakeholders hope to see changes in the research ecosystem that will enable a greater diversity in the types of people who take part in medicines research studies. This section explores what those desired changes are and the barriers that need to be overcome.

Research in a wider range of settings: beyond the major hospitals to include community settings

Conversations with both professional and public stakeholders explored the issue of most medicines research taking place in large hospitals in major cities. Some public stakeholders talked about personal experience of being offered places on research trials but having to turn them down because they lived in rural or suburban areas too far away from the trial centre.

Several professional stakeholders expressed a strong hope for research to take place in more community and smaller hospital settings. They see this as enabling a wider range of people to take part in research and therefore more closely replicating how the medicine would be prescribed and taken in the real world. But they put forward several barriers to this happening.

- A lack of equipment and staff: for example scanners may be needed as part of the study protocol, but research access to these is limited or impossible because they are overwhelmed by treatment demands.
- Pharmacy issues include:
    - Variance in pharmacy IT systems across different organisations (particularly community pharmacies) making it impossible to share information
    - Lack of training in clinical trials for pharmacists
    - Only large hospital trusts have the capacity to train a team to dispense for clinical trials
- The need for speed: when research sponsors look at locations for their studies, if it is quicker to run the study in a large hospital rather than several GP surgeries, they will choose the hospital.

> *"If you say your trial is going to take an extra year to run because we need to get 100 GP practices on board and therefore the set-up time is going to be longer, or you can do it in a small number of large hospitals that run a cardiovascular service, that's what gets picked."* **Professional stakeholder, interview**

A change that could help diversify the types of settings for research is appointing a wider range of health professionals, such as nurses, as Chief Investigators of Clinical Trials. Professional participants spoke about there being no barrier in law or

regulation for this to happen. But they said that long standing conventions and global practices were preventing this from happening as much as it could in the UK.

Another desired change that could diversify research locations is for non-commercial funders to add stipulations to their funding grants about running research in community locations that better reflect the treatment pathway. However, this is seen as a distant prospect.

> *Non-commercial funders "could have a lot more power in this space because they can set conditions that the sponsors and investigators have to respond to and make it requirements of funding required."* **Professional stakeholder, interview**

Research design and recruitment including those previously underrepresented: older people, women, minoritised ethnicities and children

The diversity of participants in medicines research is better than it was, but still not as it should be. This is the view of several professional stakeholders. For example some said that children are better accounted for in medicines research now compared to 20 years ago. This has been driven by the "regulatory incentive" of paediatric investigation plans for medicines research.

At the other end of the age range, the situation is different. Older people are the highest consumers of medicines but are currently underrepresented in medicines research. Professional stakeholders lamented this situation. They pointed to some studies involving 50 and 60 year olds. But for the most part they spoke of the reluctance of the pharmaceutical industry to involve people in their 70s and 80s, potentially because of their more fragile health and likelihood of being on medications for multiple conditions, which precludes their participation. They also spoke about the reluctance of some older people to travel to trial sites because they are limited by mobility or lack of transport.

> *"When you develop a drug, you often test it in a 50 or 60 year old with one disease and then you give it to an 80 year old with seven diseases and, and you're extrapolating from the 50 year old to 80 year old."* **Professional stakeholder, interview**

A past lack of ethnic diversity in research is a concern across all of our participants. Some are conscious that medicines being used today have only been researched among people of European heritage. Public stakeholders raised the Tuskegee Experiment[7] as one of the root causes of some minoritised ethnic people's distrust in medicines research and their reluctance to take part.

When discussing the historic absence of females in medicines research, one participant pointed out that even when testing medicines on rats, the rats were male.

[7] The Untreated Syphilis Study at Tuskegee

> *"We have developed drugs which have been developed in male rats and then tested in males, humans and then are given to women and men."* **Professional stakeholder, interview**

Some public stakeholders spoke about the lack of information on what medicines are safe for pregnant women to take. They understand that research is difficult in this area given the health and wellbeing of mother and child but they believe more should be being done to resolve this, rather than accepting this gap in medicines understanding.

Better communication of research opportunities: the need for a push and pull approach

Both public and professional stakeholders said there is a lack of communication about medicines research studies. Public stakeholders said their clinician had rarely talked to them about a study. They do not see opportunities to take part in medicines research promoted through healthcare settings. They hope to see more promoted in health settings but also more everyday channels and settings such as social media, supermarkets and TV.

Some participants spoke about experiencing a circuitous route into research. One participant knew of the wife of a patient looking up their psoriasis diagnosis on an NHS website and finding out about a research opportunity through that. They hold the impression that research opportunities have to be hunted out. Some professional stakeholders hope that in the future the patient-clinician relationship could evolve. They hope that patients would speak to their clinician about taking part in research, the latest evidence for treatments and what medical advances there have been for their condition. They saw this as a lever for change that would open up research to a wider cross section of society.

> *"I think if more people were going to ask their GP... "Are you running trials? Are you up to date with the latest evidence? You know, are you using the latest approved stuff?" It's putting a lot on the patient. I think we should be doing this ourselves, but patients are great advocates for that and actually creating that sense of demand amongst the public would result in change across the system."* **Professional stakeholder, interview**

3.3 Shared ambition 2: more research into multiple conditions, rare diseases and greater involvement in deciding what is researched

Another shared ambition among all participants is to see an expansion in the types of medicines research conducted. There are hopes for a shift from focusing largely on single drug research for common conditions that affect wealthy nations, to more research on treatments for people with multiple long term conditions (MLTC), rare diseases and medicines that will benefit low and middle-income countries.

More research into multiple conditions and polypharmacy

Several public stakeholders said they had been excluded from research because they were on more than one medication or had more than one health condition. They feel strongly that this means medicines are not being researched in a real world situation. Some professional stakeholders share this frustration. Increasingly, they see regulators consider multiple conditions as a factor in the assessment of medicines, but less so in the research process itself.

> *"In the real world, it [the drug] might be used in a sicker population or a population where there's a lot of polypharmacy. So I guess we have to do as much as we can during the [regulation] assessment to ask the questions and to try and work out whether this could be an issue in the real world."* **Professional stakeholder, interview**

Frustration and unfairness: a different financial and global model needed for rare disease medicines research

The point was raised at the start of this chapter about public stakeholders' perception and frustration with the profit motive driving what does and does not get researched. Several feel their lives and those of their loved ones are directly affected by the lack of research into medicines for rarer conditions.

> *"They can do so much in medicine, but it feels like money's got a big issue to play in it. My daughter's type [of epilepsy] is very rare. There's never going to be that much input into the research, and I find that very frustrating. The medicines don't work ... I'm sure they could come up with something. So I feel quite angry about it actually."* **Public stakeholder, workshop**

Professional stakeholders spoke about more rare diseases being identified as the population ages and how this challenge needs to be addressed by not only by the UK's medicines research and regulation system, but also globally.

> *"With a growing or older population with a growing understanding of rare diseases, the number of medicines required which are specific to those diseases is a challenge for the UK system."* **Professional stakeholder, interview**

The nature of rare diseases means that regulators are faced with reviewing research studies with small numbers of patients involved.

Some participants want to see more effective collaboration between countries around the world. They said collaboration is needed to increase the number of rare and ultra rare disease research participants to improve the quality and robustness of research. Professional stakeholders also spoke about the current differences in the way that medicines for rare and ultra rare disease are assessed across the world. This makes it complex for pharmaceutical companies to manage the different processes and forecast the market for their treatment.

Assessing rare disease research treatment impacts is more complex compared to e.g. some forms of cancer, where survivorship is the key measure. As is assessing the financial case for potential new treatments. Professional stakeholders spoke about the need for flexibility when reviewing the evidence, outcomes and costs for rare disease medicines.

> *"In cancer it's quite clear cut. Overall survival is a very clean outcome measure and progression is very clearly defined often. But in a rare disease it could be more suited to different problems, you know, from seizures to abnormal bone growth...So that is a real mixture of outcomes which are not well defined and not easily measured."* ***Professional stakeholder, interview***

> *"There are some major challenges in the rare disease space and NICE needs to be and are more flexible in considering that evidence when something comes a long way [through the drug development process] and think OK, this might be useful in that population."* ***Professional stakeholder, interview***

3.4 Public hopes for the future of medicines research

There is a lot of common ground between public and professional participants when considering hopes for the future of medicines research. However, we now look at three areas that drew the attention of the public more so than the professional stakeholders.

More research into long term effectiveness and impact of medicines

Many public participants believe that the main focus of medicines research is on new treatments rather than on the impact of taking medicines for several years and they think this is wrong. They attribute this focus on new treatments to the profit motive of most research. They believe that once a drug is approved for use, the pharmaceutical company switches to their next new development.

> *"Why does it feel like the emphasis and focusing on learning kind of just stops once that medicine has been developed and signed off and on the shelf ? That learning and therefore the role for research again, to sort of keep bringing research in to learn and gather feedback from how it's actually affecting people."* ***Public stakeholder***

Participants feel that this situation is unjust, because it leaves them living with a medicine which may help in some ways but also harm in others.

> *"I was thinking about asthma medication and people like myself. Lots of people who are on inhaled steroids over a very long time find that they then have so thin skin that they cut easily, require stitches, all sorts of side effects that are nothing to do with the condition. And you still need the steroids anyway, so there's nothing about how do you mitigate the damage that can happen while they're helping you. It's a strange situation*

where you're getting both help and hindrance from the same set of drugs." **Public stakeholder**

Making it more attractive to take part in medicines research: time and incentives

Practical and financial suggestions to enable more people to take part in medicines research in the future included a form of 'Jury Service for research.' This would mean participants would get protected time and money to take part in research, as they do for jury service. Some public participants see taking part in medicines research as a civic duty, which should be supported by government interventions.

"Some kind of legislation that you can get unpaid time off or time off paid for the better of our country, you know, jury duty, for example." **Public stakeholder**

Media coverage of medicines research: balancing sensational breakthroughs with better follow up about impact and availability

Discussions often touched on how medicines research is covered in the media. More often than not, public participants find this coverage frustrating. They dislike the pattern of hearing about sensational scientific breakthroughs that either never materialise or take many years, by which time it may be too late to benefit from them.

"I see on a regular basis, breaking news coming through from a news app about a way of breaking down proteins in the fragile proteins in the brain that is like a breakthrough drug for Alzheimer's dementia. And then you hear nothing more of it." **Public stakeholder**

Participants hope for media coverage in the future to include:

- More information on who has been involved in the reported research trials
- Information on a realistic timeline for when the medicine may come into use
- Coverage of progress that follows up on the scientific breakthrough headlines: e.g. now being researched in clinical trials or if the breakthrough fails, why this is.

3.5 Levers for change in medicines research raised by public and professional participants

Throughout this chapter, we have explored the participants' hopes and concerns about the current medicines research system and its outputs. This section focuses on what they see as the major factors that could change the way medicines research happens in the future.

Changing the financial model of health research

Both public and professional participants think that to make any significant changes to what gets researched, the financial model needs to change. No change means that the profit motive will always prevail, at the cost of research into important but less profitable areas such as rare conditions, multiple conditions and long term impacts.

> *"You get a lot of good original research through charities and universities, but the profit motive comes into it a lot. So then when it's handed over to the pharmaceutical companies, they can be very, very selective because they want to know where they're going to get a profit to it."* **Public stakeholder, interview**

Some professional stakeholders want to see the contribution of public bodies, universities and charities and access to health data in commercial drug development better recognised and rewarded. This could be in the form of more widespread sharing of financial earnings from medicines innovations or reduction in the costs of new medicines.

> *"We should be giving more thought to changing the economic model of drug development and recognising the public sector, the academic sector, charitable sector contribution to that early phase of drug development in a different way. Maybe the value contribution from that knowledge that's being used then by the pharmaceutical industry should be recognised in some way and I think it will need some discussion and some economic expertise as to how that could happen but could it be in the form of a revenue stream, a proportion of the profit being returned, recognition of the contribution in the pricing of new drugs, etcetera."* **Professional stakeholder, interview**

Better connections between what is researched and what medicines are commissioned

Some professional participants are frustrated by the "un-joined-up-ness" of the medicines system in terms of deciding what gets researched and then approved for use. They are frustrated with the amount of research that doesn't then lead to a treatment being commissioned for use in the NHS. They would like to see efforts to improve connections between what research funders are supporting and what bodies such as the MHRA and NICE end up approving for use.

> *"It's not very curated: there are organisations that set priorities or research charities that are responding to the needs of their supporters and, you know, fund us with specific remits to then fill gaps. And none of those organisations are the ultimate decision maker about buying things at the other end. The fact that they're so completely disconnected is problematic."* **Professional stakeholder, interview**

Applying AI and technology

AI needs careful handling but could be a force for good in medicines research. This is the perspective of several public participants. On the one hand, they fear that because AI works on available data, it will therefore benefit those with more common conditions with lots of data.

> *"AI is going to probably be a lot more successful in the beginning, at least in the realms of, you know, the more common conditions or more common cases. Whereas I think it's going to need a lot more data and a lot more time and work when it comes to people with multiple conditions, rarer conditions and personal circumstances, because less data is going to mean less progress."* **Public stakeholder**

But there is also significant optimism that AI will lead to faster and more accurate progress in medicines research.

> *"AI can quickly analyse the results from experiments in the clinical trials and you could also identify patterns and insights, for example, that could be missed by human researchers because, humans, of course, are not, very accurate. So I feel like AI, it could help therefore speed up the process to develop new medicines."* **Public stakeholder**

There are also hopes that the combination of monitoring technology and genetic developments will lead to more personalised medicines, delivered more quickly and in a way that suits the individual.

> *"You've got a microchip on your arm and it's going to monitor all your vital statistics on your phone or whatever or send it off to a central database. And they'll be able to highlight things and say, well, you're feeling a bit depressed today, here's some lithium for you."* **Public stakeholder**

4. Medicines policy and regulation

A trusted policy and regulatory system, with questions about medicines availability, approval time and information availability

What you will find in this chapter…

This chapter explores participants' perceptions of the UK's medicines policy and regulation. It starts with policy, where discussions mainly focused on medicines availability (what some refer to as "the postcode lottery"), differences in prescription cost policies across the UK and who has the ability to prescribe.

