

Research on the Role of Patient Information Leaflets in Meeting the Information Needs of Patients

Main Report

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Executive Summary

The research had five objectives:

- To map the different user journeys that exist to access medicines.
- To understand how individuals currently engage with health information relating to medicines.
- To understand how individuals currently engage with the Patient Information Leaflet (PIL).
- To understand what factors influence an individual's access and engagement with a PIL.
- To understand the best way to highlight additional safety warnings within a PIL.

It used a mixed-method approach combining 16 focus groups with a total of 128 patients and an online survey of a representative sample of over 2,000 UK adults placed on the YouGov survey platform, supported by desk research. The evidence and analysis included behavioural modelling; mapping of the information patients want and need about their medicines; and mapping the sources of information available to them as they journey through the health and care system.

Patient Journeys

The research identified a **core patient journey** that starts with symptoms and proceeds through diagnosis and consultation to prescription and dispensing. It also identified **significant variations** in that journey: for example, if people self-diagnose and buy a medicine 'over the counter', they may not receive HCP advice. Other significant variations include whether patients are in **primary or secondary care**; whether the consultation is with a **pharmacist, a doctor or another prescribing HCP**; and whether consultations or dispensing are **remote or face-to-face**. Each stage on the journey has **opportunities to give patients information** about their medicines. But each stage can also **generate new questions** or information needs.

Information Needs

Most people feel they **have the information they need** to take medicines safely and effectively, drawing on a range of sources. For example, 77% of survey respondents said the last time they obtained prescription medicine from a doctor or in hospital they had

“all” the information they needed and a further 18% said they had “some” of the information they needed.¹

Information needs are linked to **three broad questions**: is this the **appropriate** medicine for me? How do I make sure it is **effective**? And is it **safe**? Appropriateness could involve serious choices linked closely to discussions with their HCP and informed consent, and what alternatives were available. Effectiveness is generally a practical matter of taking the right dose in the right way at the right time. Safety could include a range of more complex questions including side effects, contra-indications and allergic reactions.

Information needs **vary strongly** depending on familiarity with the medicine, the seriousness of the condition, the perceived potency of the medicine (including prescribed versus non-prescribed), and any underlying health conditions. For example, as explored in Chapter 5, patients are considerably less likely to seek out information from the PIL for a medicine they feel familiar with than one they are taking for the first time. **Patient activation** and other factors such as general attitudes to risk, educational attainment and confidence in challenging authority also play a part.

Sources of Information

Overall, **people say they get the information they need about their medicines**, though hospital prescriptions present significant challenges including where patients are so ill that they would struggle to obtain or retain information about their medicines. People use **multiple sources of information**. The PIL is a key resource but seldom relied on alone. For example, in the survey, 53% of respondents said they would use the PIL to get information about a medicine prescribed by a GP or dentist. This was the second most likely source of information (53% said they would take the prescriber) and much higher than, for instance, those who would use a general internet search (20%). However, only 5% of respondents indicated they would *only* use a PIL as a source of information. This is explored in more detail in Chapter 4.

Some sources were **‘formal’** or ‘core’: prescriber, pharmacist, packaging, NHS Online. They may vary according to the ‘patient journey’ being followed, for example between a GP consultation or a hospital visit. Other sources of information were **‘informal’** or ‘supplemental’: internet, forums, friends and family. These were used to fill gaps or for uncertainties or anxieties. Some used the PIL mainly as a ‘core’ source, reading or skimming it when first taking their medicine. Others used it when seeking supplemental information, such as after a suspected adverse event. Some sources (such as a GP

¹ Information needs and variability by different contexts are explored in more detail in Chapter 3.

appointment) were more trusted but harder to access. Other (such as an internet search) were convenient but could not always be relied on.

Patient Information Leaflets

Participants thought the leaflet was intended to provide information on using the product safely and effectively and to provide the manufacturer with legal protection. The likelihood of a patient using the PIL depended on several factors, such as how familiar they feel with the medicine. The focus groups participants typically said the PIL was useful in case they had any doubts about the medicine.

The sections of the PIL that individuals engage with also vary considerably. In the focus groups, a small number of participants claimed to always read the PIL in detail and similarly some said they never did. Respondents to the survey were asked which sections of the PIL they would typically read for a new medicine. On the one hand, 69% said they would read in detail the section on how to take the medicine; on the other, just 15% would read in detail when the leaflet was last updated. This is explored further in Chapter 5.

Participants generally felt the leaflet was comprehensive and could be trusted, but was not 'user-friendly'. They were more likely to read the leaflet if they were taking the medicine for the first time, if the medicine was to treat a serious condition, if the patient had pre-existing health concerns or if the person who obtained the medicine was giving it to a child or acting as a carer. Like any instruction leaflet or Terms and Conditions, they might choose not to read it, but they wanted to have the option to skim it or keep it for reference and would be worried if their medicine packaging did not include one.

Making Leaflets More Effective

People thought the single most helpful change would be to have **a summary of key information at the start of the leaflet**, as they sometimes found on the medicine packaging. They felt the design could be improved with **more diagrams, bold text, bullet lists and spot colour** (such as red for warnings). All agreed the **text should be larger**, though views were mixed on whether the text could or should be simplified.

The survey respondents were asked their views about two potential changes to the PIL. There was **strong support for using a QR code** to link to further information (58% support vs. 13% oppose). People thought this would also facilitate more accessible versions (audio, alternative languages) without making the PIL even longer. There was **strong support for using NHS Apps** to provide more (and personalised) information about the medicines people were taking (66% support vs. 9% oppose). Participants

thought that if the PIL were significantly updated, this should be **flagged on the external packaging**.

Findings

The main findings for the **leaflets as a whole** are that patients and the public would as a whole welcome:

- Basic design standards to deliver “legible, clear and easy to use”. This would include bullets, line spacing, font size, spot colour and pictograms.
- A summary of key facts at the start of each leaflet, focusing on “how to take, how much to take, do not take if...”.
- More use of standard design including contents, headings and pictograms.
- Text or pictograms to help users assess side effect risks and avoid scaring them.
- Using the packaging to highlight where the PIL has been updated.
- Linking to online information via QR codes and NHS Apps and explore how these could involve links to patient records or other health information to be more personalised and interactive.
- Retaining the paper leaflet – for now – but pursue digital enhancements and alternatives.

1. Introduction

Key Points

Research aim: to understand how patients use the patient information leaflets and how they can be made more effective.

Context: mapping what information patients want and need about their medicines and the sources of information available to them.

Approach: mixed methods including desk research and qualitative and quantitative fieldwork.

Qualitative: 16 focus groups with 128 patients.

Quantitative: an online survey of c2,000 UK adults.

Analysis including mapping patient journeys and behavioural modelling.

1.1 Background

The purpose of the Patient Information Leaflet (PIL or “Leaflet”) is to provide patients or their carers with information about the medicine and in particular: how to administer it safely and effectively; any precautions; and potential side effects. It is a legal requirement to include a Leaflet in the medicine packaging, although for some medicines sold without the need for a prescription, the information that would otherwise be contained in the Leaflet may be printed on the packaging itself.

Prior research² suggests that a high proportion of patients do not read the Leaflet before taking their medicine. In some cases, this may be because patients already have the information they need from other sources, such as their GP or pharmacist. But prior research also suggests that significant numbers of patients find it hard to gain the information they need from the Leaflet because of the language used or the design and layout. Further, even when a patient does read the Leaflet when first prescribed a medicine, they are unlikely to read it through on every subsequent occasion they receive a new supply. This means that important updates to Leaflets may not be read by those using the medicine.

² For example, ‘One Size Doesn’t Fit All: Reimagining medicine information for patients’ (March 2023) <https://healthinnovation-kss.com/wp-content/uploads/2023/03/State-of-the-Nation-Report-FINAL.pdf>

Further, patients are often prescribed multiple medicines – ten or more is not uncommon – and each will have different requirements, precautions, risks and potential side effects. Leaflets generally deal only with a single medicine and it can be very challenging for patients to try to assimilate information from multiple Leaflets.

Leaflets are one tool for providing patients with the information they need to make informed choices about their treatment and take medicines safely and effectively. Some patients – for example, when being treated as a hospital inpatient – may receive all the information they need direct from healthcare professionals. But others – such as a carer – may not have had any contact with the prescriber or other healthcare professional and may be heavily reliant on the Leaflet in helping a relative with their medication. This is why the Leaflet ought to:

- Provide a patient or carer with all the information they need.
- Not assume they will receive that information from another source, such as a HCP.
- Not lead them to seek out other, potentially inaccurate sources because the information is incomplete or not sufficiently clear or accessible.

In judging the extent to which Leaflets fulfil these three requirements, it is vital to keep in mind that the information patients need is likely to vary according to several factors including: their overall health and the condition or conditions they have; the potency of the medicine; their capacity to engage with the information provided; and their confidence in making decisions about their own health. This in turn means that some groups of people may be disadvantaged:

- Those with disabilities including blindness, colour-blindness, dyslexia, or cognitive impairment.
- Those with serious and/or long-term health conditions.
- Those who are less confident in using the English language.
- Those with a lower level of educational attainment.

These concerns apply to all classes of conditions and medicines, but there are also some situations which give rise to particular concerns. For example, some medicines may pose risks to a foetus: but for a range of reasons, including that around half of pregnancies in the UK are unplanned, people may not seek out or retain this information, or may continue to take the medicine until they become aware that they or their partner are pregnant.

Finally, as well as concerns about the effectiveness of Leaflets, new technologies and channels, such as QR codes and the NHS App, offer additional ways to provide the information contained in the Leaflets to people in different and potentially more effective ways, including by supporting patients in assessing the interactions between different medicines.

1.2 Research Objectives

This context has led the MHRA to adopt a programme of work to address the question:

“How might we make Patient Information Leaflets more accessible so the patient can optimise their healthcare, improving the capability to drive engagement with medicinal products?”

This project aims to contribute to that programme through five objectives:

- To map the different **user journeys** that exist to access medicines.
- To understand how individuals **currently engage with health information** relating to medicines.
- To understand how individuals **currently engage with Leaflets**.
- To understand **what factors influence an individual’s access and engagement** with a Leaflet.

1.3 Methodology

For this project, Woodnewton combined desk research, qualitative and quantitative fieldwork and analysis. This mixed-methods approach was chosen as providing the most effective way to deal with a complex research area. When it comes to engaging with medicines, people will have distinct experiences and preferences. They may also experience emotions such as anxiety, and face nuanced decisions about the risks and benefits of different forms of treatment.

Qualitative research techniques, such as focus groups and in-depth interviews, are ideal in exploring complex and interlocking issues, giving participants time and space to share their perceptions and experiences, including in the case of focus groups, responding to the views of their peers. However, it is not practical to include sufficient participants in qualitative research to provide results that can be reliably extrapolated to the population as a whole, let alone allow for analysis for specific demographic or other subgroups. This is where surveys, using mainly closed or scaled questions, based on reliable and representative samples, can

provide a robust picture of the extent to which the general population has shared or different views or experiences. In short, quantitative research is better at showing how many people think or do something, while qualitative research's strength is revealing why.

In addition, the fieldwork included two validation sessions. These were face-to-face focus groups held at the end of the fieldwork period to help validate findings and test emerging conclusions. These sessions were also an opportunity to help ensure the qualitative fieldwork was inclusive of especially hard-to-reach groups, and particularly the digitally excluded.

Desk Research

The desk research had two main purposes:

- To establish the existing knowledge base on the information that patients wanted or needed to know about their medicines, so that fieldwork and analysis could focus on new and more productive areas.
- To help development of a theory of change model, which in turn would inform the design of the fieldwork.

It used a series of search terms to identify potential sources, covering academic studies, surveys and other research commissioned by healthcare providers and research institutes, and grey literature such as presentations to conferences. The potential sources were reviewed and scored for their potential relevance and quality, and this scoring was in turn used to prioritise those documents which were analysed in full. The analysis used behavioural modelling centred around a series of patient journeys.

Qualitative Research

The qualitative strand involved facilitated discussions with patients and the public in 14 focus groups, each with five to seven participants. Ten of these groups were conducted in person: two each in London, Liverpool, Newport, Nottingham and Skegness. Four groups were conducted online to maximise the geographic spread of participants. In addition, Woodnewton interviewed six participants in one-to-one depth interviews.

In total, 105 participants took part in the qualitative strand, which was slightly more than the target of 100 participants set at project inception. A breakdown of participant demographics is included in the annex.

Participants were recruited through working with Woodnewton's specialist qualitative recruitment partner, Roots Research, who have a database of more than 500,000 UK residents who had previously indicated their willingness to take part in research. Demographic

data is held about each participant so that research invites can be sent to specific groups who are then asked to complete a screening questionnaire before potentially being invited to take part. This allows the research team to develop and recruit to specific demographic and other criteria.

The focus groups and depth interviews followed a semi-structured approach, in which the moderator used a topic guide to steer the discussion. This guide was designed by Woodnewton with input and sign-off from the MHRA project team, and it set out the broad themes and questions to be covered in the discussions while also providing for a lot of flexibility so that participants could raise points of their own and express themselves in their own words. All qualitative discussions were moderated by senior researchers from Woodnewton.

The focus groups typically lasted 80 minutes. The qualitative fieldwork took place in July and August 2025.

In addition, Woodnewton convened two validation sessions on 27 September 2025 and 2 October 2025 with 23 participants who would not normally be recruited for these types of projects. Of these, 13 were recruited by the Kent Association for the Blind and 10 by the Sunlight Community Centre. These participants tended to be older (the oldest was 100 years) and with low digital experience or skills to ensure a more inclusive research methodology.

Therefore, in total 128 patients and the public from across the UK contributed to the qualitative data research strand.

Quantitative Research

The insights from the qualitative strand helped to inform the design of a set of survey questions, which were placed on the YouGov UK general public omnibus survey. This omnibus survey is a tool that allows researchers to gather feedback from a representative sample of the UK public (adults, aged 18+) in a robust and cost-effective manner.

Woodnewton designed the surveys in close collaboration with the MHRA project team. The questionnaire was designed to elicit quantitative data on how well-informed people feel about medicines they have taken through different routes, the role of the PIL in informing patients, the extent to which people engage with different parts of the PIL, and support for future changes. The majority of the survey used 'closed questions' where respondents selected one or more answers from a list or scale. A small number of 'open questions' were also included where respondents were able to write in their answers in their own words.

Fieldwork for the quantitative survey was 30th September to 1st October 2025.

Analysis

The research used a grounded theory approach with evidence rooted in participants' own experiences and interpretations. The analysis method took the evidence from interviews, focus groups and the survey of the general public and mapped awareness, understanding, and behaviour. This was used to explore differences in the drivers that generated information needs in relation to medicines, and the ways in which users sought to meet those needs, including demographic subgroups where the sample size permitted. The change model evolved during the desk research, including identifying and exploring factors which would give rise to questions or concerns about medicine, and the different ways in which the resulting 'information needs' could be met. The analysis also considered the language used by participants, including comparisons and imagery, which could inform the future design of patient information leaflets or other communications.

1.4 Reporting

This report brings together the key findings, analysis and recommendations from the project as a whole. In addition, the reporting included:

- Regular feedback to the project team (typically weekly meetings).
- An interim presentation of emerging finding (PowerPoint).
- A topline report providing the population-wide responses to each of the survey questions (Word).
- Data tables from the general public survey (Excel).
- Full data set from the general public survey (SPSS).

This Report is structured as follows:

- Chapter 2. The core patient journey that patients take through the healthcare system, and the main variants on that journey, to provide the context for mapping the needs patients have for information about their medicine and how they might be met.
- Chapter 3. What information needs patients have in making sure they are taking the right medicine for them and that they do so safely and effectively, and how these may vary.

- Chapter 4. What formal and informal sources patients use to meet their information needs
- Chapter 5. The role of Patient Information Leaflets in providing patients with information within the wider patient journey.
- Chapter 6. How the Leaflet could be made more effective both directly and through other changes such as using QR codes.
- Chapter 8. Conclusions and recommendations.

Terminology

In this report, some terms are used in specific ways as set out below.

- ‘Folk wisdom’. This is used to reflect how participants in the research frequently said they drew part of their information from their previous life experience, including what they had learned about health and medicines from their parents, from others around them, or from the media (which could include fiction or drama).
- ‘General Sales List’ medicines are ones that may be sold without a prescription in general retail outlets such as petrol stations or corner shops. (These are sometimes loosely referred to as ‘Over the Counter’ medicines, though OTC would also include ‘Pharmacy-Only’ medicines which can be sold without a prescription but only in a pharmacy.)
- ‘Label’ and ‘Printed Label’ are used for the label printed and attached to the medicine packaging by the dispenser with the name of the patient and the dose.
- ‘Leaflet’ refers to the Patient Information Leaflet.
- ‘NHS apps’ refers to the four apps used in the four UK nations: the NHS App in England, the NHS Wales App in Wales, the NHS 24 Online app in Scotland and My Care in Northern Ireland.
- ‘Packaging’ refers to the bottle, box, blister pack or sachet that the medicine is supplied in, including the patient information leaflet.
- ‘Patient activation’ refers to the knowledge, skills and confidence each patient has to take or share responsibility for their own care.
- ‘Patient Journey’ refers to how a patient moves through the healthcare system, from diagnosis to outcome, in relation to a specific condition or set of symptoms.
- ‘Participants’ refers to those who took part in the focus groups.

- ‘Potency’ reflects how participants perceived the strength or impact of a medicine, which in turn affected the information they needed about its risks and benefits and how to take it safely and effectively.
- ‘The Public’ refers to the findings from the survey or other quantitative research sourced through the desk research which included a representative sample of the UK adult population.
- ‘Respondents’ refers to those who took part in the online survey.
- ‘Self-dispensing’ refers to where someone would diagnose their condition themselves and choose and obtain non-prescription medicine without reference to pharmacist or other healthcare professional.
- ‘Self-prescribing’ refers to where patients decide to use a particular medicine which has not been prescribed by a healthcare professional: it would usually be a ‘General Sales List’ medicine, although on some occasions people may choose to take a prescription medicine they have not themselves been prescribed, or not for that condition.

Interpreting Qualitative Research

With qualitative research, there is always a question of the extent to which the findings from the sample of participants can be extrapolated to the wider population. For example, we cannot say that a certain percentage of the population hold a particular view or behave in a particular way. What we can say is that these views or behaviours are highly likely to reflect in broad terms those of the public. In the report, we have used terms such as ‘some’ or ‘many’ as a guide to the prevalence of these views or behaviours amongst participants; and also our judgement about the likely prevalence in the wider population. Similarly, we have included verbatim comments from participants where we think these are broadly representative of people’s experiences both within the research and in society more widely.

2. Patient Journeys

Key Findings There is a **core patient journey** that starts with symptoms and proceeds through diagnosis and consultation to prescription and dispensing.

There are **significant variations** in that journey: for example, if people self-diagnose and buy a medicine ‘over the counter’, they may not benefit from HCP advice.

Other significant variations include whether patients are in **primary or secondary care**; if they have **long-term conditions and/or taking multiple medicines**, and whether consultations or dispensing are **remote or face-to-face**.

Each stage on the journey has **opportunities to give patients information** about their medicines.

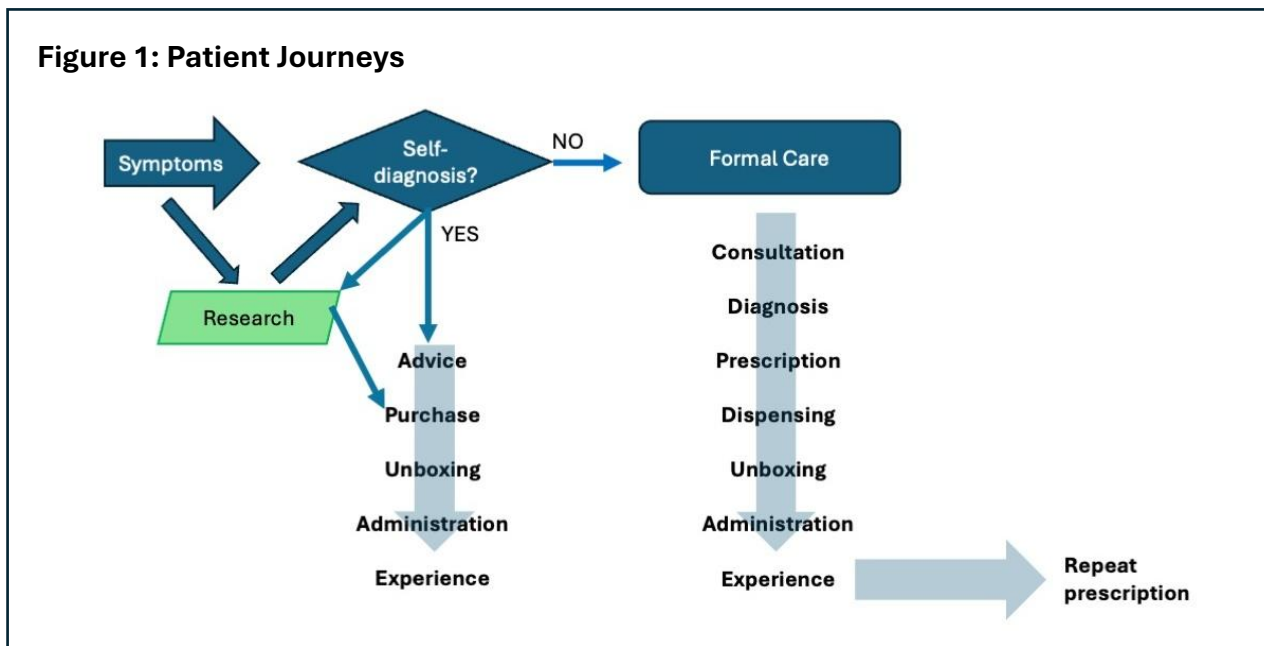
But each stage can also **generate new questions** or information needs.