The regulation of medicines in the UK is seen as a point of pride but participants also identified opportunities for improvement. These include increasing awareness for the Yellow Card reporting scheme and reviewing the medicine information available to the public, including the content of Patient Information Leaflets.

The key differences in perspectives on policy and regulation between public and professional stakeholders is on the postcode lottery, the differences in care across the UK and differences in regulation between the UK and other countries, particularly the US.

- Public stakeholders see the differences in medicines availability as an example of inequality, and many are surprised that discrepancies depending on location existed. There is a prevailing view that care should be consistent no matter where in the country someone is.
- Professional stakeholders are more accepting of the differences by location and many see the regional differences as a strength, enabling care to be tailored more to the needs of the region.
- Some public stakeholders view the US as having far more choice in medicines, particularly when it comes to medication for mental health conditions, and for many this is a point of frustration as they cannot access the same medication through the NHS.

4.1 Is difference inevitable or an indication of wider inequality?

The "postcode lottery" of medicines availability

The "postcode lottery" is a key theme throughout the discussions. The term refers to how the availability of medicines and care can differ depending on where a patient is in the UK.

Some public stakeholders had experience of receiving different medicines for the same health condition, based on where they live. One participant spoke of a family

member who had access to a pump for insulin delivery, but she did not. The system of medicines availability based on where you live is seen as unjust by many public participants. There is a strong sentiment that, as we all contribute to the NHS, we should all receive the same quality of care and have access to the same medicine.

> *"I don't think where you live should have an influence on what drugs you get."* **Public stakeholder, workshop**

One participant shared their experience of having to fight to get access to medicine that was not available in their area.

> *"I have had to really, really fight to get the drugs that I wanted and that are going to give me the best outcome and the best quality of life."* **Public stakeholder, workshop**

However, when discussing the postcode lottery, professional stakeholders have different perspectives. Many said that whilst the discrepancies are not ideal, they are inevitable given the current structure of medicines policy. Furthermore, some pointed out that whilst there are differences depending on region, more often than not access to most common and vital medicines is widespread.

> *"So, I think that variation exists, but I think reassuringly there's much less variation than there might be, were there no formulary committees for example, or optimization committees."* **Professional stakeholder, interview**

Some professional stakeholders argue that there are benefits to Integrated Care Boards (ICBs) covering specific regions. This localisation allows ICBs to account for the needs of that area more effectively. They suggest that a nationwide approach could create more consistency, but that consistency could also lead to a more limited choice of medicines.

> *"For example, if all the money came out centrally, you didn't have to worry about the costs of the medicines at a local level, then that would be one of these solutions which you could entertain, but it probably wouldn't be taken up because it's this idea of the blanket approach, everyone has access to the same things, but it may be limited. More limited than if you had a localised approach."* **Professional stakeholder, interview**

Other differences in medicines governance and policy

Participants also drew attention to differences in the cost of prescriptions across the UK. In England a patient must pay a fee for a prescription, however, in Scotland and Wales prescriptions are free. Many of the public participants see this variation in policy as unfair, similar to the postcode lottery for availability of medicines. Some feel that instead of the NHS being split into different services by country, it should be more centralised to enable greater consistency throughout the UK.

> *"You know, it's supposed to be a National Health Service and we're not separate nations."* **Public stakeholder, workshop**

To address this perceived inequality some public participants, argued for more centralisation in the NHS. They felt that this would create a more consistent service

and reduce confusion amongst the public about what to expect in each part of the country.

Comparisons with medicines policy in other countries

Professional stakeholders have more to say on how UK medicines policy compares with other countries, particularly in the context of post-Brexit Britain.

Many highlight the impact that Brexit has had on the UK's access to medicines. Before Brexit the UK was a member of the EU's European Medicines Agency and drugs could pass smoothly through the EU/UK border. However, since leaving the EU the UK approves drugs independently and has become a smaller market.

> *"Then you've got big companies who are prioritising a massive market of the EU minus UK and we're a relatively small fish in this."* **Professional stakeholder, interview**

However, some stakeholders argue that whilst Brexit has brought limitations, our centralized decision-making process for drug approval has cut back on bureaucracy and makes it easier to navigate.

> *"So, when we're not the biggest market, clearly, we have a very strong centralised system in England and Wales where we've got one HTA body that makes all the decisions -NICE- and we have one essential buyer of the majority of drugs, which is the NHS. So one of our advantages is that we have a centralised system which is clear and easy to navigate, which is, you know, compared to Spain for example, it's quite different."* **Professional stakeholder, interview**

4.2 What part should government play in medicines policy?

More collaboration with industry to speed up and broaden medicines development

Many professional stakeholders feel that the Government should be collaborating more with industry to make medicines development more efficient and ensure that all health conditions are catered for.

It was pointed out that pharmaceutical companies are profit focused and therefore have limited reasons to carry out the expensive process of research and development for rare conditions. Therefore, some stakeholders argue that government should assist by financing the development of medicines for rarer conditions.

> *"So, whereas if you were to ask a company to develop a drug, they take all the risks of making that drug themselves and with the rising standard, obviously that not all drugs get through... The fallout for that is that you only develop things which can be sold for more money, more available to the bigger population set rather than the rare diseases... A big change was it [government] would support, or part support the development of drugs through financing."* **Professional stakeholder, interview**

The successful development of the Covid-19 vaccine over a short time period was frequently noted as an example of where industry and government collaboration can lead to greater efficiency and an outcome that suits all parties involved.

> *"So, a classic case would have been the UK and other European governments being intimately involved with the promotion of the academia interaction between Oxford, AstraZeneca in driving through the availability of the first set of vaccines. That's never been done before. So that's, in my view, a harmonious way of everyone working together."* **Professional stakeholder, interview**

The role of public involvement in medicines policy: awareness and accountability

Whilst collaboration between industry and government was a theme that frequently came up in professional stakeholder discussions, public stakeholders feel that there is a place for more public involvement in medicines policy and review. There is a general sentiment that this would increase public awareness in medicines policy and create some accountability.

> *"It feels like a dense topic and a topic that we as the public don't often get asked to think about. We seem often to be removed from discussions on policy and regulation."* **Public stakeholder, workshop**

Government roles in medicines availability for high cost treatments

Several professional stakeholders are concerned that as new treatments - such as gene therapies and stem cell therapies - emerge for rare diseases, their high cost and dependence on associated resources (e.g., specialist staff, scanners) makes them available only to wealthy countries and individuals. They worry about a widening divide in treatment availability around the world. An example of this is a new treatment for sickle cell anaemia.

> *"There is a gene editing therapy now available which potentially is curable as well, you know, but you need not only to be able to access the therapy, which is expensive, but actually you need all the infrastructure service around it because you know, you need your bone marrow to be ablated and in order to do that, you need all the infrastructure of a modern hospital, modern nursing etc. So if you consider sickle cell disease mostly affects people in Africa, how are they requiring access to this?"* **Professional stakeholder, interview**

> *"As we develop ways of being able to treat more rare diseases, develop these new therapies, it's becoming more and more expensive. And how do you make sure people have access to the medicines that they need so that we're not just developing medicines for the rich?"* **Professional stakeholder, interview**

4.3 Who can prescribe and how does it impact patient outcomes?

Both groups feel that the number of healthcare professionals with prescriber status should be increased. This would lighten the burden on the NHS and, if done properly, should not come at a higher risk. There is a general frustration, amongst public participants especially, that most of the responsibility of prescribing medication falls to GPs. Many argue that, given the state of the NHS, a wider range and number of healthcare professionals, such as pharmacists and paramedics, should be supported and encouraged to handle prescriptions relating to the field they work in and where they have the relevant expert knowledge.

Professional stakeholders also pointed out that secondary care consultants have no system through which they can change the drug therapy treatment of a patient. Instead, they have to instruct patients to have their GP do it instead.

4.4 Opinions on the UK system of medicines regulation

Overview

Public and professional stakeholders were asked to consider the current system for UK medicines regulation and draw upon their own experiences to highlight what we do well and where the key areas for improvement are.

Whilst participants highlighted some positives, the overwhelming consensus amongst both groups is that there are many issues that need to be fixed.

What the UK does well: medicines safety

Many public participants have a lot of trust in the institutions that regulate medicines to make the correct decisions on drug safety. Whilst there is frustration over the time it takes for new medicines to be approved, many participants feel that when a decision is made, patient safety is at the centre.

> *"The regulation, from what I see certainly in the UK, seems effective ... I'm fairly trusting of the medical profession in this country ... their safety-first approach sort of reassured me about the process we have in the UK."* **Public participant, workshop**

Safety and speed: between a rock and a hard place

Overall, both public and professional stakeholders recognise that there is a balance between safety and speed that needs to be struck. The example of the thalidomide scandal was brought up multiple times by public participants to highlight the damaging consequences for public health and trust when drug regulation fails. However, the development of the Covid-19 vaccination is seen as an example of how, with enough resources dedicated, fast development can be successful.

Conversely, one public participant provided a lived experience example of how shortened drug approval times can impact public trust. They did not vaccinate their children against Covid-19 as they did not believe that a thorough enough safety evaluation could have been done on the effects of the drug on children in such a short time.

> *"I've chosen not to vaccinate my children because I don't think there was enough research done on children ... I have two boys and I don't think [there is] research into what impact it has on reproduction. I wouldn't want to ... have impacted their ability to have children if they so wish to ... He is vaccinated against everything else, the usual children's vaccinations both my children are, but I chose not to vaccinate [against Covid-19]"* **Public stakeholder, interview**

Professional stakeholders spoke about mechanisms in the review and approval system that are enabling earlier access to promising medicines, such as NICE's 'Managed Access[8]' programme. They said that there is strong pressure on regulators to approve treatments that appear to be working and are relatively safe. They noted a greater acceptance by regulators that for some treatments, "speed is more important than having perfect information".

One public participant likened the difficulty of striking a balance between efficiency and safety as like being between a "rock and hard place" arguing that no matter what call is made there will always be a party that is dissatisfied or a risk that is taken.

[8] Nice Managed Access:

4.5 Comparisons with other countries

There is a difference in opinion between stakeholders and public participants on how the UK system for regulation compares to that of other countries.

Stakeholders see a lot of consistency internationally when it comes to drug regulation, however some public participants feel there is a lot of difference. The most frequently mentioned comparison is with US medicine regulation.

> *"I think a good sign of that is certainly now you very rarely see differences in regulation decisions except at the margin and about safety and efficacy between FDA, EMEA and the UK."* **Professional stakeholder, interview**

Public participants feel that medication, particularly for treating mental health conditions available in the US is "years ahead of anything that they'll give you over here". However, many public participants feel that this perceived greater variety of choice and availability is due to privatised health insurance. Whilst in many respects this greater choice is seen as a strength, there is a recognition that it comes at a cost, both monetarily and in the form of an increased risk of dependency.

> *"I had a conversation about this with my doctor and I mentioned the name of the medication and he said you might as well be talking about crack cocaine because, you know, it's highly addictive and it's not available over here. To even get diazepam over here is like asking for a kidney."* **Public stakeholder, workshop**

Some professional and public participants argue that the perceived greater choice of medication in the USA could be due to the fact that pharmaceutical companies are able to promote their prescription medicines through direct consumer advertising, which is illegal in the UK.

> *"With American patients big pharma can market their drugs and encourage people to choose their brand."* **Public participant, workshop**

4.6 Reporting side-effects: better awareness of the Yellow Card scheme needed

Many professional stakeholders highlight the need to improve the awareness and efficiency of the medicines side-effects reporting system. They argue that responsibility lies both with drug developers and regulators. They want drug developers to be more transparent and pro-active about potential side-effects. They believe that regulators should raise more awareness amongst the public on how to report problems, for example through the Yellow Card Scheme[9], run by the MHRA to collect, collate and investigate reports of suspected adverse drug reactions.

[9] The Yellow Card scheme guidance

> *"We need to develop much more robust systems for identifying safety issues as early as possible so that people do not develop serious adverse effects (that) may cause death and so on."* **Professional stakeholder, interview**

Professional stakeholders in particular, spoke of the importance of getting the Yellow Card scheme right. The scheme is particularly relevant for rare side-effects as they often do not show up in trials due to limitations on time and resources. As such, there is a reliance on patient centred reporting to identify these rare, serious side effects.

Many of the public participants feel that the Yellow Card scheme is not advertised to them as widely as it should be and there needs to be more clarity on how reports are acted upon.

> *"I hadn't heard of yellow card reporting before COVID"* **Public stakeholder**

One professional stakeholder highlighted that some evidence suggests that patient complaints are more useful for identifying issues than incident reports as they are unfiltered, and they have no organisational loyalty.

> *"There are other pieces of evidence that are coming in saying complaints actually have more useful information for looking at mortality than incidents do because the patients are unfiltered."* **Professional stakeholder, interview**

4.7 Do we need to change the regulations around what information about a drug is shared with the patient?

Some professional stakeholders said they have noticed an increasing public appetite for the right to access more information in many aspects of life, including medicines. They feel that the current regulated approach to medicines information wasn't keeping up with this; for example, the kind of information included in the Patient Information Leaflet (PIL) provided with all medicines.

An example of the kind of information that they believe should be shared is the predicted efficacy of the medicine e.g. the percentage of people it is expected to work in. They feel this could be shared in a simple and direct way.

> *"Take an anti-lipid lipidic drug and you say, well, actually trial show that it will be effective in reducing lipids in 20% of the patients. But none of the literature would actually ever tell you that in the product sheet...It's really simple digested information which has been submitted to regulators, but that never gets passed on to the patients."* **Professional stakeholder, interview**

5. Medicines prescribing and information

A complex picture in which professionals are struggling to meet patients' expectations, and as many patients' knowledge and influence is growing, professional guidance remains crucial.

What you will find in this chapter

In this chapter you will learn more about participants' views on prescribing practices and the information accessed in relation to medicines.