2.1 Mapping Patient Journeys

The NHS issues over a billion prescriptions each year, involving different healthcare professions and care settings from hospital clinics to dental practices and supporting millions of patients across a vast range of conditions. Millions more self-diagnose their conditions and ‘self-dispense’ by choosing their own ‘over the counter’ medicines without a prescription from community pharmacies and other retail outlets. As a consequence, there is no single patient journey: but it is possible to identify stages common to many patients that can form a ‘core’ patient journey; and then identify some of the most significant variations. This in turn will form a crucial context for understanding the information that patients need to make informed choices about their medicines, and then take them safely and effectively.

2.2 Core Patient Journey

The desk research was used to map the main journeys that would lead to a patient taking a medicine. The core journey – the one followed most commonly – is set out in Figure 1, along with the main variation, in which a patient diagnoses their condition themselves and decides to use a non-prescription medicine.



Symptoms

People will have some reason for starting their health journey. It could be specific symptoms, though also could be the result of screening or other tests or a wish to check their health. In judging what to do next, they are likely to draw on their prior experience and their frame of reference. This framing comprises their understanding of health, symptoms, conditions and treatments, built up over their lifetime and include, for example, wisdom passed down from parents, media coverage (including fiction), and the experiences of friends and family.

Research

Depending on the symptoms and their prior experience and frames of reference, patients may carry out their own research on the symptoms, for example through an internet search or asking friends and family. In doing so, they may gain some information about potential treatments and relevant medicines.

Self-Care

Once they have carried out sufficient research, and assuming they decide to act on the symptoms and not just ignore them, learn to live with them or hope they go away, patients may reach their own conclusion about the cause of their symptoms (see self-diagnosis below). They then may decide to follow a self-care route or seek formal care from an HCP.

Formal Care

Patients will choose a healthcare professional to approach for a diagnosis or treatment. Most commonly this will be their GP surgery. In other cases, they may go to their community pharmacy and ask to speak to the pharmacist. They may also go to a range of clinics and treatment centres which allow walk-ins or self-referrals. They may choose to go to a private GP or pharmacist, or an online GP or pharmacist. If they are already receiving treatment, they may contact a specialist such as an Allied Health Professional (AHP) or hospital consultant.

Diagnosis

Formal care routes should lead to a consultation involving an assessment by the HCP, which in turn would lead to either a diagnosis and treatment plan, or tests, or a referral to a specialist. The consultation should involve the patient in making an informed choice about their treatment, based on an understanding of the risks and benefits of the treatment and any alternatives. This may include information and advice on medicines, including interactions with other medicines or conditions, other precautions, risks and side effects.

Each HCP will make a judgement about how much information the patient needs to make this choice. In some cases, the patient may have additional questions or information needs at the time which they do not feel able to raise (for example, because the HCP appears very busy, or they are reluctant to challenge an authority figure); or will think of new questions or concerns once the consultation is over.

Each HCP will also make a judgement about how best to convey that information: for example, some might explain orally how the medicine works, while others will print out an information sheet. Again, the way the HCP conveys information may not always be effective (for example, if the fact sheet is not optimised for a range of reading abilities).

Prescribing

Once the treatment plan is agreed, the HCP may give the patient a prescription and may provide information on how the medicine is to be taken safely and effectively. Again, HCPs make individual judgements about what information their patient needs, and how best to convey it; and again there is the risk the patient will not have their information needs met at this stage: for example, because the diagnosis creates a sense of shock which lessens their ability to absorb information thereafter.

Dispensing

The prescription will lead to the patient having their medicine dispensed. This may be face-to-face in a community pharmacy, and the dispensing pharmacist may check the patient understands how to take the medicine and ask if they have any questions nor concerns; or the patient may ask the pharmacist for advice. But the pharmacist may not always be available, or the patient may choose not to seek advice.

Unboxing

Once they have collected their medicine, the patient will remove it from its packaging. This has three elements:

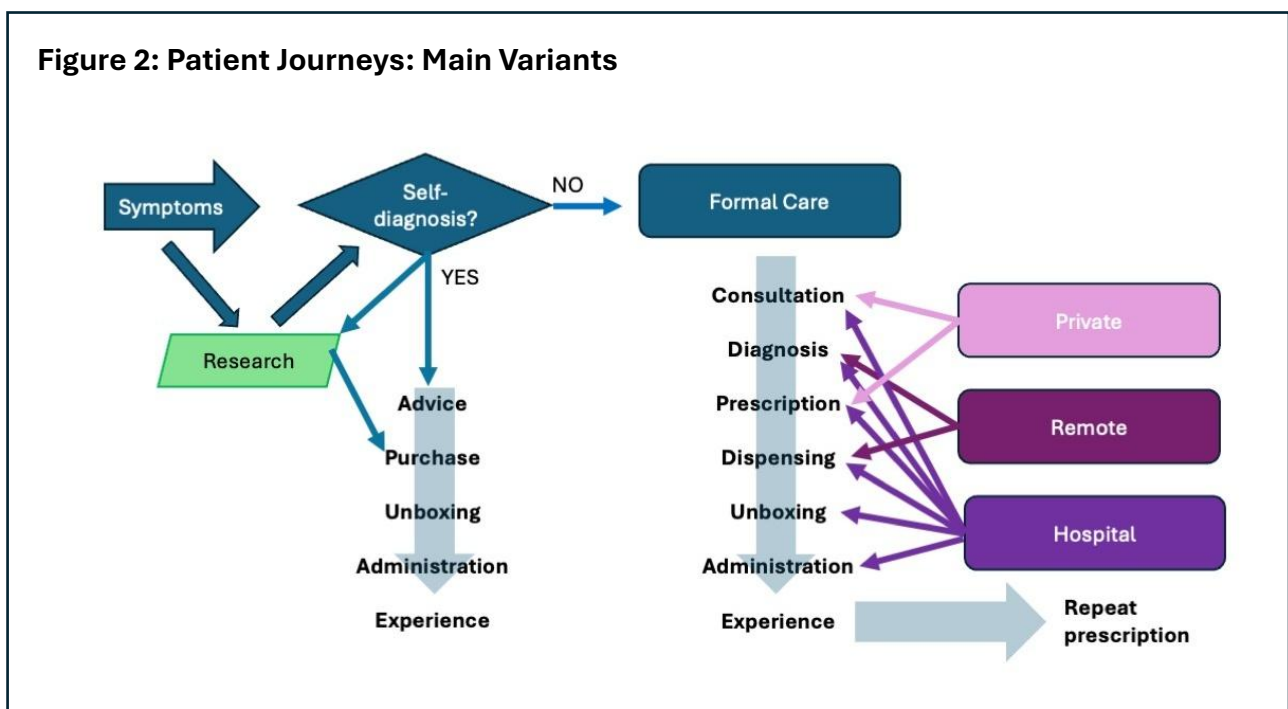
- An individual printed label which usually has the name of the patient and the dosage.
- The packet, bottle, tube, blister pack or sachet holding the medicine, which will have further generic information about the medicine.
- The Patient Information Leaflet (except where the rest of the packaging contains the required information and no PIL is needed). Patients are very likely to check the label; they may or may not look at the rest of the packaging and the PIL. As this is the final decision-point before taking the medicine, which may crystallise any remaining concerns, the patient may undertake further research. Typically this would be online or by consulting family and friends, but may also involve reading the PIL.

Experience

As the patient takes their course of medicine, they may experience a range of positive or negative effects, which may be expected or not. They may seek further advice or information either through their own research or by consulting a pharmacist, their prescriber or another HCP.

2.3 Main Variations in Patient Journeys

The main variations identified in patient journeys were: self-diagnosis leading to self-care; remote prescribing or dispensing; private prescribing or dispensing; hospital treatment. These are shown in Figure 2. The journey was also different in a range of ways for those patients being prescribed multiple medicines.



Self-Prescribing

Patients may use prior experience with similar symptoms, sources of information such as NHS Online or ‘folk wisdom’ to ‘self-diagnose’ or link their symptoms to a specific medical condition. They may then go to their GP, a pharmacist or another healthcare professional for a ‘second opinion’ or to have their diagnosis confirmed or challenged, or because they see the formal health system as necessary to provide them with the necessary medicine or other treatment. This in effect returns them to the formal patient pathway, with the ‘self-diagnosis’ becoming a developed form of the research that many patients undertake at this stage.

Other patients may move from ‘self-diagnosis’ to developing their own ‘self-treatment plan’ in which they decide how to respond to the symptoms or the underlying condition: such as taking time off work for a cold or resting a sore elbow for rheumatism. They may

also ‘self-prescribe’ medicines to help with this self-care, such as a hot lemon drink containing paracetamol or a topical cream containing ibuprofen. They may then ‘self-dispense’ by obtaining these from a retail that either does not have a pharmacist (such as a petrol station) or where a pharmacist may be on-site but they do not avail of this (such as a supermarket with an in-house pharmacy but the medicine is displayed separately, or a community pharmacy where they do not speak to a pharmacist).

If buying medicine without discussing with a pharmacist, they may read the information on the package to check that the medicine is appropriate for them and there are no safety or other concerns, such as ingredients that might give them an allergic reaction. They may also search for information on the medicine on their smartphone. They are very unlikely to open the packaging to look at the Leaflet prior to purchase.

Remote Prescribing and Dispensing

Where the consultation takes place remotely – by telephone, online messaging or video link – the patient experience will inevitably be different. The HCP may not pick up on non-verbal clues exhibited by the patient, or the patient may not feel the rapport and so confidence in sharing concerns as they would in a face-to-face setting. Equally, patients may feel more confident about sharing or challenging, for example because of the distancing effect of remote consultations or because they feel more comfortable in their own home than in a GP surgery or hospital clinic.

Those participants in the qualitative research who had direct experience of remote prescribing were in general positive, largely because they could see a GP faster remotely than waiting for a face-to-face appointment, or because it was more convenient. In general, the consultation and prescribing were for less serious conditions or less potent medicines, and participants did not raise any concerns about their ability to gain the information they needed compared to a face-to-face consultation.

Remote dispensing came in two main forms: where ‘High Street’ community pharmacists delivered the prescription to the patient’s home; and where the patient used an online pharmacy who would then deliver the medicine by post or courier.

Participants in the focus group discussions had experience of both forms. In general, the High Street / home delivery route was seen as a valued additional service for those who would struggle to collect their medicines from the pharmacy. There were also examples of pharmacists providing the same additional advice and support to a patient at home as to a patient collecting the medicine in person.

Where participants had used an online pharmacist, it was usually for repeat medicines or where they had been prescribed the medicine in the past and were confident it was ‘what they needed’. In general, participants felt that had they had more questions, would have had just as much opportunity to receive the information they needed about their medicine from an online pharmacist as from one based on the High Street.

Private Prescribing or Dispensing

As with remote prescribing or dispensing, participants tended to report positive experiences with using private doctors or pharmacists, again citing speed and convenience. They did not raise concerns about the opportunities for asking questions, and in a few cases said they felt they had more scope to do so ‘because they were paying for it’.

However, some participants expressed concerns about private GPs or pharmacists as part of a ‘creeping privatisation’ of health services. Some thought that the greater use of private doctors would undermine the NHS and leave those who could not pay in a much worse situation; and that it would also introduce ‘US-style’ healthcare which was seen as much less ethical and more exploitative, and likely to lead to bad patient outcomes for example through the promotion of unsuitable medicines (as with USN opioid crisis, which several participants cited).

They also expressed some of these concerns over private pharmacists, including that the ‘personal touch’ or willingness to ‘go the extra mile’ of local pharmacists would be lost over time if online pharmacies became more widespread. This connects to the wider theme of trust in the information provided about medicines which is explored further in section 5.4.

Hospital Treatment

Where patients were seen or treated in hospitals or other forms of secondary care, their journey could look very different to the ‘core’ journey in primary care, even when some stages such as diagnosis and prescription were the same. This reflects the diverse settings, conditions and treatments prevailing in secondary care, from a specialist cancer clinic a patient might visit regularly to an emergency admission following a road traffic accident. The information needs of each patient would vary, as would the way in which those needs would be addressed: for example, specialist clinics would often prepare comprehensive guides for patients on the nature of their condition and treatment, or they may be more likely to be in touch with others through patient support groups. The most significant difference, compared to most clinics and most primary care patient journeys, was where patients had a reduced capacity to engage with the system:

in other words, they would be too ill – and potentially also too scared – to understand the care they were being given, to formulate questions or concerns, to communicate these to staff, or process any information they received.

Some participants also saw a hospital pharmacy as a very different experience than their local community pharmacy. It was less personal, they might have to wait a long time to receive their medicines, they did not always feel they were given as much information when the medicine was handed over, and they could not ‘pop back’ if they subsequently had questions about the medication, as they could with a community pharmacy.

Stage	Potential Differences
Research	In an emergency, patients were much less likely to have carried out prior research into the condition or the potential benefits and risks of different medicines.
Diagnosis	The patient might not be conscious or might not be in a position to process information or ask questions effectively.
Prescribing	Prescribing might not involve the patient or be communicated to the patient, and decisions might be taken by a consultant and not the resident doctor or other HCP who interacts with the patient.
Dispensing	Medicines might be administered by nursing staff who might not have specialist knowledge compared to the prescriber or a pharmacist. At discharge, a patient might go home with a bagful of medicines which they might not understand in terms of risks, benefits or potential side effects.
Unboxing	Medicines were likely to be administered in single doses and the patient would not see or retain the packaging or the PIL.
Experience	Patients might struggle to distinguish the effects of their condition from any medicine used to deal with it.

The differences were not always problematic: for example, where pharmacists made ward rounds, this was an ideal opportunity for patients to ask questions and receive information personalised to them and to their condition, including relating to multiple medication. Similarly, while some participants in the research spoke of wards being chaotic or being unwilling to ask many questions, hospital care also provided opportunities for full and inclusive conversations between patients and HCPs in which they would have the time, space and information to make informed choices about their treatment and understand how to take their medicines safely and effectively.

Multiple Medicines

The treatment plan may involve prescribing multiple medicines: there is then the additional challenge for HCP and patient of having to give and receive more information, and also the complexities of how medicines may interact. Also, more than one HCP may prescribe for the same condition: for example, a GP may prescribe a cream to treat a skin reaction arising from a medicine prescribed by a specialist clinic.

Similarly, a patient may be dispensed their medicines by a number of different pharmacists who may not have a full picture of the patient's condition and treatment plan and so will be less able to provide advice specific to the patient or identify potential issues through the interaction of different medicines.

3. Information Needs

Key Findings Information needs are linked to three broad questions: is this the **appropriate** medicine for me? How do I make sure it is **effective**? And is it **safe**?

Appropriateness could involve serious choices linked closely to discussions with their HCP and informed consent, and alternatives.

Effectiveness was generally a practical matter of taking the right dose in the right way at the right time.

Safety could include a range of more complex questions including side effects, contra-indications and allergic reactions.

Information needs **varied strongly** depending on **familiarity** with the medicine, the seriousness of the **condition**, the perceived **potency** of the medicine and any **underlying health conditions**.

Other factors such as general attitudes to risk, educational attainment and confidence in challenging authority also played a part.

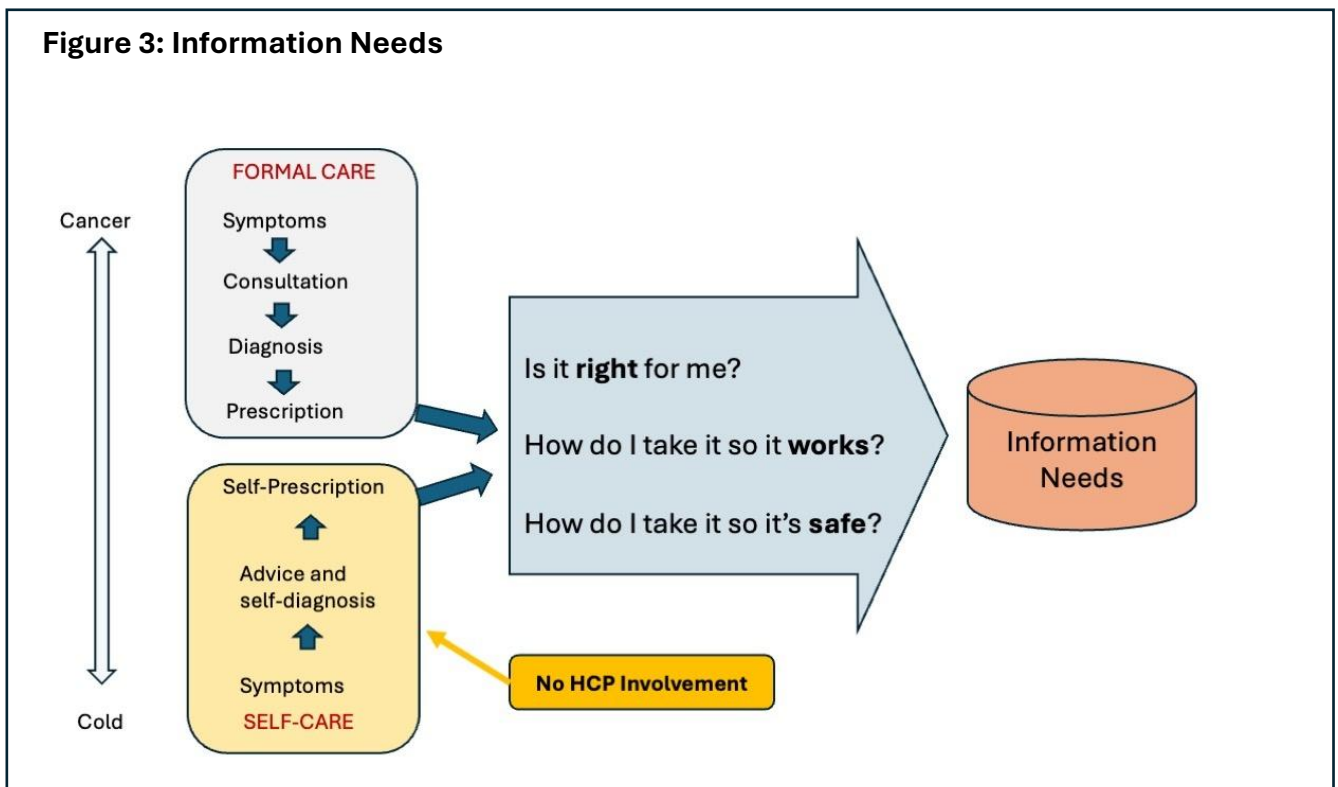
3.1 Fundamental Questions

As patients pass through the various stages and variations on their journey, they will have a wide range of specific information needs, which are set out in this chapter. But behind these lie three fundamental questions that all patients want to know: is this the right or **appropriate** medicine for them, how to ensure it is **effective**, and any **safety** issues.

- **Appropriate.** This covers understanding what the medicine is and what it is intended to treat; that they have been given the correct medicine (for example, by checking their name is on the label); that they are aware of the implications of taking it (such as needing to take it for life); and any alternatives (such as diet or herbal remedies).
- **Effective.** This covers the dosage, when to take it (such as times of day or before or after a meal), how to take it (dissolved, with water), what to do if they miss a dose, and how to store it (such as in the fridge).

- **Safety.** This covers side effects, contra-indications (other medicines, genetic conditions), and risks such as dependency or addiction.

There are some specific information needs which covered both efficacy and safety: for example, whether to take with alcohol (which could reduce the benefit or increase the risk of side effects) and the expiry date (as the medicine could become less effective or less safe).



These three broad areas in turn help patients to assess and **balance the risks and rewards** the medicine offered, compared to the alternatives. In some cases, participants were explicit about this risk/reward judgement.

“So if you read the pamphlets for the medicine, it’ll probably say one in a hundred people may contract pancreatitis or something like that. So then I suppose you have to make a sort of decision as to whether what you’re taking benefits you more than any of the risks.”

3.2 Appropriate

At a basic level, participants wanted to be sure that they had been given the correct medicine, and they did this by checking that it was their name on the packaging. Some reported occasions when they had been given the wrong medicine either for themselves or someone they were caring for. Patients might also want to be sure that the medicine was an – or the most – appropriate response to their condition.

- Would the benefits outweigh the known negatives (such as with chemotherapy) or the potential for adverse events?
- Were there alternative medicines, including herbal or traditional medicines or supplements?
- Were there alternative forms of treatment, such as physiotherapy, psychotherapy or changes to their diet?

This set of needs links closely to patient activation and shared decision-making between patient and prescriber about treatment options, including medicine. This is explored further in section 3.7.

Some participants also stressed that while there were many sources of information, most of these were generic, and **not tailored to their specific circumstances**.

“It can be easy to get the information, but in terms of actually getting it personalised to you can be quite difficult sometimes.”

3.3 Effective

Participants wanted to know how to use the medicine effectively. This included:

- How much to take (each dose, plus limits on how much to take each day).
- When to take it (frequency and time of day).
- How to take it (including whether to take with or without water or food or on a full or empty stomach).
- How long to take it for, and whether they needed to finish the course even if the symptoms had gone.
- How to store the medicine (such as in the fridge).
- The expiry date of the medicine.