The first half of this chapter explores views on who is involved in prescribing medicines. It begins by exploring the role of GPs, pharmacists and specialists, before considering the role of patients. The views shared in relation to each of these roles are predominantly those of public stakeholders, who were asked directly about their views and experiences of the various roles involved in prescribing.

The second half considers key issues in prescribing raised by both professional and public stakeholders across the engagement activities. These issues are health system infrastructure, navigating between specialist and GP care, branded and generic medicines, and polypharmacy and deprescribing. The chapter ends by exploring views on alternatives to prescription medicines and sharing both public and professional hopes for the future of prescribing.

For public participants, the most significant areas of concern for medicines prescribing are frustration with the lack of time to discuss medication with a GP and not seeing the same GP on a regular basis. For professional stakeholders, concerns with prescribing tend to focus on the issue that existing systems have not been designed to involve and combine the contributions of multiple professionals.

5.1 The roles of GPs, pharmacists and specialists in prescribing medicines

The role of GPs: a stretched service struggling to provide patients with continuity and reassurance when prescribing medicines

GPs are at the centre of the prescribing actions experienced by patients. The capacity of GPs to play this core role is seen to be diminishing as they are placed under greater and greater pressures. It is in this context that many participants express dissatisfaction with the current state of prescribing. They related experiences in which they feel let down by GPs or their taking of medicines had suffered because of receiving unclear or inconsistent information.

Participants dealt directly with systemic problems, such as the frenetic conditions in which GPs are required to work, when raising issues with prescribing. More often

this led participants to challenge the primary care system rather than individuals within it. Participants described how these pressures shape their experience of prescribing, particularly through long waiting times and short consultations, and the consequences of this.

> *"The relationship with the GP and also with the pharmacy, the service that I feel that we're getting from both of those has diminished, primarily due to the extraordinary pressure that both of them are under with the number of people that they need to serve."* **Public stakeholder, workshop**

Longer waiting times have impacted how participants navigate the primary care system. Some now make an appointment as soon as they start a new medication so that this can be reviewed before their supply runs out. Short consultations leave participants feeling that they have not been treated as an individual, that they have been rushed onto a new medication, or that their problems have not been listened to or addressed in the round. Their comments suggest the need for greater depth or seeking more underlying explanation to the problems they are experiencing which cannot be fully considered in the short time available to them.

> *"They just treat symptoms mainly and don't really get a good understanding of you in your physiology or your psychology or anything like that and what could be causing it."* **Public stakeholder, interview**

This participant also referred to feeling "like a number" because "even when you're talking to them, it's like they're not even there … because they're so rushed off their feet and stressed". When asked about their understanding of patient-centred care, they cited this experience as an example of its "opposite".

Short consultation times also mean a shortage of time for explaining medications. One participant described how they had been prescribed a new anti-depressant so they could be taken off another one which was causing unpleasant side effects. However, the new medicine, mirtazapine, caused them to feel like a 'zombie' and they asked to be taken off it. The doctor asked them when they had been taking it and it transpired they had been taking it at the same time of day as the previous medicine, rather than at the end of the day as intended. At the workshop, this person reflected:

> *"I was like, why did you not tell me that? Of course, I take responsibility as well because I should have read the label that nobody reads. But I think that there is responsibility from a GP to also give a bit of a conversation about when to take your medication, because that three weeks … I couldn't focus and I just felt like I was walking around and half in a dream, and I was driving as well."* **Public stakeholder, workshop**

Participants also sometimes expressed negative feelings about the patient-doctor interaction itself. For some, this is a consequence of seeing a different GP every time, which results in having to repeat information and prevents a constructive relationship developing. Relatedly, a few participants had left consultations without feeling reassured about the medication they are taking, for instance because the GP is "asking you questions that sometimes I feel they should know the answer to". A

few described situations in which a poor interaction has led to them not taking their medication at all.

> *"He refused to give me the painkillers that I need. He's making me earn them, prove that I need them by starting me off on this low dose of this codeine painkiller which I know there's no point in me taking because they don't work and I don't want to routinely take codeine that's not working ... But when he told me off for not taking them routinely, he was very, very rude. And I'll be honest, it did not change how I took those medications because he was just so rude. And I just thought you're not listening to my concerns."* **Public stakeholder, interview**

When participants described more positive encounters with GPs, they emphasised the impact that quality consultations and more established relationships can have on their use of medicines and trust in them. When GPs demonstrate existing knowledge of their condition(s) and concern(s), and subsequently factor this into how they communicate with them, this is seen as particularly valuable.

> *"She knows all illnesses and she knows I have a lot of anxiety in that, as well. So she understands sometimes I get quite anxious when I'm talking about things. She knows that it might take a wee bit longer for me to explain things.* **Public stakeholder, workshop**

For many, living with a long-term condition has resulted in a deep knowledge of their condition. For these participants, it matters a great deal when doctors balance this experiential knowledge alongside their own medical training and knowledge.

> *"As somebody that's had a lifelong health condition and they're telling me what they think is going to be best... And you're a bit like, you've probably done a two-hour seminar on that. I've lived my life with this. So I think some consultants are really good and some of the GPs are really good at kind of listening to what you've got to say."* **Public stakeholder, workshop**

Participants also highlight when the advice they receive from their GP about their medicines leads to positive impacts on their day-to-day life. One participant described how a conversation with their GP about asthma and exercise resulted in advice to use their inhaler 30 minutes before exercising. They emphasised the value of this information exchange leading to a better understanding of their medicine and to a better quality of life.

The role of pharmacists: medicines specialists with the time, attention to detail and knowledge to improve prescribing experiences

Pharmacists play an important and effective role in communities which generally promotes positive experiences of prescribing. Participants described pharmacists as effective communicators who draw on a wealth of relevant knowledge about medicines. The potential impact of interactions with individual pharmacists is summed up by one participant as:

> *"You talk to one really good member of staff and they can just make such a difference to the path you're going down with your medication and your illnesses."* **Public stakeholder, interview**

Participants spoke about pharmacists being a first port of call for advice on the medicines they take. Some feel more comfortable approaching or speaking with pharmacists and often highlighted the information they received as being clear, informed and easy to action. Sometimes this could be as simple as the pharmacist writing information down.

> *"I found pharmacists are amazing for really breaking down information ... When I was on my chemotherapy and I could take paracetamol, but I couldn't take ibuprofen, and I couldn't remember what she was telling me. And she wrote it all down for me."* **Public stakeholder, interview**

These kinds of interactions can make pharmacists seem "more knowledgeable" about medicines for some participants and encourage them to seek out their advice over others in the system.

> *"Some of the time, instead of going to the GP, I tend to call the pharmacy and speak to a pharmacist. I find that they're better sort of, well, they seem maybe more knowledgeable in some sense, in some ways. And I think the way they get that information across or any answers to any questions, I find more reassuring."* **Public stakeholder, workshop**

Many of the factors contributing to dissatisfaction with the role of GPs in prescribing medicines inform the more positive view of the role played by pharmacists. The latter are seen as easier to reach and more likely to be available to respond to spontaneous questions about medicines. Participants described how medication questions, such as about side effects, may not occur to them until just before or just after they take a medicine, when they are usually at home. By then, some prefer "a quick call to the pharmacist" over trying to get through to their GP.

Whereas GPs are seen as likely to deal with one problem per visit, pharmacists are considered able to help with lots of problems at once. Not only do public participants appreciate being understood in this more holistic sense but they also feel it improves the quality of the advice given, such as when pharmacists flag potential interactions between different medications. Some participants put this down to pharmacists having time to listen to concerns and shape their advice accordingly.

> *"Maybe they have the time to really listen and to give anecdotal advice and information and say, 'oh, a lot of patients say this and oh, let me go and I'll look into this medication for you'. It feels a lot more hands on and knowledge-based."* **Public stakeholder, interview**

Pharmacists are generally seen as being extremely knowledgeable about medicines. Whereas medication is seen as their wheelhouse, GPs are understood as needing to maintain knowledge across many aspects of healthcare. As in the quote above,

pharmacists' knowledge is seen as particularly practical, "hands on" or close to the "frontline". One participant described this in terms of the physical act of "touching and feeling and moving" medicines, as though this proximity gives them greater awareness of what it is like to take them.

> *"Because they're on the frontline and actually touching and feeling and moving the medication around, then they seem to be much more in touch with the medication."* **Public stakeholder, interview**

This expertise is underscored by a number of the professional stakeholders spoken to during the project. One described them as "true experts in the medicines", whilst another agreed with public stakeholders when they stated that because pharmacists "have more time, they usually have a bit more information". Another professional also highlighted the emerging and growing capacity of pharmacists to prescribe medicines. They described the fact that new pharmacy graduates automatically come out "as fully-fledged prescribers[10]" as "massively important."

One public interviewee outlined the growing importance of the pharmacist within their local GP surgery to their experience of medicines. This participant described how, over time, they had spoken more and more to the pharmacist, and less and less to their GP or specialist asthma nurse. The participant is concerned about the environmental impact of their asthma medicines and recounted how they were able to explore alternatives with their pharmacist. The participant's awareness of the pros and cons of different asthma medicines spoke to the effective way in which the pharmacist had communicated this to them. Experiences like these inform a wish by participants for more widespread awareness of pharmacists' expertise and for more people to seek their advice.

> *"I used to think, well, pharmacists have some training on medication, but they can't advise you in the way a doctor can. But actually they can. And they have so much knowledge at their fingertips... I think a lot of people have no idea how useful their pharmacist is."* **Public stakeholder, interview**

Where participants drew attention to issues relating to pharmacies and the role of pharmacists, these primarily focus on waiting times and the availability of medicines. A few participants described the process for ordering repeat medications as frustrating or placing them at risk of running out due to tight timings. One participant described how their pharmacy had changed the way it worked. They feel that due to the "extraordinary pressure" the service is under, her pharmacy now only started to dispense their child's prescription when they arrived at the pharmacy, despite them regularly collecting medication for their child's long-term condition over a period of several years.

> *"[It] is extremely frustrating because that then turns into another half an hour or 45 minutes time for me for every visit there. And my kid's still got this lifelong condition. We are definitely going to turn up."* **Public stakeholder, workshop**

[10] General Pharmacy Council

The role of specialists: important for explaining complex medicines information but not always effectively communicated to the patient

Participants identify a similar set of pros and cons for the role played by specialists in prescribing medicines. For example, close attention to the patient's experience of their condition or concerns stands out as a likely contributor to a successful consultation from participants' perspective. Going the extra mile to understand and avoid the side effects patients are most concerned with is given as a concrete example of such attention as illustrated in this participant's experience with their diabetes nurse specialist.

> *"When I went back onto blood pressure medications again, I was concerned that I might be put on one that would cause hair thinning. So she looked into the ones that I had been on before and she tried to pick a medication that was in a different class, and she checked the side effects to make sure that it wasn't listed as a side effect before she put me on it. So that was a really positive experience. It wasn't just, well, here's what we give everybody."* **Public stakeholder, interview**

One quality attributed to specialist practitioners in particular is around the level of detail they can go into when explaining a medicine and its effects. More than once, participants with diabetes favourably described the comprehensive advice they had received about how to use insulin.

> *"They've been very clear about doses, about how to take it, showing me. I think my first ever dose, an injection that I had to take, a community nurse came out and did it with me... And she was brilliant at talking me through parts of my body where it wouldn't hurt as much as others. Gave me a number for a team to call if there were any issues. So it was very reassuring that they were there to help."* **Public stakeholder, workshop**

Another participant appreciated a specialist's advice relating to epilepsy medication because it was tailored to the wider context of their life and focused on the potential side effects and drug interactions most relevant for them.

> *"We talk about the wider picture of who I am, what I need to take as a female that doesn't want to have any more children."* **Public stakeholder, interview**

Some of the main issues participants spoke about in relation to the role of specialists in prescribing medicines are similar to those associated with GPs, such as a failure to engage with concerns more holistically. One participant described how a change in their haematologist did not suit them because the new consultant prioritised blood test results and the importance of taking medications over the broader context of their life. This led the participant to carrying out more independent research and placing more responsibility on themselves to improve their condition. They said:

> *"Whenever I've written down questions and said, 'I've been told this, can I get some clarification?' I've kind of been shut down and told, well, 'we don't believe that to be true' and that's it... I wouldn't go back to this haematologist for it's almost like he*

> *doesn't want to know and he doesn't want to understand. He just wants to look at the platelet levels and make sure that I'm taking my aspirin every day and as long as my platelets aren't really, really high again, [it's] 'see you in six months'. So I do all my research elsewhere and I suppose I focus on the lifestyle".* **Public stakeholder, interview**

Whilst a number of participants spoke highly of the advice they received specifically in relation to diabetes treatment, someone else explained this isn't the case for them because advice was relayed in a fast-paced and overwhelming hospital environment. They said the shock of receiving the diagnosis meant they were not in a state to absorb all the new technical information. This left them thinking the following when they left hospital:

> *"I didn't know where to inject the insulin. I couldn't remember anything, do I put it in my tummy? Do I put it in my arms?"* **Public stakeholder, workshop**

Likewise, another participant who was a parent of a child with epilepsy finds the specialist instruction they need is lacking. They described how the emergency medication they had been provided with required healthcare professionals to undergo a whole day of training in order to administer it. As parents, on the other hand, they said it had just been given to them. They later found out that the advice on how to administer the medication had subsequently changed but this information had not been passed on to them.

> *"It just feels very odd to me that professionals have to have such training and parents are just told to go and give it without any talking through."* **Public stakeholder, workshop**

Participants also identified psychiatry as a specialism with its own particular issues in relation to prescribing. One participant recounted how they were prescribed an anti-psychotic medication called zuclopenthixol in hospital, whereas previously they had taken olanzapine. They described the experience of taking the new medication as follows:

> *"I genuinely thought I had brain damage at one point in the hospital because it was like I was trapped in my own body screaming, but I couldn't do anything. I was a total zombie."* **Public stakeholder, interview**

Most relevant for prescribing is that this participant went on to explain how, had the possibility of such side effects been explained to them beforehand, the experience would not have felt as though "I'm never going to get out of this", and they would have felt "more at ease".

Another participant said that their level of understanding or interest in their medications could be underestimated. This informed their view that the approach to prescribing such medicines is closer to what drug is currently in favour at the expense of the priorities and wellbeing of the patient.

> *"I like to know how things work. I'll read up on how the antidepressant works with serotonin or dopamine. I just think if I understood it a bit better, I'd be a bit more motivated to take it, especially with mental health drugs, and how they come to decide what drug it is I'm going to try. Is it just because it's the going one at the moment or is it the one that's actually better for me?"* **Public stakeholder, interview**

5.2 The role of patients in prescribing

Positive experiences of growing influence and voice of patients

Participants who have contributed to prescribing decisions frequently described the benefits of doing so. Positive impacts of growing patient influence and voice in this context include feeling understood, respected and heard, and approaching decisions collaboratively and on a level playing field. A number of participants explored how this influence and voice has evolved gradually. They compare feeling more empowered now with being quieter, less interested and less involved previously.

> *"I think it's taught me ... to actually voice out more and speak up for yourself and advocate for yourself. Whereas before I was diagnosed with my illnesses, I was very quiet, listened to the doctors, to the hospital."* **Public stakeholder, workshop**

A big part of this appears to be about being more comfortable to ask questions as part of any discussion on medicines. This is often supported by growing knowledge and confidence. Participants are also motivated by the positive response they receive from doctors and other healthcare professionals when they do demonstrate interest and awareness. This is sometimes described in terms of reciprocity:

> *"I have found once I have kind of engaged in the process, I have received that engagement back."* **Public stakeholder, workshop**

Participants described these experiences as having wide-ranging impacts, from small adjustments that make a big difference, such as changes to a medication so that it can be taken at the same time as others, to increasing trust in the healthcare system. Patient influence can be particularly important in the context of rare conditions, with one participant explaining how they carry literature to help healthcare professionals understand their condition and have even been asked which antibiotics they can take when these need to be prescribed.

Concern for those who are without influence and voice

Several participants raised concerns about the ability of some patients to advocate for themselves and positively influence prescribing decisions. This concern comes partly from those who have successfully influenced their own situation and therefore appreciate the sheer amount of research and communication that can be necessary to achieve that. When participants have experienced the direct benefit of having influence over their own or their child's treatment, this makes them worry about the standard of treatment afforded to those who do not have that influence.

"We're really lucky that my kids' treatment has gone the way it has just because I've been able to communicate stuff and communicate needs and communicate our awareness of the benefits of different kinds of treatment." ***Public stakeholder, workshop***

Different characteristics are suggested as factors which can make it more difficult for a patient to exert influence in a healthcare setting. These include age (being both younger and older); sex (being female); education (being less equipped to carry out research); having a cognitive impairment; and not having a diagnosis.

Factor	Illustrative quote
Age	*"I do worry, for example, my Gran who can't use the Internet and she's not super educated or whatever. She would just go sit in the doctor's surgery and hope that the doctor would prescribe her the right thing and take it religiously."* ***Public stakeholder***
Sex	*"When it comes to anything related to women in pain, it can often be overlooked."* ***Public stakeholder***
No diagnosis	*"Before [the diagnosis of a mild cognitive impairment], it's like, 'oh, well, maybe it's because you've been a bit stressed. Maybe it's because of this, maybe it's because of that, there's a lot of gaslighting goes on'. Unfortunately, when you have multiple health conditions, especially something as broad as fibromyalgia, they tend to [say] everything is, 'oh, that's just part of your fibromyalgia'."* ***Public stakeholder***
Cognitive issues	*"The work that the CQC have done around epistemic injustice and the human rights approach has shown that it's also people who've got cognitive problems that are even lower down in the pecking order. So that would include patients with learning disabilities or autistic people and people with dementia. And I think there's something really important about that because we've got to think about how we support the most vulnerable people that we look after because if we get it right for them, we get it better for everybody."* ***Professional stakeholder***

Based on these concerns, there is hope that a balance can be found in which those patients who influence their healthcare can benefit from doing so, without introducing disparity between the standard of their care and the care of those who have less agency.

> *"There needs to be a better kind of balance. So those who can't come in armed with lots of research still get good direction."* **Public stakeholder, workshop**

Patient-led information seeking: positives

Public participants also spoke about their own role in seeking out medicine information. Their experiences and the impacts of this are mixed, but many identified positive reasons and results. A lot of medicines information is accessed online, via a wide range of sources including the NHS, American medical sites such as the Mayo Clinic, YouTube channels run by doctors, and peer support groups. One participant also referenced an online platform which gathers reviews of medicines by those taking them.

The NHS website is described in contrasting terms: as a first port of call and "safe middle ground" with up-to-date information, but also as "dumbed down". Some participants value what they see as the more comprehensive information available on American websites. One participant, who accesses US sites when they are dissatisfied by the information available via the NHS, sees it as a "blessing and a curse."

> *"If it doesn't give me what I want to know, I'll just go to the Americans, their equivalent sort of drug pharmacy type website, and find out what they've got written about it as well... One of the ones in America where people can ... leave reviews about their own personal experience of being on that medication."* **Public stakeholder**

One of the biggest positives participants associate with seeking out their own information is the access this provides to other people's experiences. Peer support groups are said to be one of the most helpful sources of information in this regard. Some value listening to the experience of others with the same condition above anything else. This appears to be particularly important for those who have rare conditions themselves or in their family after finding a lack of information and advice in the healthcare system.

> *"We just joined every group going on Facebook essentially. And was it in those groups that then you started to find information more easily ... It was switching a light on. It was brilliant ... Now, we do it all the time."* **Public stakeholder, workshop**

One participant spoke about drawing inspiration from peer support groups, in which they discovered others with the same condition using different medication and experiencing a better quality of life. They described how they are summoning the courage to take this new understanding into their next NHS consultation in the hope of improving their own situation:

> *"I am on those peer groups that are of people who have Addison's, and who are having such a great quality of life. I would like to live long and I'd like to have a good quality of life and be able to be part of society and contribute to society for as long as possible and not become a burden to anyone. And those outcomes are better for those people*

> *who are successfully on the pump ... I am going to be very brave and bring all my research and, and data and present it to him [the consultant]."* **Public stakeholder, workshop**

Patient-led information seeking: negatives

Participants also caution against patient-led information seeking, noting its downsides. Here, concerns focus on both the experience of searching for information, and the information itself. The experience of searching for information can be "hard", "exhausting" and "never ending". This can be made more difficult if you are also trying to look after yourself and live with debilitating symptoms. Likewise, sometimes the available information about medicines was described as not very accessible or as meaning "very little".

On top of this, when participants seek out information they sometimes found answers which were contradictory or they felt the need to evaluate what they came across. Concern about the rise in online misinformation feeds into participants' views on this, with several worrying about how the Covid-19 vaccine was portrayed online and the proliferation of false information about it. This does not tend to put participants off from using the internet as a source of information about medicines, but it complicates the task of seeking it out and impacts overall levels of trust.

> *"How do you, as a parent with no medical background, decipher what's true, what's not, what's accurate, without harming your child, but you're trying to help them. It's a lot to navigate constantly having to evaluate what you're reading."* **Public stakeholder**

5.3 Key issues to address for more effective prescribing

Health system infrastructure

Professional stakeholders drew attention to a number of NHS infrastructure issues which can impact prescribing. This includes the idea that existing systems are designed to involve and combine the contributions of multiple professionals. Instead, in the words of one interviewee:

> *"They were designed essentially for one person to be doing all the prescribing and to know when they've done a medication review and to know what other monitoring was required and to know whether they've done it or not."* **Professional stakeholder, interview**

This has become increasingly impossible as the number of specialities, medication options and guidelines proliferate. When public stakeholders heard these concerns for the first time in the final workshop, they found it difficult to imagine how they could be overcome.

> *"Are there models in other countries where there is more multidisciplinary approaches that work? Because I can't even imagine how they would even begin to put that into practise in such a pressurised system."* ***Public stakeholder, workshop***

Another issue raised by professional stakeholders is what they see as the slow uptake of new treatments within the NHS. It was said this is partly because in order for a new treatment to be deployed successfully, it requires a clear pathway via which patients can access it. This may include the proper assessment of patients and allied health and support services. New medicines also face the challenge of overcoming existing prescription habits.

Navigating specialist and GP care

Difficulties in moving between specialist and GP care are familiar and troubling to both professional and public stakeholders. The way in which the system currently operates is not seen as benefitting patients or providers. Whilst professional stakeholders spoke of efforts to improve the current situation, the sense is that improvements need to be quicker and more widespread. At the heart of these difficulties, there are at least three challenges to do with inconsistency, inefficiency and bureaucracy. These are illuminated by the quotes from different interviewees below.

Inconsistency: multiple lists of medications

> *"If I see a patient in an outpatient clinic, I make some change to their medications, a communication should go back to the GP indicating what happened at that consultation. If a GP sees the patient and makes a change, the change will be recorded in the patient record in primary care, but secondary care won't necessarily see that... You can run it into a situation where there's a list of medicines the patient thinks they're taking, there's a list of medicines the GP thinks they're taking, there's a list of medicines their secondary care doctor thinks they're taking, and then there's the list they're actually taking and they may not all be the same. And so that's suboptimal and potentially in some cases could generate risk and harm."* ***Professional stakeholder, interview***

Inefficiency: GPs needed to change a prescription

> *"If you're a secondary care consultant and you do a remote consultation ... you get the results back and want to change their drug therapy, the most efficient way to do that would be for the consultant to issue a prescription in primary care for the patient to pick up. We can't do that. There is no system. So then you have to write to the GP or say to the patient, go and get your GP to do this."* ***Professional stakeholder, interview***

Bureaucracy (specifically the financial obligations of different parts of the system):

> *"It seems utterly crazy to me that I sit in a hospital clinic, I make a recommendation for a medicine. I can't prescribe it for the patients because of the financial flows within the NHS."* **Professional stakeholder, interview**

Public stakeholders have experienced the consequences of these issues first hand. One participant described how the medication recommended for their child by a specialist was changed in primary care. This was done, in their view, on cost grounds, placing them in a situation where they had to involve their specialist once again to correct it. Multiple participants mentioned feeling as though they had to enter into a negotiation due to inconsistencies in the approaches of their specialist and their GP. This is described as a waste of everybody's time, not just the patient's but also the specialist and primary care teams.

> *"We've had these conversations with someone who absolutely understands my son and we've had detailed in depth conversations about how he's reacted to this, how he hasn't reacted to this. We have a plan, right? This is what we're going to do for the next six months, 12 months, 18 months, whatever to then have to get dragged in to go, 'Oh no, we're not giving you more of that' at the GP level, it's just a pointless waste of everyone's time."* **Public stakeholder, workshop**

Branded and generic medicines

The topic of switching from branded to generic medicines was also discussed. Although the benefit of heavily reduced costs is clear to both professional and public stakeholders, there are concerns about the extent to which this switch is currently carried out successfully. Both cohorts said there is a lack of strategy when it comes to initiating these switches and promoting the widespread adoption of generic medicines.

This is complicated by the idea that it is also seen as important to explore any such switches with each patient and ensure it is right for them as an individual. Professional and public stakeholders both suggest a one-size-fits-all approach isn't helpful.

> *"I think there's something about the individual, that 'what matters to you' conversation, and most people don't notice the difference between taking a branded or a generic form. But for some people it does make a difference. And that's why, in terms of prescribing, we don't have to have 100% of people on the on the branded form, but that's often quite a sensitive conversation to have with patients because people worry that they're getting something that's not as good, even though the safety and efficacy is exactly the same."* **Professional stakeholder, interview**

The fact that the switch can make a difference for some patients is reflected in the experiences of one or two public participants. One participant explained the

importance of exploring this switch gradually and on a case-by-case basis in the context of their epilepsy medication. They emphasised the need to involve specialists in these decisions in order to avoid any potential harm or unintended consequences of switching from branded to generic medicines.

In general, however, participants are broadly comfortable with the idea of making this switch. When it caused participants concern, this was typically because it had not been clearly communicated to them. This could lead to confusion and occasionally distrust as participants noticed sudden and unexplained changes to names, packaging, shape or colour of their medicines.

> *"It's called ABC and they say, 'oh, this is just the same, it's just called XYZ'. I don't trust that process very much. I can understand the need to save costs, but one of those incidents happened with me and I found that the one they changed me on didn't work as well. So they have to change me back."* **Public stakeholder, interview**

A number of participants said they feel the switch to generic could be communicated better. Even participants who are comfortable with the switch could appreciate that some people's attitudes may be shaped by consumerism and that specific brands may hold particular appeal. They think there should be more education on the relationship between branded and generic medicines to push back against the assumption that "cheaper means worse and more expensive is better". They wonder if some people may be inclined to compare it with the difference between "Tesco Finest" and "Tesco own brand".

> *"I think there needs to be more education in terms of how that process works and how that thought process that 'if this is cheaper, it's not going to be as good', doesn't actually apply in this scenario. Sometimes the explanation of the change is, 'oh, because this is cheaper for the NHS", sometimes can actually even make people double-down in terms of, 'oh, well, that's definitely not good then'. Because I actually think if you told somebody you were changing their medication to a more expensive one, they'd be happy about that because they think it was better. But if you're changing it, it's a cost saving measure. They'd be like, 'oh, the NHS is going down the toilet, but this is going to be terrible'. So I think it's an explanation of how that process has been arrived to and that the core ingredients are the same would be helpful."* **Public stakeholder, interview**

Polypharmacy and deprescribing

In line with the interest participants expressed towards seeing more research into polypharmacy, this was also raised in the context of prescribing practices. For professional stakeholders, rising rates of polypharmacy present a number of challenges, including in relation to deprescribing practices. On the frontline of healthcare, polypharmacy prompts a range of questions, as this interviewee described:

> *"So a patient will come into clinic with a bag of drugs. Are they taking them? Are they not taking them? Who's prescribing them? Are they recent, old, all that kind of stuff.*

> *And then if you're becoming really unwell, we stop a load of drugs, do we restart them?"* **Professional stakeholder, interview**

At the same time, this professional suggested, doctors may feel compelled to intervene with medication. Introducing a new medication seems more sensible than not, or continuing an existing one seems better than stopping it. This tendency towards prescribing was summed up by another interviewee who said it can be more difficult to justify not prescribing a medication than it is to prescribe it.