This was seen as similar to the ‘how to use’ instructions that might accompany any other product, and participants tended to want to know all this information. Participants particularly mentioned the label attached to the packet or bottle the medicine by the pharmacist when dispensing the medicine as the main source of information they would check before starting to take the medicine. For non-prescribed medicine, they would check the standard label or instructions on the packaging. In general, this type of information was seen as very straightforward.

3.4 Safety

In contrast, information on safe use was seen as a little more difficult both to obtain and to assess. The main areas they might want to know more about were: contra-indications, ingredients, manufacture, overdoses or missed doses, safe use, and side effects (also known as ‘adverse events’). Again, in contrast to information on how to use, participants tended to want to know more only about a few of these areas.

Contra-indications

Some participants would check to see if there were any pre-existing medical conditions which would preclude them taking the medicine or heighten the risk of adverse reactions. Some participants would also check to see if there were any other medicines that should not be taken at the same time as the prescribed medicine without first consulting their doctor. Some participants referred to both as ‘contra-indications’, and this term appeared to be familiar to most participants.

Ingredients

Some participants would check medicines to identify the active ingredient, particularly if the product was a non-prescribed treatment for colds or sore throats, where they might prefer one analgesic such as paracetamol over another such as ibuprofen. Participants might also want to check the other ingredients such as water, starch or gelatine used to hold the active ingredient (known collectively as ‘excipients’). This was mainly to ensure that there were no ingredients that would cause allergic reactions or similar problems, such as being hard to digest, or to ensure the product as vegan or halal. This covered when first taking a medicine and when they were supplied with a new brand or formulation of the same medicine.

“I have to take Thyroxine each day. And certain brands, I can't take because I'm allergic to the fillers. So me, as soon as I get my repeat prescription in, I'm looking at what brand they've given me.”

Manufacture

A few participants said they would check the name of the manufacturer and/or the place of manufacture. One reason given was to ensure the medicines were produced for the UK market and were not ‘grey’ imports (that is, produced for another international market and not licensed for distribution in the UK). Another was to check that the product was not different in any way from their usual medicine; for example in the dosage or ingredients.

Overdose / Missed Dose

Some participants said they would want to know what to do if they accidentally took an overdose of the medicine, or they missed a scheduled dose. This included where a participant was providing care or support to someone else, such as an aged parent, where they felt a strong responsibility for ensuring the dose was taken correctly and what to do if they made a mistake.

Safe Use

Participants were often able to recall several potential activities that those taking the medicine should avoid, particularly drinking alcohol, driving a vehicle, operating heavy machinery and being or becoming pregnant. They generally understood these were examples that stemmed from the potential effect of the medicine: for example, that some medicines could make you drowsy, and there would be other tasks that ought to be avoided as well as the ones listed. In some cases, such as alcohol and grapefruit, the warning could relate both to the safety and the efficacy of the medicine (such as the widely-held view that alcohol would make antibiotics less effective).

Side Effects

Almost all participants said they wanted to be informed about potential side effects. This was so:

- They could make an informed decision about whether to take the medicine.
- If they did experience an adverse reaction, they would be more likely to link it to the medication and then either ‘put up with it’, stop taking it and/or consult an HCP.

“Years ago I was on the pill and overexposure can actually give you migraines. That's why I have more extreme migraines now. So I would think of more risks on prescription stuff now.”

Some said that side effects might not show for some time, which meant that their need for more information might also occur a long time after the initial prescription.

“I was on a medication for... It took a year, but in the end I had so many side effects of taking it, but it took a year to actually get to that point.”

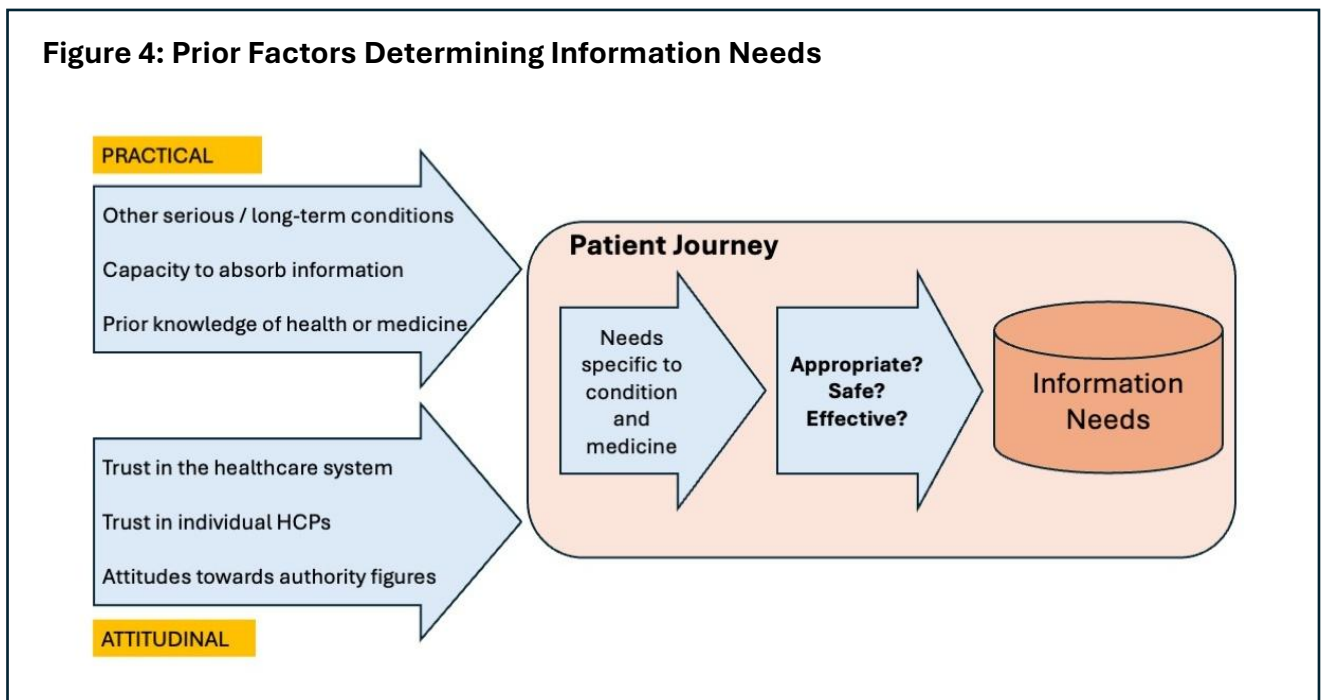
Some commented that the long lists of adverse events listed within the PIL or to be found via the internet could be very worrying or off-putting. Some deliberately avoided reading them because it would make them worried. A few also thought that sensitising patients to potential side effects might lead people to develop those symptoms.

3.5 Prior Factors

Even before beginning on their patient journey, each individual would bring with them a number of prior factors that would influence both the information they wanted and needed and how their needs would develop along that journey.

- Some of these factors were **practical**: for example, if they had another serious or long-term condition or underlying health issues. Here, **prior experience** was particularly important.
- Others were **attitudinal**, such as the extent to which they trusted in healthcare professional or the health system. Here, **patient activation** was particularly important.

These are shown in Figure 4. Together, these factors can be as or even more important that the patient journey itself in determining information needs.



3.6 Prior Experience

People’s information needs were directly affected by their prior experience with health and medicine. Those who had long-term or recurring conditions might be very familiar with the medicines they used to treat these, while having friends or family members who had used particular medicines also added to their knowledge and could influence their attitudes. This shaded into a deeper layer of knowledge about health and medicines which each individual had acquired over their lifetime from a variety of sources, from

information passed down to them by their parents to how illness was incorporated into TV drama. In the focus groups, participants often had views about conditions or medicines without knowing where they had acquired it.

3.7 Patient Activation

One of the most important influences on how each patient's information needs was the extent to which they felt willing and empowered to take an active role in their own care, including decisions about their medicines. Some tended to take responsibility onto themselves, while others tended to place more reliance on healthcare professionals.

This relates very closely to the concept of 'patient activation' or the extent to which the patient understands their role in the care process and has the knowledge, skill and confidence to manage their health and care.³ Higher levels of patient activation are linked to better health outcomes.⁴

Patient activation is also linked to 'Shared Decision-Making' (SDM), in which the patient has the information they need to make informed decisions about their health and care collaboratively with their healthcare provider. This is in contrast to the more traditional 'medical model' in which the clinician makes a judgement about the most appropriate treatment and the patient is expected to rely on it. The Academy of Medical Royal Colleges highlights four questions at the heart of SDM in relation to treatment options, which will often include medication:

- What are the benefits?
- What are the risks?
- What are the alternatives?
- What if I do nothing?

These correspond closely to the question '*Is this the right medicine for me?*' which forms one of the three fundamental questions at the heart of patient information needs (see 3.2 above). Patient activation and shared decision-making are both relevant to successful health outcomes in relation to the prescribing of medicines,⁵ and the provision of

³ Hibbert et al. 2004

⁴ <https://www.strategyunitwm.nhs.uk/sites/default/files/2021-03/Subproduct-8-Patient-activation-final.pdf>

⁵ For example, see the 2021 National Overprescribing Review final report (Good for you, good for us, good for everybody: a plan to reduce overprescribing to make patient care better and safer, support the NHS, and reduce carbon emissions), especially section 5.4.

appropriate and accessible information to patients about their medicines is central to this. However, while higher patient activation has positive associations, it should not imply any criticism of patients who have a lower level of activation or who choose to rely more on clinicians in relation to decisions about their care.

Participants in the focus groups displayed a wide range attitudes in terms of activation, and some were explicit that they preferred to place their trust in healthcare professionals to make informed judgements on their behalf.

“I tend to trust what the doctors tell me with my tablets now because they've said to me, you can't take this one because you're on that one, I can't take HRT for menopause because I take other tablets and I just believe them now with what they say because they're the professionals. I can't go against what they say, I have no idea.”

Others were much more likely to carry out their own research either before or after a consultation with a healthcare professional, either to be prepared for an informed discussion with the HCP about the condition and treatment options, or to understand more about the condition and treatment options after the consultation. This did not necessarily imply a lack of trust in their HCP: it was often a way of approaching significant decisions that they would apply in other major decisions in their life, such as reading contracts or taking up references.

Where participants had responsibility for the care of others, such as a child or aged parent, they often said they would take a more active role in decisions about medicines, including checking it was appropriate and making sure it was being taken safely and effectively.

3.8 Demographic Differences

The sample size means that some demographic differences can be identified with confidence. However, that confidence differs with the size of each demographic segment: for example, while the segment for males is around 49% (reflecting the UK population), the proportion for each age segment would be smaller, and the segments for specific ethnicities smaller still. This means that there may be important demographic differences which cannot be identified and reported with as much confidence: in other words, if no difference is reported, this does not mean it is established that no difference exists.