> *"When you've actually got somebody in front of you and they've got condition X and they're suitable for drug Y, the process you have to go through for them not to have the drug treatment is far more convoluted now than the process to just prescribe it. You have to write down all the reasons why you've not given them the drug."* **Professional stakeholder, interview**

This approach is likely reinforced by the inclinations of some patients who would prefer to be on a medication than not, as expressed by some public stakeholders.

> *"I think people are scared to also come off of things. They're scared to go back to having those issues. So they just stay on it because their quality of life is stable."* **Public stakeholder, interview**

But public participants also express concern about being on multiple medications, or about the interaction between different medications. This concern is particularly stark for participants who have been prescribed something to combat the effects of another medicine they are on.

> *"So you are also chasing the side effects, having to take other medications to combat the other medication side effects."* **Public stakeholder, interview**

Other participants taking multiple medications can be concerned about the interactions between them. Although participants generally appeared to be clear about when one drug could be taken with another, there is still concern about the cumulative effects. This is mentioned in particular in relation to psychiatric medications, where the combined "strength" of taking multiple medications is "adding up to me being a bit drowsy in the morning", as one participant described it.

Professional stakeholders also emphasised that polypharmacy is not a single issue but made up of multiple issues. For instance, there is potential harm from being on multiple medicines, but there is also the extent to which multiple medicines can be sufficiently explained to patients. It is also said that polypharmacy can be framed differently as an issue depending on who is looking at it. For some, addressing polypharmacy can be seen as a way to reduce costs, for others it can be about requiring and potentially facilitating more informed decision-making with patients.

> *"The general perception of polypharmacy is it's a bad thing. If you're having to take lots of medicines there's potential for harm from the medicines and of course that's*

absolutely true, but of course it's also inevitable if you've got many diseases for which there are many different treatments that you're going to be taking many. So I think a challenge that people have who have multiple long term conditions is a) the burden of medicines, b) I think receiving sufficient information about what each medicine is doing and route for them to discuss their medications with a clinician or healthcare professional. Because the system is so pressurised at the moment, I think those avenues to discuss and optimise these medicines in an individual person, [there is] relatively limited time and resources available to do that." **Professional stakeholder, interview**

5.4 Views on alternatives to medicines

Public and professional stakeholders involved in this project are keen to keep sight of alternatives to medicines throughout the discussions. They understand that medicines are imperfect and believe that the prescribing system could function more effectively if discussion on medicines takes into consideration alternatives.

> *"I know we're talking about the medicines lifecycle, but sometimes the lifecycle shouldn't involve medicines."* **Professional stakeholder, interview**

The previously mentioned idea that taking medicines can drive the need to take more medicines provides important context for this interest in alternatives. One participant with experience of this described it as entering "a rabbit hole of prescriptions", in which it feels like the opportunity to explore alternatives shrinks.

> *"It becomes a rabbit hole of prescriptions. And I find that if we do just go down a medicine approach, sometimes it's just the medications keep piling up and piling up and the results become, I find, even more convoluted sometimes."* **Public stakeholder, workshop**

From a professional perspective, it can sometimes feel easier to prescribe a medication than any alternative. One interviewee said this can be because effective and evidence-based alternatives sometimes simply don't exist, but that it can also be because the alternatives which are available can be more difficult to find. This bias is apparent to some public stakeholders given their experience of the medicines system.

> *"My impression has always been that it's a little bit too easy to get medication for things. I'm not saying that's a bad thing, but it seems to be sometimes a very quick and easy answer to write a prescription."* **Public stakeholder, interview**

> *"It's very easy for me to look up a medicine and prescribe it. Whereas actually trying to remember 'who do we refer to now in terms of the obesity service locally?' Because it's always changing [is more difficult]."* **Professional stakeholder, interview**

Several participants share positive views and examples of alternatives to medicines. Professional stakeholders referenced the successful use of pulmonary rehabilitation to combat COPD, and increased exercise to address hypertension. In both examples, at least initially, these interventions are considered second to medication.

> *"I think sometimes we become over reliant on prescribed medication, but there's a lot of stuff out there that can help day-to-day conditions as well. So it's like I take a holistic approach to my illness and my condition."* ***Public stakeholder, workshop***

5.5 Hopes for the future of prescribing

During the discussions, public and professional stakeholders raised hopes for the future of prescribing. These are summarised in the table below, which groups similar hopes together and highlights where they were raised by professional or public stakeholders, or both.

Hopes	Public stakeholder views	Professional stakeholder views
Better medicines information, and better access to it.	• Accessible and trustworthy information sources which reduce the need to carry out internet searches e.g. QR codes to short videos on medicines • 'Open evenings' in which patients can access prescribers and medicines information for a health condition in a community setting, whilst reducing the need for 1-2-1 appointments • Access to the same information across different parts of the health system • Being informed about longer-term side effects	• Prescriptions include the reason the medicine has been prescribed (indication) start dates and finish dates, so that any repeat prescriptions are more carefully considered
Personalised medicines	• Medications which are tailored to you	• Use genetic data to help give the right drug and the right dose to the patient more consistently
Automation	• To process and share information about patients' lifestyles, which prescribers can then consider when prescribing or in consultation	• Use AI to assimilate clinical guidelines to inform prescribing decisions, as there is currently too much information for clinicians to consider

	• To help produce treatment plans best-suited to individuals	
Patient-prescriber relationships	• Increased rapport with prescribers	
Avoiding unnecessary medications	• More time spent with patients to understand their situation and address underlying causes over symptom management • Less stigma around pushing back on medications	
Shared decision-making	• Patients have more of a say in the medication they are prescribed, especially when there is a choice	

6. Medicine taking and reviewing

Public appetite for more involvement in medicine reviews and hopes for how to reduce medicine wastage

What you will find in this chapter

In this chapter you will learn more about public and professional stakeholder views on the strengths and weakness associated with taking and reviewing medicines.

Public issues with medicine taking focus on:

- The unreliable availability of medicines because of shortages
- Lack of support when you/ the person you care for is having difficulty taking a new medicine
- Alternatives to medicines, including ways to take fewer medicines and improve health

Issues that garner more professional stakeholder attention are:

- The disruption of medicine routines caused by transitions between care settings

Both participant cohorts think it is important to explore:

- The role of patients in deciding which medicines and how they take medicines – how to encourage a partnership between patient and healthcare professional
- How to reduce medicine wastage

6.1 Patients' ownership over their medication helps them to take it effectively

Public participants spoke about the systems they put in place to help them remember to take their medicines as prescribed. This is particularly important for those on multiple medications. Some public participants spoke about using pill boxes, and particularly dosette boxes marked with days of the week.

> *"So mine's the pure dosette box... and it's my daughter's actually because she's the one who has to take medication every day. She was born with a blood condition and so she's dependent on medication, but being young, she's only 12, so I have to organise her medicines for her so she can just go to the box, get her dose for the day and take it."*
> ***Public stakeholder, workshop***

Other systems that public participants use to help them take their medications correctly include setting reminders on their phone or keeping the medication in the same place and taking it at the same time each day.

> *"The way that I'm organised is my medication that I take in the day goes by the kettle in a little container. When I make a cup of tea, I think 'right take them'. And then, because I have to take aspirin and an antidepressant, I take those two together with my cup of tea and then I have to take medication at night. So they all get put in a little drawer next to where I'm sat on the sofa and my nighttime medications get put together."* **Public stakeholder, interview**

Participants also spoke about how they have integrated medicines into their lives and routine to the extent where taking their medications has become something they do on auto-pilot. Other participants spoke about the efficacy of medicines as a motivation for taking them, or that pharmacy staff help with organising their medication so that it's easier to access.

> *"My amitriptyline and my sertraline are actually grouped together as a prescription, which the pharmacist did for me, which really helped."* **Public stakeholder, interview**

Professional stakeholders spoke about patients' understanding and feeling a sense of ownership over their medications as important to helping them take them correctly.

> *"When I ask patients what drugs they're taking, I don't want them to come and tell me they're on a pink and a white drug. I want them to tell me 'I'm on Propranolol 18 milligrams a day. I'm on this particular drug at 10 milligrams a day. I take it at this time.' So they are aware of what medicines they're taking, why they're taking it, and so that patient education in this area, patient participation is critical in terms of how we move forward."* **Professional stakeholder, interview**

Other stakeholders also spoke about making medications information clearer and more accessible to patients, including through care from specialist nurses and through digitising the information into audio or video formats.

> *"One of the things which we're trying to do is to digitise the patient information leaflet and then have it in multimedia format so you can listen to it or you can look online or you could get it through your app. And the advantage of that is that we want people to really engage with the medicines because the research shows that only 10% of people actually read the leaflet."* **Professional stakeholder, interview**

As seen in the earlier chapter on prescribing and information, this view about the importance of clear instructions and information to help take medicines as prescribed is also shared by public stakeholders.

Some public participants spoke about the responsibility they take on themselves to check for the risks of their multiple medicines interacting problematically with each other by reading the medicine information leaflet and checking these interactions themselves.

"The whole idea about people that take lots of medications and how they interact with each other. So I do tend to run down the list of who shouldn't just in case the GP's not noticed because they're not infallible." ***Public stakeholder, interview***

6.2 What hinders effective medicine-taking

Undesirable medicine formats, instructions that are poorly communicated

Public participants expressed concerns about the format that certain medications come in. Large tablets that are hard to swallow and injections that are unpleasant to administer are the most common complaints.

> *"I had an experience in hospital a really long time ago when my daughter was born where I was prescribed very, very strong painkillers in the hospital. And they were those big, massive, rough uncoated tablets that you have to swallow. And I physically couldn't swallow them, and they had to give me a children's syrup instead."* ***Public stakeholder, interview***

Other public participants cited medicines coming in blister packs that are hard to open and the fact that many pills look similar to each other, which can be confusing. Some patients also spoke about their difficulty in administering medicines in certain formats to people with learning difficulties or children.

> *"When she was younger, we had to dissolve a tablet into a certain amount of liquid, and she just didn't like it. She wasn't even two and she couldn't take it. It was something she didn't want to take, and I had no support. If I told the consultant that, there was no alternative, there was nothing out there for her. So she either had to take it or just not take it. But if she wouldn't take it, obviously it was going to have a consequence on her health. So that was our very difficult phase. We really struggled with her medication at that time."* ***Public stakeholder, workshop***

Professional stakeholders spoke about the importance of ensuring patients can take their medicines properly so that their full benefits are felt. Inhalers are held up as an example of medication that many patients are not taking properly. This is attributed to a lack of quality, tailored instructions and hands on guidance.

> *"There's a whole issue about giving people things for which we then don't skill them. If you look at inhaler technique, an awful lot of asthmatics are out there and their inhaler technique is inadequate. So they're not actually getting the benefit from that product. The same for maybe Parkinson's, the same for maybe diabetes. So it's about*

skilling the patient to be really good with the product that they've got, making sure that the product they've got is actually the one they're prepared to take." **Professional stakeholder, interview**

Public participants also spoke about the need for better instructions for medicine taking. They said information about how to take medicines is not effectively communicated and this can hinder them being taken as prescribed.

"I've got an underactive thyroid and I have to have some medicine in the morning. And for a number of years I didn't realise that I can't have anything to eat or drink tea or coffee to half an hour after I've taken the medication. And I didn't realise that literally for years. And that must have had an impact in terms of the medication not working so well." **Public stakeholder, workshop**

Medicines accessibility and out of stock issues

Public participants spoke about their experiences being unable to access and take their prescription medicines due to them being out of stock and/ or widely unavailable.

"A big example is that my son has ADHD. My middle-aged son got diagnosed two years ago. He takes pregabalin and can't get a hold of his drugs hardly ever. He's living on a knife edge because he can't get a hold of his drugs." **Public stakeholder, interview**

They also spoke about the negative health impacts of changing medicines due to a lack of availability of their prescribed medication. Public participants also raised concerns about the onus of sourcing their medications being put on the patients, especially for patients that are elderly, disabled, or without transport.

"So even if you're on a long term medication that you rely on, you can go to collect your medication one week and be told we don't have it. And that's extremely worrying. That's very worrying, especially for people that are disabled or have mobility problems, and you can't run around from pharmacy to pharmacy trying to source your own medication, especially if you don't have transport." **Public stakeholder, interview**

Unpleasant side effects

The experience of side effects prompts a range of responses from people taking medications, as demonstrated in our discussions. Some public participants report that experiencing unpleasant side-effects can discourage them from taking their medicines as prescribed or indeed lead to stopping them from taking them altogether. Tiredness and drowsiness are the most commonly reported side-effects among public participants.

> *"There's one of my medications I take and it just wipes me out like I'm fit for nothing after taking it. It just makes me so tired and it almost makes me reluctant to take it."* **Public stakeholder, workshop**

Reasons for not addressing the problem of experiencing side-effects include the physical impact of the side effects themselves e.g. drowsiness and not having the time to seek help to get their medication changed but instead simply stop taking it.

> *"So getting a new prescription, starting to take it, maybe getting side effects, if you're working especially or you've got a family, not having the time to go to the GP and sort it out."* **Public stakeholder, workshop**

However a few public participants spoke about taking a more proactive approach before issues arise, by researching the side-effects that their medications might cause, for example because of their age or frailty, and asking their health care professionals for a change of medication.

> *"The bladder medication, I recently spoke to the GP and got that changed because I had found out that it was known to, I didn't know this until I specifically researched it, but it's known to cause cognitive decline and it's not to be prescribed in the elderly. So I thought, well, if I've already got a cognitive impairment, I probably shouldn't be taking this tablet. So they've changed that and luckily the new one seems to be helping."* **Public stakeholder, interview**

When the drugs don't work

Public participants spoke about medications not working as a barrier to taking them, either because they don't work as expected or because they take a long time to start working.

> *"I think a lot of people maybe don't understand that some medications take quite a long time to build up in the system before you can really tell whether they're working or not. And that you do need to have a lot of patience to just try things and keep trying until you find the one that works. So I think maybe some people will just go 'oh, I can't be bothered. I don't have time for that.'"* **Public stakeholder, interview**

They also spoke about having to take increasing doses of medicines to ensure efficacy and balancing this heightened need with concerns about side effects or dependency.

> *"So they'd prescribe me gabapentin and it would work for a little while and stop working and they would put the dose up and then it'd work for a little while and stop working and put the dose up. And eventually I was like, 'I don't want to keep going on like this. It's a very powerful drug and I don't want to be in a situation where I'm on such a*

high dose that coming off it is ever going to cause a problem.'" **Public stakeholder, interview**

Transitions of care e.g. from hospital to home

Professional stakeholders identified moments when patients transition between different care settings as a key issue that disrupts how medicines are taken. They spoke about patients moving between primary and secondary care, between hospital and domiciliary care, between GP and pharmacist care and raised concerns about these different care settings not being joined up.
Taking a patient centred approach to organising transitions of care would mean that every professional involved in their care would know if and how the medicines have changed.

"I want us to improve the quality of the transitions of care, to take a really patient centred approach to how we make the system join up better around the patient so that they get care when it moves from setting to setting. They are kept safe - I go to the care home and I'm sent back from the hospital to the care home. It's clarity about what I'm now on and what I'm not on and why. And that's all of the people who are going to care for me. My GP and my pharmacy all know that. Yes, nothing falls between the cracks." **Professional stakeholder, interview**

Public participants raised concerns about the transition between paediatric and adult care. Children with lifelong health conditions, who have had support throughout their lives, should not be left without support just because they have turned 18.

"What I found is when my daughter was diagnosed and coming across all this new mountain of information, because what we've heard is when the child transitions to adult care, all of a sudden everything's put onto that new adult. But because all their life they've had somebody helping them, a lot of children who go into adult care stop taking their meds. And a few odd cases have been fatal. And I feel a bit more needs to be put into that area. And the child, as soon as they're an adult, not just thrown into adult care, a bit more support needs to be given to them." **Public stakeholder, workshop**

Other factors that hinder taking medicine as prescribed

Some public participants are especially cautious about their children taking medications, wanting to make sure that the benefits definitely outweigh the potential harms. Public participants also spoke about some people's reluctance to take mental health medication because of general stigma around mental health medication.

"With antidepressants, I know a lot of people who've been prescribed them and took them for a week. And then they said, 'well, I don't like them. I don't want to be on antidepressants. I'm going to stop taking them.'" **Public stakeholder, interview**

Other participants spoke about their reluctance to take some medication due to the lack of research around taking certain medications during pregnancy or breastfeeding. One participant spoke about feeling unclear about the tangible risks and benefits associated with a specific medication they were offered during pregnancy. Her point echoes the issue in section 3.2 about the lack of research involving pregnant women.

> *"I had hyperemesis during my pregnancy and was incredibly ill. I was prescribed anti-sickness medication and I was like, 'well, what are the risks for this?' And they're just like 'well, the benefits outweigh the risks'. So I ended up not taking it and being very ill."* **Public stakeholder, workshop**

6.3 Processes for monitoring and reviewing medicines

This section explores public and professional stakeholder experiences and views on the range of ways in which medicines are monitored and reviewed. It includes formal patient/healthcare professional meetings where all the patient's medications are considered. It also includes mechanisms to review individual drugs e.g. time limited prescriptions.

Comprehensive medicines reviews are valuable

Public participants value patient and healthcare professional medicines review discussions. They spoke about a good medicines review being characterised by feeling heard, respected and not rushed.

> *"When you feel heard and listened to and respected and supported, that sort of makes a big part of what feels positive."* **Public stakeholder, workshop**

Other participants sometimes spoke about reviews with GPs and pharmacists as positive experiences or had good experiences in particular with specialist health care professionals such as asthma and diabetes nurses. They value the collaborative, personalised, thorough and flexible nature of the review discussions, particularly when part of an ongoing relationship.

> *"My diabetic nurse is wonderful. Honestly she lets me just chat to her about all sorts of stuff... I'm in to see her every three months. We agree whether we want face to face or over the phone. We review the bloods in a lot of depth. We review what it means and we kind of look over periods of time how they've changed and if she's concerned. So at the moment, she's trying to persuade me to go onto my third drug for diabetes. Because the first two are doing OK, but not good enough in her mind. So we chatted about that. She gives me some information to take away and then she gives me a call a couple of weeks later or I go in to see her and we discuss the pros and cons, any concerns I've got after I've done a bit of research and we make a decision. She will never force me into anything. She's openly said 'now's the time given your age, we need to get on top of this now. We can't really let it get any worse.' She will have a very open conversation where she'll put her case forward, I'll moan and then we'll agree that she's right and*

I'm wrong. So she's due to phone me in a couple of weeks when I've started taking this new one. Honestly, I really can't fault it." **Public stakeholder, workshop**

Patients aren't getting enough medicines reviews (knowingly or in person)

Some participants also expressed concerns that comprehensive medicines reviews that involve the patient aren't happening often enough, that the timing of the reviews seems random, or that it is down to the patient themselves to organise and advocate for medicine reviews. Several workshop participants said they have never heard of or experienced a medicines review.

"My experience is that there isn't really ever a review of medication. You know, you're put on medication and that's kind of it. The onus is on you to see if there's any side effects, reach out to your GP and then have another conversation." **Public stakeholder, workshop**

This view is shared by stakeholders who said that a lack of regular medicine reviews can create further problems, such as the additional administration time needed for each extra medicine.

"You've just not got that time to review or even some practices limit the opportunities for GPs to review their patients because they've got so many new patients coming in. But what I try to say is if you don't do this, it makes the whole thing worse. Every single micro decision about this, add this medicine, add this medicine all creates work down the line, even if it's simply the work of processing one extra prescription per month or per two months." **Professional stakeholder, interview**

Some participants described their experience of medicine reviews with GPs as feeling like a box-ticking exercise, that they are rushed in medicines reviews or feel like they weren't being listened to.

"My negative experiences have been reviews with GPs. It feels like a bit of a tick box exercise, you know? They're talking at me. They're not really having a conversation." **Public stakeholder, workshop**

Both professional and public stakeholders spoke about medicines wastage as a serious consequence of too few or ineffective medicine reviews.

Suggestions to improve medicines monitoring and reviews

Whilst a few participants spoke of positive experiences of how medicine reviews, most have never experienced one themselves and are unaware of how to access one. So improving awareness and access is a strong hope. A few participants spoke about having medicines reviews with their GP Practice Pharmacist that they find extremely helpful. However, most participants are largely unaware of who performs

reviews. Some suggested that pharmacists or specialist nurses could play a greater role in medicine reviews, with some suggesting a new role should be created especially for reviews.

> *"It would be good if there was a review team and medicines team when you're starting on a new drug and that it can be really scary ... to have somebody that they can go to speak to without taking up a whole doctor's appointment or having, the pharmacist take you into spare rooms."* **Public stakeholder, workshop**

There is a shared view that more monitoring of how a medicine is working for an individual would be a positive development. Many participants hope that this would lead to more finely tuned adjustments to medicines, either coming off them as soon as the time is right or switching to something else if they aren't working as hoped. One professional stakeholder suggested patients and care professionals discussing more specifically the timeframe for taking a drug and when the patient could expect to stop taking it if health has improved. This would help to set and manage expectations and avoid concern or clashes of perspectives further down the line.

> *"So if I take antidepressants, if somebody's told, well, we normally would prescribe them for three to six months. What we should do is start on the 1st of October 2023, finish by April 24. Patient must be reviewed and then at the six month point you can say to the patient how are you feeling? If they say I feel fine, you say well let's get you off them then. And if they're not feeling fine, we say well now that we'll refer you on for some additional support, not just keep the prescription going for the next 10 years."* **Professional stakeholder, interview**

Other participants highlighted the importance of seeing the same health care professional every time their medicine is reviewed.

Public participants made other recommendations as to how reviews can be improved; specifically reviews that feel like a two-way conversation and healthcare professionals being respectful of patients' competency and knowledge and then tailoring their behaviour accordingly.

> *"When you're dealing with a personal case of someone who's had it their whole lives or in a severe case, I think trusting the competency or more tailored understanding to the patient that you're dealing with. And just that quick consideration I think can go a long way."* **Public stakeholder, workshop**

Both public and professional stakeholders recommended system digitisation as a way to improve reviews.

> *"It would be quite nice if the app would say, we noticed you haven't requested this for a while. By the way, you do need to do a medication review first. So could you please fill in this form. And then once you've done that, you can request your next prescription. That would be just dreamy all round, wouldn't it?"* **Professional stakeholder, interview**

6.4 Wasting medicines

Why medication is wasted and the impact of waste

Many issues, some of which have been already mentioned, contribute to medicines being wasted. Figure 4 below looks at some of these reasons at a glance.

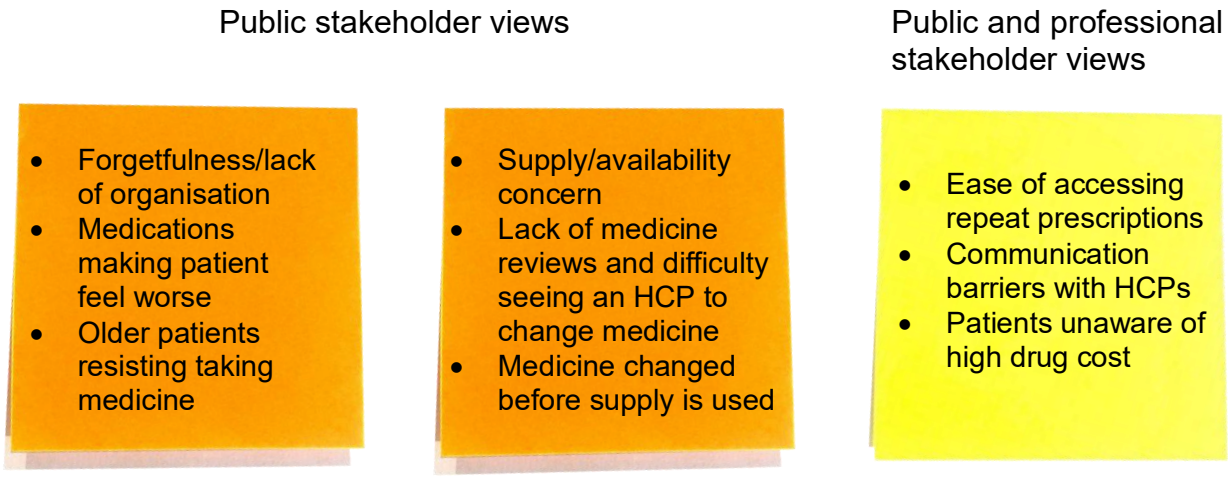


Figure 4: Views on causes of medicine wastage

The issues most frequently mentioned were: forgetfulness and/or a lack of organisation and the ease for some people of getting medicines via repeat prescription.

> *"If you can just go and repeat order your prescription. It's just too easy to repeat order and I think that that can cause wastage."* ***Public stakeholder, workshop***

Public participants are also unsure about how they should dispose of their leftover medicines; whether they should put them in the bin or return them to the pharmacy. Both public and professional stakeholders raised concerns about the environmental impact of medicines wastage, particularly through certain delivery methods such as inhalers, as well as the high financial cost of wastage to the NHS.

Solutions to medicine wastage

Some public participants feel that making patients aware of how much medicines actually cost the NHS could be effective in preventing wastage.

> *"If people were more aware of the cost of medicines to the National Health Service, I wonder if that would change some of those behaviours. It would for me. I mean, that's something that I'm mindful of."* ***Public stakeholder, workshop***

Some participants see regular reviews where the patient is listened to as key solutions to preventing medicine wastage on the NHS.

> *"The reviews I think are pretty vital, even if you, get reviewed with a nurse, I think there needs to be something in to make sure we're keeping on track of the prescriptions and not wasting a load of it."* **Public stakeholder, interview**

Section 3

Final conclusions

- Emerging themes
- Hopes and opportunities for future research

8. Final conclusions

8.1 Emerging themes

By exploring the full medicines lifecycle from the perspectives of those taking medicines, those who care for them and those who work in the sector, we have heard a wide range of concerns, hopes and experiences.

In this section we draw together some findings that emerge as opportunities for further exploration, starting with the large overarching theme of more meaningful public involvement throughout the medicines lifecycle.

Patient choice in medicines

The findings in our report suggest an emerging opportunity for patient-healthcare professional relationships to become a partnership at various points in the medicines lifecycle. Public stakeholders who contributed to prescription decisions expressed how this makes them feel respected, empowered and heard. This is particularly true for those with rare conditions whose lived experiences can greatly contribute to HCP knowledge.

Professional stakeholders emphasised the importance of growing awareness of the Yellow Card Scheme – which public stakeholders feel needs improved communications and clarity on how patient-initiated reports improves knowledge of side effects. Many of the future opportunities could use technology as an enabler of improved medicines e.g., digitising the Yellow Card Scheme, as well as Participant Information Leaflets.

Inclusivity in research

A clear area for future consideration, put forward by both public and professional stakeholders, is how to engage those largely excluded from healthcare research on the basis of ethnicity, sex, age, or other factors. Public stakeholders consider the need for improved incentives and communication for research opportunities, whilst professional stakeholders consider the structural barriers to improving medicines research (e.g., easier funding access for larger hospitals). Both groups, however, see evolving the largely profit-driven financial model of health research and the use of technology as potential opportunities to drive the needed change.

Personal and holistic prescribing: is technology the answer?

Public and professional stakeholders highlighted the need for more patient-led and holistic approaches to prescribing medicines, currently hindered by factors such as GP time. Both groups share a hope that prescribing should take into account other health and lifestyle factors. Professional stakeholders note the potential of automation in processing information about participants' backgrounds, which could be quickly translated to provide a background for prescription providers and therefore mitigate the time limitations which hinder a holistic approach.