Figure 4a shows results of two questions from the general public survey, broken down by key demographic segments. Overall, public views on whether they feel they have “all” the information they need to take medicines safely and effectively (both for prescription and

non-prescription) are broadly consistent. A person’s age does seem to have some impact with fewer younger adults saying they had “all” the information they needed.

Figure 4a: Information needs demographic analysis

% who had **“all the information I needed”** when they last received a prescription medicine from, for example a GP

- 83% Overall
- 84% Male
- 83% Female
- 72% 18-34 years
- 82% 35-54 years
- 89% 55+ years
- 85% White
- 73% Non-white
- 82% Less than a university degree
- 86% University degree or above
- 83% Based in England
- 85% Based in Northern Ireland, Scotland or Wales

% who had **“all the information I needed”** when they last obtained a non-prescription medicine from, for example from a local supermarket

- 82% Overall
 - 81% Male
 - 84% Female
 - 70% 18-34 years
 - 88% 35-54 years
 - 84% 55+ years
 - 84% White
 - 80% Non-white
 - 82% Less than a university degree
 - 84% University degree or above
 - 82% Based in England
 - 86% Based in Northern Ireland, Scotland or Wales
-

4. Sources of Information

Key Findings Overall, **most people get the information they need** about their medicines, though hospital prescriptions present significant challenges.

People use **multiple sources of information**. The PIL is a key resource, but no-one relies on it alone.

Some sources were **'formal'** or 'core': prescriber, pharmacist, packaging, NHS Online. This followed their individual 'patient journey', varying between for example a GP or a hospital prescription.

Other were **'informal'** or 'supplemental': internet, forums, friends and family. These were used to fill gaps or for uncertainties or anxieties.

Some used the PIL as a **'core' source**, reading or skimming it when first taking their medicine. Others used it when seeking **supplemental** information, such as after a suspected adverse event.

Some sources (such as a GP appointment) were **more trusted** but **harder to access**. Other (such as an internet search) were **convenient** but could **not always be relied on**.

4.1 Satisfaction with Information Provision

Although people have complex and varied information needs in relation to their medicines, in general they are satisfied those needs are being met. For medicines prescribed by GPs or otherwise through the primary care system, 82% of survey respondents said they had all the information they needed to take the medicine safely or effectively, and a further 12% said they had some of the information. Only 1% said they did not have any of the information they needed.

There were very similar results for non-prescription medicines and for prescription medicines prescribed online, as set out in Figure 5 below.

For hospital prescriptions, 77% said they had all the information they needed, and 18% some of the information, which was reflected in the qualitative research. The particular

challenges of providing patients in hospital with the information they need is discussed further below.

With online sales of non-prescription medicines, confidence was still high but lower: 74% felt they had all the information they needed, 18% said they had some, and 6% said they did not have any of the information they needed.

These results also reflect the public’s overall confidence in medicine safety and regulation.

Figure 5: Satisfaction with Meeting Information Needs

Q) Thinking about the last time you obtained medicines in the following way, did you feel you had enough information to take that medicine safely and effectively or not?						
A)	Prescription medicine from a doctor in a hospital					
B)	Prescription medicine from elsewhere, for example from a GP or dentist (including repeat prescriptions)					
C)	Non-prescription medicine from a pharmacy (including from a pharmacy counter in a supermarket)					
D)	Non-prescription medicine from a supermarket or local shop					
E)	Prescription medicine online					
F)	Non-prescription medicine online					
(A)	(B)	(C)	(D)	(E)	(F)	
464	1198	759	908	208	112	<i>Base: those who have obtained medicines in this way</i>
%	%	%	%	%	%	
77	83	82	82	87	74	I had all the information I needed
18	12	14	15	10	18	I had some of the information I needed
3	1	1	1	2	6	I did not have any of the information I needed
2	3	2	2	2	2	Don’t remember / can’t recall

4.2 Information Journeys

More than a billion prescription items are dispensed in the UK each year, and over half the population is taking at least one prescription medicine at any one time.⁶ Unsurprisingly, there are substantial differences in people’s experiences with their medicines and consequently in what sources they use to meet their information needs. Nevertheless, there are clear patterns in what sources people use, and the factors that influence their choice of sources and how they use them. These can be explored through

⁶ [YouGov ‘Big Survey on Drugs’ September 2021.](#)

three ‘journeys’ which reflect how patients gain information from different sources as they pass from symptoms through diagnosis, prescription and dispensing (or self-dispensing if using non-prescription medicines) to administration.

- **GP-prescribed.** The patient would have a consultation with a GP (face-to-face, by phone or in some cases online) and be given a prescription which they would usually have dispensed by their community pharmacy. This implied the GP would have access to the patient’s full records and there would be an opportunity for a discussion about how best to take the medicine and any potential risks or side effects.
- **Hospital-prescribed.** The patient might have an acute and/or serious condition and be treated as an in-patient or at A+E or be seen in a specialist clinic. Experiences were very varied. On an acute ward, a patient might be too ill to ask questions or absorb information. A clinic might provide even more information on the medicine than a GP ever could, but might also focus on a specific condition, not the whole patient.
- **Self-dispensed.** The patient would diagnose their own condition and obtain a suitable non-prescription medicine from a pharmacy or a general retailer, potentially including online ordering and delivery.

Around two-thirds of prescriptions are issued by GPs and this was the ‘default’ journey that most participants initially thought about in discussions. Consequently, the description of each source of information below follows the GP-prescribed journey. The differences for hospital-prescribed and self-dispensed journeys are then explored in turn.

4.3 Prescribers

In an ideal world, prescribers would be the main source of information. They were best placed to advise on the most appropriate medicine, explain how best to take it and also any potential risks or side effects.

“You’d like to think they know more about it than you do.”

“I take my direction from the GP or Health Professional.”

They also had direct access to their patient’s medical records, which would help in identifying risks such as allergies or contra-indications for other medication or conditions. But participants recognised that prescribers were working under considerable time pressures and could not always spend the time needed to meet all their information needs. This was particularly true for GPs, where appointments were typically no more than 10 minutes.

Participants also said that they did not always want to ‘bother the doctor’ with questions, even when they would have had the time to do so. In part, this was because they were conscious that prescribers were ‘busy people’ and they did not want to take up their time which would be better spent on other patients. Also, some prescribers might be happy to answer questions but would not volunteer information.

“I’ve never known a doctor or a medical person tell me the side effects. The possible side effects. They won’t tell you unless you ask them.”

Other participants also chose not to ask questions when they had the opportunity because they would prefer to gather information from elsewhere and in their own time.

A few participants said they could imagine sending a message to their GP to check a concern with a medicine, with the expectation they would receive a message back, rather than being given an appointment.

“You message them and request a call back or you describe your problem that you’re having and they’ll message you back the next day or something. I’ve not tried it but I imagine you can.”

4.4 Dispensers

Participants had a high awareness of the role of pharmacists in providing information and support alongside the formal dispensing of medicines. They reported multiple examples of where pharmacists had provided them with additional advice without being asked, as well as answering their questions. They were aware that they could go back to the pharmacy at any point to seek advice or reassurance, and that this was not limited to the point at which the medicine was dispensed. They also saw pharmacists as trusted sources of information.

“Obviously the pharmacist is usually really, really good with that stuff.”

However, in their experience the dispensing process did not always involve a pharmacist directly: they might for example be handed the medicine by a member of staff with no health or medical training, or it might be delivered to their home. Some mentioned that there could be a considerable wait if they did want to talk to the pharmacist, and this could be a disincentive to having their questions answered.

“If you’ve been in hospital for hours, you just want to get out of there.”

In general, the system whereby pharmacies delivered medicines was seen very positively, with the pharmacy taking the time to anticipate information needs, such as where one brand of medicine was being substituted for another.

Often, the need for information was greater as patients might be frail, have cognitive impairment (such as dementia) or have multiple conditions.

4.5 Other HCPs

Some participants mentioned advice on medicines they had received from other healthcare professionals working in specialist clinics.

“With pharmacists, I feel I would trust them more to know about the interactions with other drugs that you was on.”

For those with serious and long-term condition, other HCPs could be a very significant source of advice, in part because they would see them repeatedly over an extended time. Some participants also highlighted the role of clinical pharmacists in GP surgeries, and the provision of regular structured medicine reviews (typically every six months).

4.6 Packaging

Almost all participants said they read the label on their medicine when they first used it, mainly to check the dosage and any important advice or guidance, such as time of day or whether or not to take with food. For some, the label was the most important single source of information, to the extent that they would throw the PIL away because it made it more difficult to return the medicine to the box it came in, which had the label on it. In the survey, the label (either generic or specific to the patient) was one of the most used sources of information – see Figure 7.

The main drawback with the label was that the information it contained was limited. The packaging might also have additional advice or instructions, potentially including warning notices or symbols, and there was a general view that if there was information that patients really needed to know, it should be put on the medicine packaging.

“Highlight areas to read on the outer box.”

There was also some frustration when the packaging did not use brail or when the individual patient label was stuck on top of the brail. Some participants also commented that those on multiple medications, particularly where the medicines were removed from

the original packaging for ease of handling or arranging daily medicine regimes, were less likely to use or retain the PILs.

4.7 Online

Online research was important for many survey respondents: 21% said they would use a specialist online resource such as NHS Online or a health charity website, 20% said they would do a general internet search, and 6% said they would use an AI search function such as ChatGPT.

“I guess if it was for like a specific illness, like maybe diabetes, you could go on to like Diabetes UK or something and then, you know, there'd be a lot of information there.”

The focus group participants said they would be more likely to carry out a search if it were a new medicine or was part of trying to build a wider understanding of their condition, options for treatment and prognosis. They might also search online if the medicine were changed (including substituting a generic or alternative version of a medicine with the same active ingredient). In some cases, this was a routine check that was not prompted by specific questions or concerns, but more by habit or curiosity.

On other occasions, where patients did have specific questions or concerns that had yet to be answered from formal sources during their patient journey, they would also carry out a search. For many, this was the obvious route in the modern world.

“If you don't know who else to ask, you go onto the internet and find out.”

In some cases, patients would have first learned about their medicine from an internet search of their symptoms or condition, which would also list potential treatments, and so would have some awareness of its appropriateness, efficacy and safety prior to obtaining the medicine.

Participants had mixed views about online searches. Some used it in effect as a quick link to find information from a trusted source such as NHS Online. There was generally a recognition of the potential for online searches to contain false or misleading information, or to lead them down ‘rabbit holes’ which would potentially give them a distorted views of, say, the risks and benefits of a particular treatment; and some avoided internet searches for this reason. Others felt capable of avoiding the traps and finding the reliable information they needed.

“If you stick to the first page of the search results you're pretty safe.”

Some mentioned the risk of misinformation and how a search could lead to self-diagnosing conditions, or unnecessarily heightened concerns about side effects. At its

worst, it could expose users to deliberate disinformation or conspiracy theories. Some confessed that, despite knowing the drawbacks of ‘Dr Google’, they still experienced these negative effects. But in the main, participants felt they were able to use the internet effectively to explore questions and concerns.