Public participants also described how patient involvement in the prescription process is particularly relevant for rare conditions, where their lived experience and knowledge should be better integrated. One participant explained how they carry

literature to help HCPs understand their condition. It seems that an area for future consideration is the balance between and successful integration of human and technology interventions for a holistic approach to prescription.

Public access to medicines information: Retaining patient voice

Integrating patient knowledge of their own conditions emerges as an area of future consideration. Public participants described how they use a variety of online sources to research their health conditions. Increased availability of information is seen to have positive and negative outcomes, both providing alternative sources of knowledge and community for patients – particularly those with rarer conditions - yet also being a time-consuming process, requiring the navigation of misinformation. Future questions to consider in this area focus on patient voice: how patients can confidently share their knowledge with their HCPs, and how patients without the time and resources to research their health can nonetheless retain their voice.

Participants also suggested opportunities to improve medicines information outside of their own research – including Participant Information Leaflets. Professional stakeholders note the rise in public appetite for more healthcare information, and that the Participant Information Leaflet should incorporate things such as expected efficacy and long-term effects.

Furthermore, both public and professional stakeholders point to the need for direct communication and instructions for medicines taking, potentially digitised into audio or video format – which as above, speaks to the emerging trend that the public want a clearer, more integrated position in the medicines lifecycle.

Variations in medicines provision

There are public concerns about a postcode lottery of medicines within the supposedly ‘National Health Service’. Some public participants suggested that a nationwide approach could create more consistency, but that consistency could also lead to a more limited choice of medicines – a concern shared by professional stakeholders. Therefore the public concern of postcode lottery presents an opportunity for further consideration of how regional healthcare inequalities can be managed, whilst still catering to specific medicines needs of different areas.

However, one of the limitations of understanding this consistency is the lack of uniform data across all medicines used through primary and secondary care.

Health system infrastructure: Opportunities for improvement

In order to further a patient-focused medicines system, gaps in healthcare infrastructure should be addressed. Professional stakeholders are concerned about a system currently not designed for the input of multiple professionals, including transitions between specialist care and GPs – a concern echoed by public participants.

Ways to reduce bureaucracy and inconsistency between systems and settings is a prime area for future work. This could be through avenues such as improved medicines reviews. Improving health infrastructure presents an opportunity to

improve the patient-clinician partnership – a recurring theme – and to combat issues such as medicine wastage.

8.1 Hopes and opportunities for future research to address the better use of medicines

In this final section of the report, we set out a list of potential topics for further research into the medicines lifecycle, drawn from what matters to professional and public stakeholders.

Medicines Research

- How can medicines research be enabled to take place in a wider range of health settings, particularly more community settings?
- What are the barriers and enablers to a greater diversity of people being involved in medicines research?
    - older people
    - women, including pregnant and childbearing age
    - people from minoritised communities
    - children
- How can the media coverage of medicines research be improved, to move away from the 'sensational breakthrough headlines… then tumbleweed' style of communication?
- How can more research effort be put into exploring the long term effects of taking medicines?
- How can the public have a bigger say in setting the priorities for medicines research?
- How can the financial model of medicines research be addressed to make it work for rare conditions?
- How can technology (e.g. AI) accelerate medicines research safely and effectively?

Medicine Policy and Regulation

- What role can medicines policy and regulation play in accelerating medicines research safely and effectively?
- What can be done to address the postcode lottery perception of medicine availability, and the views of unfair disparities rather than tailored allocation based on need?
- How can the number and quality of public reporting of medicine side effects be increased?
    - E.g. a review of the Yellow Card Scheme?

Medicine Prescribing and Information

- How would public and professionals like to see prescribing tasks divided between specialists, GPs, pharmacists and other clinicians in the future?
- How information on patients' medicines should be made available across health care settings: what are the barriers and enablers to doing this and preventing the information gaps that harm patient care?
- How could the medicines information patients can access via official channels be improved?

- As patients' voices become a growing influence over the healthcare they receive, what needs to be done to protect the interests of people who are less able to advocate for themselves?
- How can public awareness and engagement on the switch from branded to generic medicines be improved?
- Polypharmacy as "a rabbit hole of prescribing": How should the growing number of medicines, and the number of people taking multiple medicines, be balanced with the potential risks and challenges of doing so?

Medicine Taking

- How can support for medicine taking be improved when a child with a long term health condition is transitioning to adult health services?
- How can we get more accurate information about the scale of medicine wastage and its causes?
    - How can the prescribing system be improved to reduce medicine wastage?
    - How can patients be supported to reduce medicine wastage in the home?
- What impact do different types of medicines reviews (paper only vs in person, GP led vs pharmacist led) have on medicine adherence and patient health outcomes?

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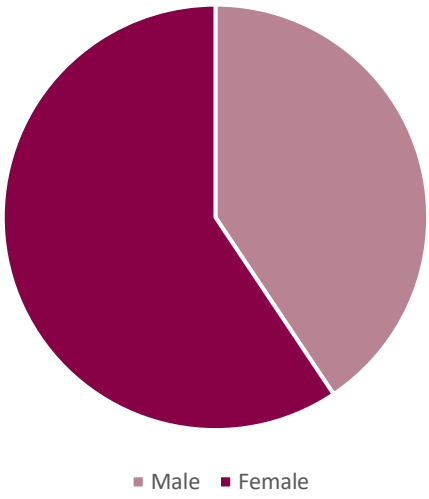
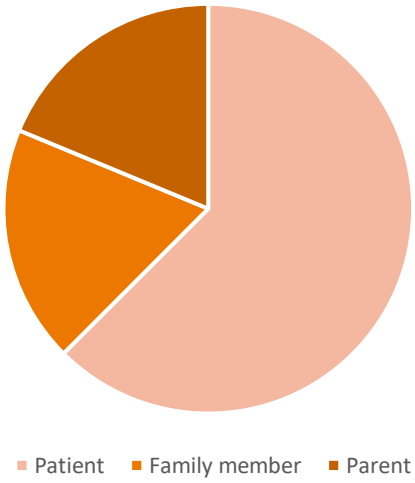
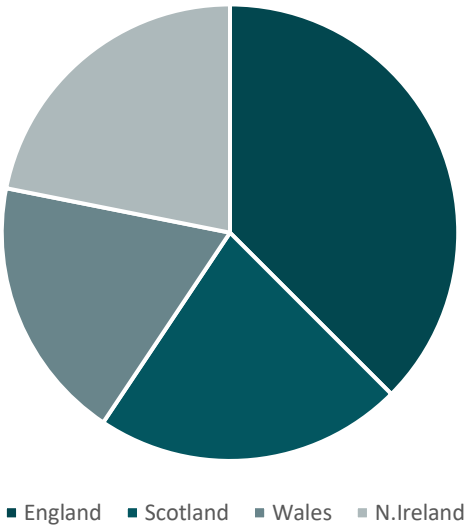
Appendix 1: Recruitment Demographics

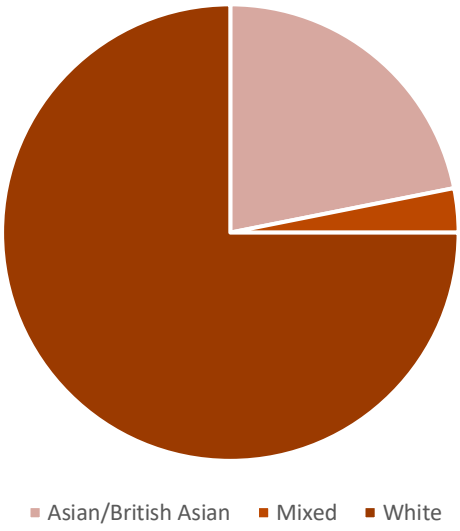
Recruitment

Recruitment	
Sex Male: 13 Female: 19	
Relationship to the medicines lifecycle Patient: 20 Parent: 6 Family Member: 6	

Location
England: 12
Scotland: 7
N. Ireland: 7
Wales: 6



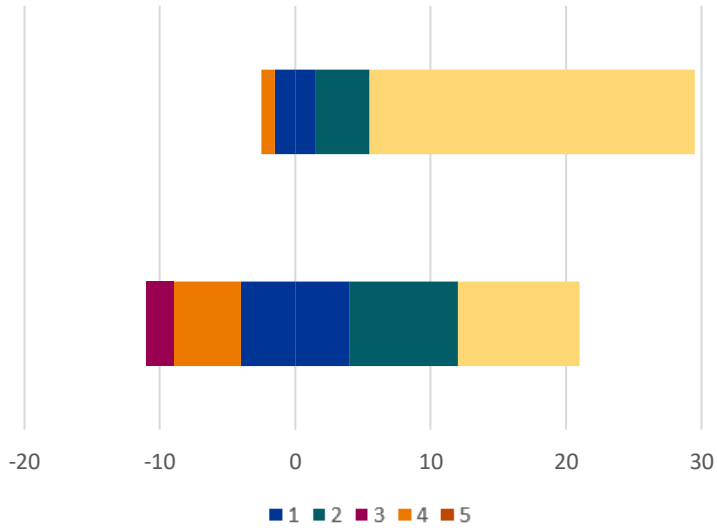
Ethnicity
White: 24
Asian/British Asian: 7
Mixed: 1



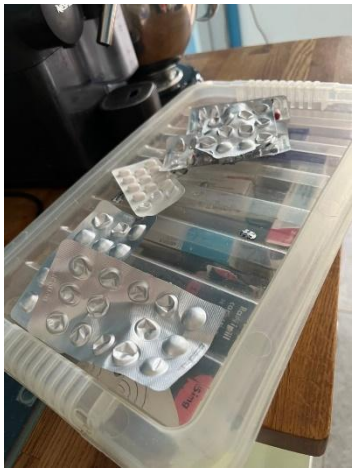
Attitudinal questions

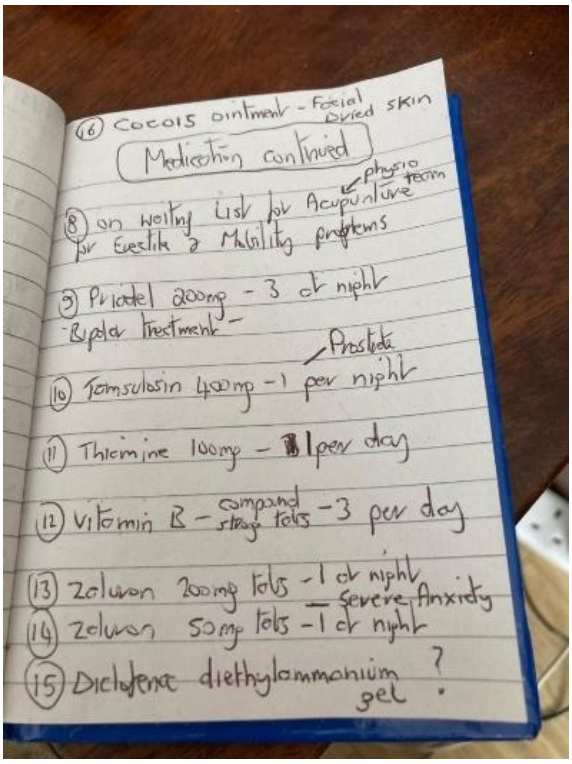
On a scale of 1-5 (where 1=very poor and 5=very good), how would you describe your experience of taking medicines?

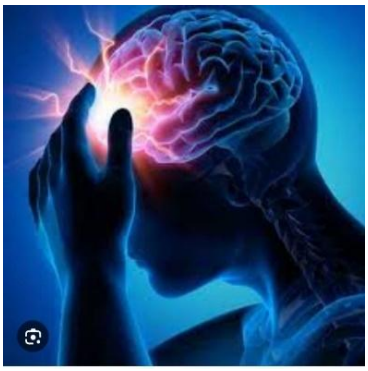
On a scale of 1-5 (where 1=not at all interested and 5= very interested) how interested are you in the development and availability of medicines?



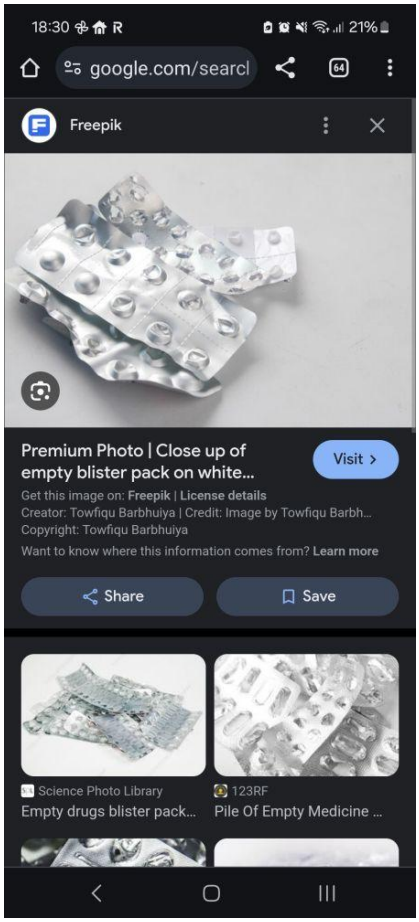
Appendix 2: Images shared by public participants before Workshop 1: their connection to medicines.








Bedtime
Teatime
Mid-day
Morning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Appendix 3: Interview Questionnaire

Discussion guides

Public Interview discussion guide – Interview 1

MINER: Medicines lifecycle and perceptions of medicines use – Public participant interview guide

1.Introduction

Thank you for agreeing to take part in this project, in the form of two one-to-one interviews. This discussion guide is being shared with you before your first interview to tell you about the questions we hope to cover. This will allow you to think about them beforehand if you would like to, but you do not need to prepare anything.

Our questions for interview one are listed from page 2 onwards. On pages 1-2, you will find the background to this project and its aims, and information on the interview format. This should be read alongside the Participant Information Sheet (Version number: 2.2 Date: 28/06/2024) and Participant Consent Form (Version number: 2.0 Date 09/05/2024) shared with you when you signed up to take part.