There were also mixed views about the use of AI. Some saw it as providing an alternative form of internet search, particularly where the AI answer provided references to the sources it relied on. For others, there was concern that AI would amplify people’s concerns, or play back their fears or preferences, so providing more digested but less reliable responses than an internet search engine. There was high awareness of the way in which AI could hallucinate and provide very misleading results, particularly where the AI was designed to ‘satisfy’ the user. This would become more of a risk, the more AI was used to personalise guidance on medicines, for example on contra-indications or the effects of taking multiple medicines.

4.8 Forums and User Groups

These were seen as a valuable way to hear and share experiences with others about a specific medicine, ideally in relation to a similar condition. Some participants specifically compared this to ‘user feedback’ which was increasingly familiar from online reviews and seen as a natural part of gathering information and making decisions, particularly for younger people.

“I think you get people who leave comments who’ve actually had the drug and had the side effects. It’s real information. I’m not saying it’s the right information, but it’s real information.”

4.9 Friends, Family and Carers

Some participants said that a lot of their knowledge about medicines had been acquired as they were growing up, particularly for more familiar medicines such as cough mixtures.

“With over the counter stuff, you’re kind of programmed from young to know that that’s how you take them. Whoever’s brought you up has told you this is how you take it.”

Some participants thought they might turn to friends and family as a sounding-board to explore their own concerns, but there was a general view that, while helpful, this would not have the same value as talking to those with direct experience of the medicine or the condition. In other circumstances, some patients rely heavily on friend, families or carers where they do not themselves have capacity to take medicines safely or effectively.

4.10 Hospitals

Some participants had experience of being prescribed or dispensed medicines by a hospital pharmacy at discharge or after attending a clinic or A+E. They felt they were much less likely to have a conversation about their medicines than in a community pharmacy, unless the hospital pharmacist themselves asked them questions or gave them information about their medicine.

“If you're discharged from hospital with a box of pills and it's a bit sticky and you've been instructed how to use it, you're never going to remember that.”

Some participants thought that hospital wards could be confusing places in terms of different staff roles and the changes of staff between shifts. This would also be at a time when the patient might be in no condition to understand complex information or formulate questions, for example if they were in a great deal of pain or anxiety or under sedation. Often, when a patient was discharged from hospital, this placed a care-giving responsibility on family members.

The survey results show a high proportion of those who have received medicine from a doctor in a hospital who felt they had some or all the information they needed about the medicine (95%). This is in line with other sources, although slightly fewer in the hospital setting felt they had “all” the information they needed. See Figure 5.

Some participants said that they were much less likely to be given information about their medicine when collecting it from a hospital pharmacy. They were also less likely to ask for information from a hospital pharmacy. Some gave the impression that hospital pharmacies assumed that the patient would have been told all they needed to know about their medicine by the specialists on the ward. Some also commented that when they picked up medicines after a visit to or stay in hospital, they just wanted to get home without any further delay.

4.11 Remote Prescribing and Dispensing

Several participants in the focus group discussions had direct experience of consulting their healthcare professional remotely, including both remote consultation with their NHS GP and with an online private GP. Generally, participants felt that they received at least the same level of information as from a face-to-face consultation and that remote consultations provided the same quality of opportunity to share any concerns. But there was a general view that the way individual HCPs approached the consultation, in terms

of the time they took and how approachable they were, was more significant than whether it was remote or in-person.

While participants thought that online private GPs provided at least as much information on medicines as NHS GPs, there were some concerns about access to their records or previous history.

“With an online doctor, I’d be worried that if they’re aware of like previous medical history and stuff, because like when you go to the GP they have all your records.”

Interestingly, 87% of those survey respondents who have been prescribed medicine online said they had all the information they needed about the medicine (the highest score of the different routes), but 74% felt the same among those who have received non-prescription medicine online (the lowest score). See Figure 5.

Participants had used an online pharmacy to supply their medicines, and they said that in general they had received at least as good a service in terms of information as with a traditional pharmacy.

4.12 Non-Prescription Medicines

Participants saw non-prescription medicines as generally posing much lower levels of risk compared to prescription medicines. Also, the medicines themselves were often familiar or being used to treat a familiar condition. They might still choose to avail themselves of advice from a pharmacist. Otherwise, they tended to rely most on the advice of other users, their own researchers or information on the packet (but not the PIL at point of sale, though it could be useful once they had bought the medicine and were going to use it). Several specifically said they would search for information online in the shop, for example by taking a photo of the packaging and uploading it to an AI search tool. This made the inclusion of a QR code on the packaging a natural and welcome development.

4.13 Core and Supplemental Sources

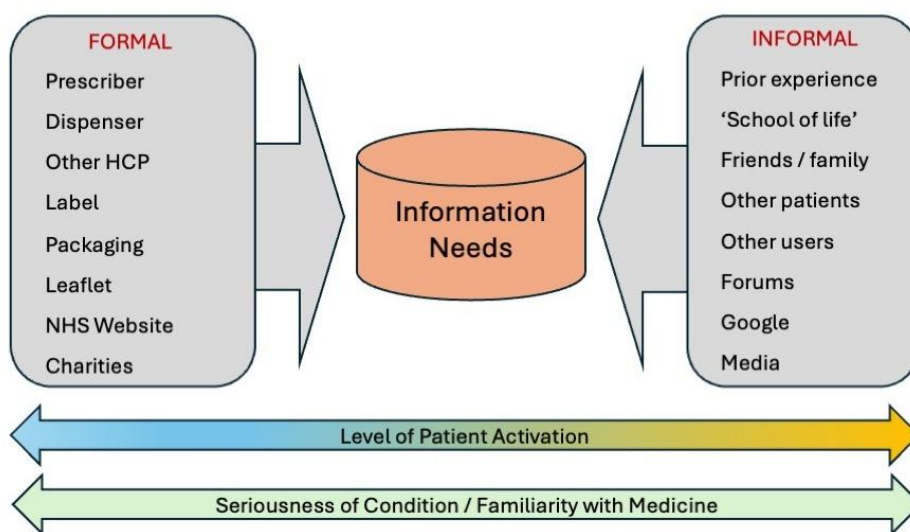
Patients use a mix of sources to meet their information needs, and this can be seen as a process with two stages.

- First, the **formal health system** provides the information it thinks patients need through a number of sources, notably prescriber, dispenser, label and packaging.

- Second, some patients may want more information and so will turn to **informal sources** such as online research, talking to friends or family, or asking other HCPs.

The PIL sits somewhere between these two. Some use it as part of the formal system, in that they will read or skim it when they are first prescribed the medicine. For others, they turn to the PIL to answer specific questions or resolve concerns alongside other informal sources, as shown in Figure 6. The balance between formal and informal sources also appears to be particularly influenced by the level of patient activation, the seriousness of the condition and the familiarity with the medicine.

Figure 6: Shaping Information Needs



4.12 Information Preferences

Participants in the focus groups made clear that they had different preferences when it came to acquiring information. Some liked to have written text they could read at their own time, while others preferred visual displays such as diagrams or pictograms, as they found this easier to absorb; and others still preferred to have information explained to them orally, ideally in person, in part so they could ask questions. No single channel – including the PIL – was able to meet their information needs in full for everyone.

This was reflected in the survey findings (Figures 7 and 8), which showed people use a wide range of sources and rarely rely on a single channel.

Figure 7: Information sources for prescribed medicines

Q)	Please imagine you were prescribed a medicine from a GP or dentist. Which, if any, of the following would do to get information about how to take the medicine safely and effectively? Multicode
%	
55	Talk to the GP or the person who prescribed the medicine
53	From the information leaflet included in the medicine packaging
46	From the specific instruction label normally printed on the bottle or package containing your medicine
42	Talk to the pharmacist who dispensed or supplied the medicine
40	From the general information on the bottle or package containing your medicine
21	From a specialist online resource such as NHS Online or a health charity website
20	From a general internet search, such as Google
9	Talk to family, friends or carers
6	Use an AI tool, such as ChatGPT
3	From social media or online community, such as Reddit or a Facebook group
1	Other
6	Don't know

Figure 8: Information sources for non-prescribed medicines

Q)	Now thinking about buying non-prescription medicine from a supermarket or local shop. Which, if any, of the following would you do to get information about how to take the medicine safely and effectively? Multicode
%	
49	From the information leaflet included in the medicine packaging
47	From the general information on the bottle or package containing your medicine
36	Talk to a pharmacist at the store / location you buy the medicine from
21	From a general internet search, such as Google
18	From a specialist online resource such as NHS Online or a health charity website
16	Talk to a GP who can prescribe medicine
10	Talk to another healthcare professional, for example in a specialist clinic
11	Talk to family, friends or carers
6	Use an AI tool, such as ChatGPT
3	From social media or online community, such as Reddit or a Facebook group
2	Other
8	Don't know

When given a list of potential sources from which they could choose more than one, (see Question 3), the public chose on average 3.1 sources for information about prescription medicines. Only 5% would rely on the PIL alone. For non-prescription medicines, the average number of sources was 2.1 and 9% of respondents would rely on the PIL alone.

The way in which people used multiple sources may also link to their views on the convenience and trustworthiness of different sources. Some participants talked about a trade-off between the two. Some sources, such as internet and AI searches, were seen

as very convenient but more likely to lead to unreliable information. Other sources – particularly GPs – were seen as very trustworthy but harder to access. Pharmacists were often seen as being both trustworthy and accessible. In general, the PIL was highly trusted but some thought it hard to access because it was long, technical and off-putting.

4.13 Demographic Differences

Use of the PIL as a source of information about a medicine varies by the type of individual. Those with problems or difficulty reading are considerably less likely to use a written document and (as discussed later) the format and layout of the PIL can put-off substantially more from using it. Analysis of the survey data in Figure 8a shows differences by key demographics. Men, younger adults and non-White respondents say they are less likely to get information from the PIL.

Figure 8a: Use PIL demographic analysis

% who would get information “**from the information leaflet included in the medicine packaging**” if they were prescribed medicine, for example from a GP

53%	Overall
47%	Male
58%	Female
46%	18-34 years
49%	35-54 years
61%	55+ years
55%	White
38%	Non-white
82%	Less than a university degree
84%	University degree or above
50%	Based in England
58%	Based in Northern Ireland, Scotland or Wales

5. Patient Information Leaflets

Key Findings Participants thought the leaflet was intended to provide **information on using the product safely and effectively** and to provide the **manufacturer with legal protection**.

Some said they **always** read the leaflet, some that they **never** did: but most would **look at it** if they had any doubts about their medicine.

They generally felt the leaflet was **comprehensive** and could be **trusted** but was **not ‘user-friendly’**.

They were **more likely to read** it if they were taking the medicine for the first time, it was to treat a serious condition, they had pre-existing health concerns or were giving it to a child or acting as a carer.