2.About this project

The project has been commissioned by the University of Liverpool. The Principal Investigator is Professor Reecha Sofat, Breckenridge Chair of Clinical Pharmacology and Therapeutics. It has been commissioned from Hopkins Van Mil (HVM), an independent social research team, with the Project Lead, Henrietta Hopkins, HVM Director. It is being conducted in collaboration with Manchester Metropolitan University and University College London. The project has received ethical approval from the University of Liverpool Central University Research Ethics Committee A (reference: 13799).

The overall project involves three stages, including workshops and one-to-one interviews with public/ patient participants and medicines professionals, as well as a nationally representative quantitative survey. A publishable report will be the main output from the research using visual and accessible formats, produced by Hopkins Van Mil, plus research papers produced by the academic partners.

The aim of this project is to explore the views and attitudes of patients and members of the public more broadly towards medicines. We are interested in finding out your views about how the medicines system does or doesn't work for you and other people you may know. We want to explore the full 'medicines lifecycle' in our interviews together, beginning from an idea for a drug and its development all the way through to how they are prescribed and used by people.

You do not need to have any specific knowledge to take part, we're interested in your views and experiences more broadly. In parallel to asking you and other public participants we will be asking people who work with medicines, including bodies like the NHS, researchers at universities and in industry, those who regulate medicines,

and those that write medicines guidelines, about their views on this topic.

3.Interview format and confidentiality

Each interview will last one hour and will be conducted over the phone or via Zoom, depending on the preference you expressed when signing up to take part. Dates of each interview have been confirmed with you separately and are included in the accompanying e-mail, alongside details of your interviewer. Your interviewer will be a member of the Hopkins Van Mil project team. As far as possible, we will try to ensure you have the same interviewer for both interviews.

We have sought your permission to audio record both interviews. Your interviewer will confirm whether you are happy for your interview to be recorded at the beginning of each interview.

If your interview takes place via Zoom, your interviewer will use the built-in recording function within Zoom. This automatically generates a video file and audio file. The video file will be deleted immediately after the interview and only the audio file will be retained. The audio file will be transcribed word-for-word before also being deleted. If your interview takes place over the phone, your interviewer will record the call audio on their device locally. In this instance, the audio file will be transcribed word-for-word before being deleted.

All interview transcripts will be anonymised before they are used for analysis and reporting purposes. Anything you say will not be associated with you directly and your name will not be included in any of this project's outputs.

4.Withdrawal

Your participation is voluntary, and you are free to withdraw at any time without giving any reason. You are also free to decline to answer any particular questions asked in the interviews.

We may use the data that you provide up to the time you wish to withdraw, if however, you would like them to not be used you should make this clear to your interviewer or another member of the project team.

5.Interview one: our questions include

1. Please tell me about a typical (day of interview e.g. Wednesday) for you, what things would you be doing and when?

2. Now, thinking about the medicines you take, or help those you care for to take:
    a. Are there medicines you take every day?
        i. If yes – can you tell me more about these medicines and why you need to take them?
        ii. If no – have you ever had to take medicines over a sustained period of time (for example, several weeks, months, years)? Can you tell me more about these medicines and why you needed to take them?

    b. Are there medicines you take occasionally? (for example, for a headache)
        i. If yes – can you tell me more about them, and why you take them?

3. Now, thinking more about the medicines you take – either occasionally or over a sustained period:
    a. Who gives you advice about the medicines to take?
    b. Who might you talk to, if anyone, about which medicines to take?
    c. What factors, if any, encourage or help your medicine-taking?
    d. What factors, if any, discourage or hinder your medicine-taking?
    e. Is there anything else you can tell me about how you decide which medicines to take?

4. Now, thinking about how you take medicines:
    a. Who gives you advice about how your medicines should be taken?
    b. Who might you talk to, if anyone, about how to take your medicines?
    c. What factors, if any, inform how you take your medicines?
    d. Is there anything else you can tell me about deciding how you take medicines?

5. We are now going to explore your initial thoughts on the 'medicines lifecycle' – this is the process which begins with carrying out research and discovering the causes of disease, leading to the testing, regulation and prescription of medicines, and finally taking them.
    a. What about how medicines are researched and discoveries are made?
    b. What about how medicines are regulated and policy is developed?
    c. What about how medicines are prescribed and the role of healthcare professionals in providing medicines?
    d. What about accessioning information about medicines?

6. Let's think more about the role of healthcare professionals, how has your interaction with them affected your experience of medicines and medicine-taking?
    a. When have they had a positive impact?
    b. When have they had a negative impact?

7. Before we wrap up, please could you describe a time when taking medicines has been more difficult or unclear – what were the reasons for this?

8. And could you describe a time when taking medicines has been easier or particularly clear – what were the reasons for this?

We will send a similar guide with the questions we would like to cover in our follow up discussion in the days before our next interview.

Public Interview discussion guide – Interview 2

MINER: Medicines lifecycle and perceptions of medicines use – Public participant interview two guide

6.Introduction

Thank you again for agreeing to take part in this project, in the form of two one-to-one interviews. This discussion guide is being shared with you before your second

interview to tell you about the questions we hope to cover. This will allow you to think about them beforehand if you would like to, but you do not need to prepare anything.

Our questions for interview two are listed from page 2 onwards. On pages 1-2, you will find the background to this project and its aims, and information on the interview format. This should be read alongside the Participant Information Sheet (Version number: 2.2 Date: 28/06/2024) and Participant Consent Form (Version number: 2.0 Date 09/05/2024) shared with you when you signed up to take part.

7.About this project

The project has been commissioned by the University of Liverpool. The Principal Investigator is Professor Reecha Sofat, Breckenridge Chair of Clinical Pharmacology and Therapeutics. It has been commissioned from Hopkins Van Mil (HVM), an independent social research team, with the Project Lead, Henrietta Hopkins, HVM Director. It is being conducted in collaboration with Manchester Metropolitan University and University College London. The project has received ethical approval from the University of Liverpool Central University Research Ethics Committee A (reference: 13799).

The overall project involves three stages, including workshops and one-to-one interviews with public/ patient participants and medicines professionals, as well as a nationally representative quantitative survey. A publishable report will be the main output from the research using visual and accessible formats, produced by Hopkins Van Mil, plus research papers produced by the academic partners.

The aim of this project is to explore the views and attitudes of patients and members of the public more broadly towards medicines. We are interested in finding out your views about how the medicines system does or doesn't work for you and other people you may know. We want to explore the full 'medicines lifecycle' in our interviews together, beginning from an idea for a drug and its development all the way through to how they are prescribed and used by people.

You do not need to have any specific knowledge to take part, we're interested in your views and experiences more broadly. In parallel to asking you and other public participants we will be asking people who work with medicines, including bodies like the NHS, researchers at universities and in industry, those who regulate medicines, and those that write medicines guidelines, about their views on this topic.

8.Interview format and confidentiality

Each interview will last one hour and will be conducted over the phone or via Zoom, depending on the preference you expressed when signing up to take part. Dates of each interview have been confirmed with you separately and are included in the accompanying e-mail, alongside details of your interviewer. Your interviewer will be a member of the Hopkins Van Mil project team. As far as possible, we will try to ensure you have the same interviewer for both interviews.

We have sought your permission to audio record both interviews. Your interviewer will confirm whether you are happy for your interview to be recorded at the beginning

of each interview.

If your interview takes place via Zoom, your interviewer will use the built-in recording function within Zoom. This automatically generates a video file and audio file. The video file will be deleted immediately after the interview and only the audio file will be retained. The audio file will be transcribed word-for-word before also being deleted. If your interview takes place over the phone, your interviewer will record the call audio on their device locally. In this instance, the audio file will be transcribed word-for-word before being deleted.

All interview transcripts will be anonymised before they are used for analysis and reporting purposes. Anything you say will not be associated with you directly and your name will not be included in any of this project's outputs.

9.Withdrawal

Your participation is voluntary, and you are free to withdraw at any time without giving any reason. You are also free to decline to answer any particular questions asked in the interviews.

We may use the data that you provide up to the time you wish to withdraw, if however, you would like them to not be used you should make this clear to your interviewer or another member of the project team.

10.Interview two: our questions include

1. What has been on your mind about medicines since our last interview?

a. From the topics we spoke about, which struck you as being most important or interesting?

For much of our discussion today, we will continue to think about different aspects of the 'medicines lifecycle'. This includes research, policy and regulation, medicine prescribing and information, and taking and reviewing medicines.

During the project, we have spoken with a range of people who take medicines, as well as people working with medicines. We would like to understand your views on some of the issues raised by others involved in the project. This includes how important you feel they are, and what they might mean for you, people you know or society in general.

2. Thinking about **medicines research:**

a. We heard the view that there was a greater willingness among patients and members of the public to take part in medicines research during the pandemic, but this has now fallen away again.
    i. Why do you think this is?
    ii. What would prompt you take part in a research study into a new medicine?
    iii. What would put you off taking part in a research study into a new medicine?

b. We heard the view that medicines research can be seen as entirely separate from a patient's healthcare, and in fact research should be seen as part of healthcare.
    i. Would you like to see taking part in medicines research become a more frequent offer as part of standard healthcare?
    ii. What impact do you think combining research into medicines with healthcare would have on you, people you know and society as a whole?

3. Thinking about **medicines policy and regulation:**

a. We heard the view that it can take too long for the medicines system to switch from prescribing patients a more expensive, branded medicine to a cheaper generic version of the same medicine (this switch happens when a patent expires, and the same branded medicine can be produced more cheaply by other manufacturers).
    i. Are you aware of ever having moved from a branded medicine to a generic version of the same medicine, either yourself or someone you know? If so, what can you tell me about this experience?
    ii. If you haven't experienced this, what do you think your response to moving from a branded medicine to a generic version of the same medicine would be? How would you expect this decision to be communicated to you?

b. Regulation is an important aspect of the medicines system. It helps to ensure the safety of medicines which are then approved for use in healthcare. It can also lengthen the time it takes to start using new medicines.
    i. What is your view on the balance between speed and safety when it comes to the approval of medicines for use in the UK?

4. Thinking about **medicine prescribing and information:**

a. We heard patients and medicines professionals report barriers when it comes to communicating with each other about the availability, prescription and use of medicines.
    i. In your perspective, what are the key barriers to having effective communication between patients and professionals about medicines?

b. We heard that patients and members of the public often find it easier to access medicines information via their pharmacist than they do via their GP.
    i. To what extent does this reflect your own experience, and what do you make of this situation?
    ii. Can you see upsides and/or downsides to this situation, if so what are they?

5. Thinking about **taking and reviewing medicines:**

a. We heard that up to 50% of the medicines prescribed for long-term conditions are not taken as intended, with negative consequences for health, the economy and the environment.

i. Drawing on your own experience, what factors do you feel are most likely to contribute to people not taking their medicines as intended?

b. We heard a range of views about medication reviews and deprescribing (stopping a medicine which was previously prescribed).
   i. What is your experience of medication reviews?
   ii. What is your experience of deprescribing?

6. What is your understanding of the phrase 'patient-centred care', or what comes to mind when you hear it now?

   a. How would you describe good patient-centred care in relation to medicines?

   b. How would you describe poor patient-centred care – or care which isn't patient-centred – in relation to medicines?

   c. To what extent do you feel you currently experience, or have previously experienced good patient-centred care?

Stakeholder Interview discussion guide

MINER: Medicines lifecycle and perceptions of medicines use – Stakeholder interview guide

1. Introduction

This project, to understand the medicines life cycle from both the patients and system point of view has been commissioned by the University of Liverpool. The Principal Investigator is Professor Reecha Sofat, Breckenridge Chair of Clinical Pharmacology and Therapeutics. It has been commissioned from Hopkins Van Mil (HVM), an independent social research team, with the Project Lead, Henrietta Hopkins, HVM Director. It is being conducted in a collaborative partnership with Manchester Metropolitan University and University College London. The study has received ethical approval from the University of Liverpool Central University Research Ethics Committee A (reference: 13799).

The aim of this project is to explore the views and attitudes of patients towards medicines, garner their understanding of the lifecycle of medicines and drill into their views and attitudes of how the system works to deliver medicines for them or for those that they care for. In addition, we will explore the views of those within the system, including health care professionals, researchers, policy and regulatory organisations, to understand their views in developing and delivering medicines. We will seek to understand mismatches to begin to elucidate mechanisms by which the system and patient interaction can be improved.

The research will use a three-stage deliberative programme including workshops and 1-2-1 interviews with public/ patient participants and medicines professionals, as well as a nationally representative quantitative survey.

A publishable report will be the main output from the research using visual and accessible formats, produced by Hopkins Van Mil, plus research papers produced by the academic partners.

2. Interview purpose and confidentiality

Thank you for giving consideration to take part in this interview. The purpose of the interview is to understand your experience and views of the medicines system as a professional working within it. We would like to explore a range of topics in this interview (see Section 3 for examples), with a focus on the aspects of the system most familiar and of interest to you. Some questions have been generated by the research team and some by pubic/ patient participants involved in this project.

The interview will be conducted by a project team member from HVM. Our interview will last no longer than 60 minutes and will be conducted on Zoom. We will send you an Outlook invitation with the Zoom link.

We would like to ask your permission to record this interview. This is so we can use the recording for the following purposes: For note-taking purposes. In this instance, we will retain the audio file and send this to a reputable external company for transcription. All transcripts will be anonymised and used in our analysis. We may include anonymous quotes from our interview in the reports we publish. Your name or other identifying information will not be included.

3. Our questions

9. Please tell me about the organisation you work for, your role and its connection to medicines.

10. What do you perceive to be key challenges or issues within the medicines system in need of addressing?

These could relate to specific actors in the system, such as Government, regulators, clinicians or the public, as well as different parts of the system, including discovery research, policy and regulation, prescription and patient interaction with services.

11. What issues in the medicines lifecycle do you think have the most impact on how patients and the public experience the medicines system?

12. What opportunities or solutions would you like to see to help address the issues we have discussed?

13. How joined up, integrated and well-managed do you consider the various organisations involved in the medicines system to be in the UK?

14. What is important to consider when balancing the cost of medicines against the benefits to individuals?

15. To what extent is medicine use and prescribing being linked to patient outcomes?

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