Like any instruction leaflet or T+Cs, they **might choose not to read it**, but they wanted to have the option to skim it or keep it for reference and would be **worried** if their medicine did not include one.

5.1 Importance of the Patient Information Leaflet

Patient information leaflets are one of the most important sources of information for those taking medicines, whether prescribed by a healthcare professional or bought as a non-prescription medicine. In the survey (see Figures 7 and 8), 53% of respondents said they used the PIL to get information they needed to take prescription medicine safely and effectively, which was second only to asking the GP or other prescriber (58%). With non-prescription medicines, 49% said they used the PIL and this was the highest of all the information sources, just ahead of information on the packaging on 47%. However, it is important to stress that almost all patients use multiple sources, so these numbers reflect who used the PIL to help meet their information needs, rather than who relied solely on the PIL.

5.2 Perceived Purpose of the PIL

Participants had two main views on the purpose of the Patient Information Leaflet (PIL): to give them information about how to take the medicine effectively and safely, and to

provide legal protection for the manufacturer. In terms of the frames of reference they brought to considering the PIL, it was a combination of the ‘instruction booklet’ that might accompany a consumer product such as a new oven, explaining how it should be used and potentially including safety information, and the ‘terms and conditions’ that might be attached to a contract or service, limiting the manufacturer’s liability.

“Make it look less like small print on a contract.”

“Don't write it in a way that is blatantly obvious the manufacturer is protecting themselves from future litigation.”

Most participants thought the leaflets did both, and even when they felt a little cynical about the motivation of the manufacturer, this did not undermine their trust in the information the leaflet contained. In part, this was because there was a general sense that the leaflet was a legal requirement and the manufacturers would be subject to regulatory oversight.

However, several patients felt that the perceived desire for manufacturers to protect themselves from litigation meant they included very rare or speculative risks in the leaflet. This made it harder for the user to make a balanced judgement about risks, as well as making the leaflet even more off-putting, both in terms of length and the ‘fright factor’ of the extensive lists of side effects.

“Even if one person in a million had a side effect with it, they'll write it so that it covers them.”

5.3 Why Patients Use the PIL

Understanding the Medicine

Some participants said they usually or always wanted to know more about any medicine they took. The PIL would provide them with valued information, though they would be likely to use other sources as well, and particularly internet searches. This might shade into addressing any doubts or concerns about the medicine.

“You want to do a bit more research to feel comfortable. Because the stuff I take, I'm not convinced why I'm taking it.”

This would also apply to those providing care and support to others.

“Let's say my mother has lots of medication and she's discharged from hospital, they'll give me this, she can have that, and then I'd be like, did they say that she should stop that? The leaflet would give me some information about it.”

Using the Medicine

Participants said they were not always given all the information they needed to use the medicine properly by their prescriber or pharmacist. This was often information that was less critical for safety or efficacy: for example, whether to take before or after a meal, or how to use the means of dispensing the medicine. The PIL was valued for providing more detailed information that they could absorb in their own time.

“I use the leaflet to double-check it’s the right thing for my health problem and how to take or use it, say if it comes with an epi-pen.”

“Like, the drug I had to take this week, the way you had to take it was very complicated. There was a certain way you had to make it up and take it. So, you know, I had to have [the leaflet] there all the time.”

Safeguard or Check

The Leaflet was used in some cases by patients to check that they had been given all the information they needed by their prescriber, or that they had understood it correctly. Even when participants said they tended to trust their HCP or would rely most on internet searches for information, the leaflet was seen as a valuable additional safeguard. Several participants had experiences of the Leaflet providing them with necessary information they had not received from other sources.

“I looked-up contra-indications on the leaflet and my GP had ignored them.”

5.4 Strengths and Positives

Overall, the main strengths of the PIL were that it was provided automatically with all medicines, and so did not need the patient to go and search or ask for the information elsewhere; that it was reliable in terms of the accuracy of the information provided; and that it was comprehensive: participants frequently said that the leaflet had all the information they needed, and few could suggest anything that was missing. Even those who had significant frustrations with the PIL recognised these advantages. Some users praised the leaflets for being clear and well-structured, but this tended to be a minority view.

Trusted

There is a very high level of trust in the PIL. For example, in the survey only 1% of respondents said that “I do not trust what the leaflet says” as a reason for not reading the PIL (see Figure 11). Similarly, very few participants in the focus groups said they did not trust the leaflet, though some did say they would want to verify information.

“I trust it better than most, but like anything in this world today, you've got to do your own research, and you've got to broaden and don't accept anything you're told. So you'd use loads of different areas to get as much information as you can, so you can be the ultimate decision-maker.”

Where there were concerns expressed about how much trust could be placed on the PIL, this was often associated with wider distrust of the pharmaceutical industry or the medical and scientific professions, rather than PILs as a specific source of misinformation.

Clear

Some participants said that the wording of the leaflets was usually very clear and tended to use relatively simple language. Some suggested that the sentences were sometimes too long, and that there was too much medical jargon, though others thought the use of medical terms was necessary and often helpful, and they valued the precision. Generally, the problem for participants was not the quality of the text, but the amount of it and the lack of design aids to finding the information they wanted easily.

Structured

Participants said that some leaflets were properly structured, with the text flowing logically within a clear sequence of headings. When leaflets used design techniques such as bullet lists, bold text, or summaries, this was particularly valued.

“I like that it's in sections and it's only like a little bit of information under each, so it's not too much.”

Most of all, they valued having a clear summary of the key information they needed at the top of the leaflet, or even on the outside of the packaging – the equivalent of a ‘quick start’ product summary often included in other product guides that recognised not everyone would go in detail through an entire manual to find what they wanted or on the chance of spotting some vital information.

“Provide a brief summary of the most important info at the start in bold type, such as dose & side effects.”

“Just have Do's and Don'ts at the top.”

5.5 Weaknesses and Negatives

While some felt the leaflets ‘did the job’, the majority felt that there were significant negatives: that leaflets were generally badly-designed, hard to read and off-putting.

Some participants also highlighted other concerns, such as their length, gaps in coverage or insufficient warnings about interactions with other medicines (which they had learned about from an internet search).

Design

Participants were generally critical of the lack of helpful design elements such as diagrams, symbols, bullet points, or the use of bold or colour to highlight key messages. This tended to reinforce the impression that leaflets were there as a legal requirement, rather than intended to be of actual help to patients. Leaflets unfavourably to other similar documents, such as assembly instructions for flatpack furniture or safety cards or aircraft, which relied almost exclusively on images.

“I’m more of a visual person so if there was pictures or anything I’d probably respond to that better and take it in better because I’m dyslexic. I can read but my concentration is very, very short. If you told me to read a paragraph I’d be like ‘nope’. If there’s a picture, and a few words then yeah probably I’d take it in a lot better.”

Hard to Read

There was strong agreement that the text of the leaflets was too small, and this meant it was hard if not impossible for some people to read, and generally off-putting to all.

Several participants commented that they found the use of columns confusing or off-putting, even though the use of columns is often recommended in design guides to make text easier to read (as the ‘ideal’ length of a line of text for legibility is around 50-70 characters per line).

“It’s normally pretty good - just the text is a bit too small sometimes.”

Length

Participants often complained that the leaflets were too long, and this made it hard to extract the information they needed.

“I’m on the second page and it’s just told me how to take the medicine.”

On reflection, they tended to accept that much of the information needed to be in the leaflet and came to see better design and the use of design tools such as headlines, bullets, bold emphasis and summaries as helping them to find the information they wanted more easily.

Interactions

Some participants said the leaflets were weak on providing information about interactions with other medicines or conditions. They did however tend to recognise that this was hard in a paper format, and that in any case they saw the primary responsibility for this as lying with the prescriber or their pharmacist.

“Usually you’d ask your GP, to see if your blood pressure tablets affect your pill or something like that. They should usually give you that information before prescribing it.”

“I’m not sure that it gives you the details you need. I prefer to go online and see what you shouldn’t, what drug you shouldn’t have with it. So quite often you’ll take a drug and it won’t say on the leaflet, don’t take with blah, but if you go online it’ll say this shouldn’t be taken with paracetamol or quite often it’s got the same drug in it as a drug you shouldn’t be taking with it.”

“I only read it because I take other medication. It would be helpful if this information is printed in bold.”

Repeat Prescriptions

Participants were clear that they would seldom or never think to read the leaflet when they were on repeat medication, which is consistent with the results from the survey.

“When you have repeat prescriptions for a long time you get to a point where it’s a pointless piece of paper that’s had a tree cut down to print it. Because once you’ve been on something for a while, you don’t even look at it any more.”

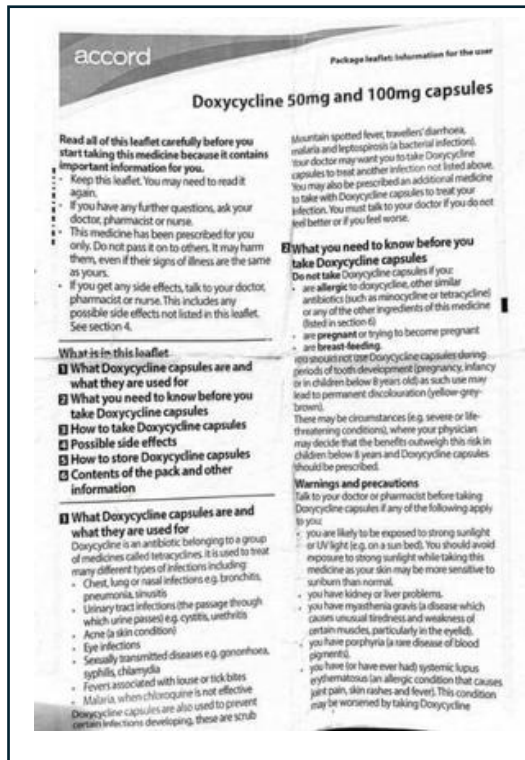
Some participants commented that, if a new problem or concern arose with a medication they were taking, they would expect their GP or specialist, or their pharmacist, to let them know directly.

Information Gaps

Some participants said that they had experienced side effects or other problems which were not included in the leaflet. This made them more likely to go to another source first, such as an internet search or a patient forum.

“I found out I was allergic to particular brands because I felt shockingly awful and none of my symptoms were on this little sheet but actually as soon as I Googled it there were so many people saying ‘we can’t take this brand either.’”

Figure 10: Patient Information Leaflet Example 2



Even basic techniques such as the use of columns and adding spaces between headings helped to bring out the information and make the leaflet more likely to be read.

The use of clear contents and sign-posting at the top of the leaflet was generally appreciated.

Some participants also questioned the differences, and apparent inconsistencies, between leaflets. For example, one leaflet might recommend that the user talk to a doctor or pharmacist if they experienced side effects, while another might recommend they talk to a doctor, pharmacist *or nurse*. This did not suggest that the leaflets were a coordinated element within a standardised approach to medicine safety.

5.6 Barriers

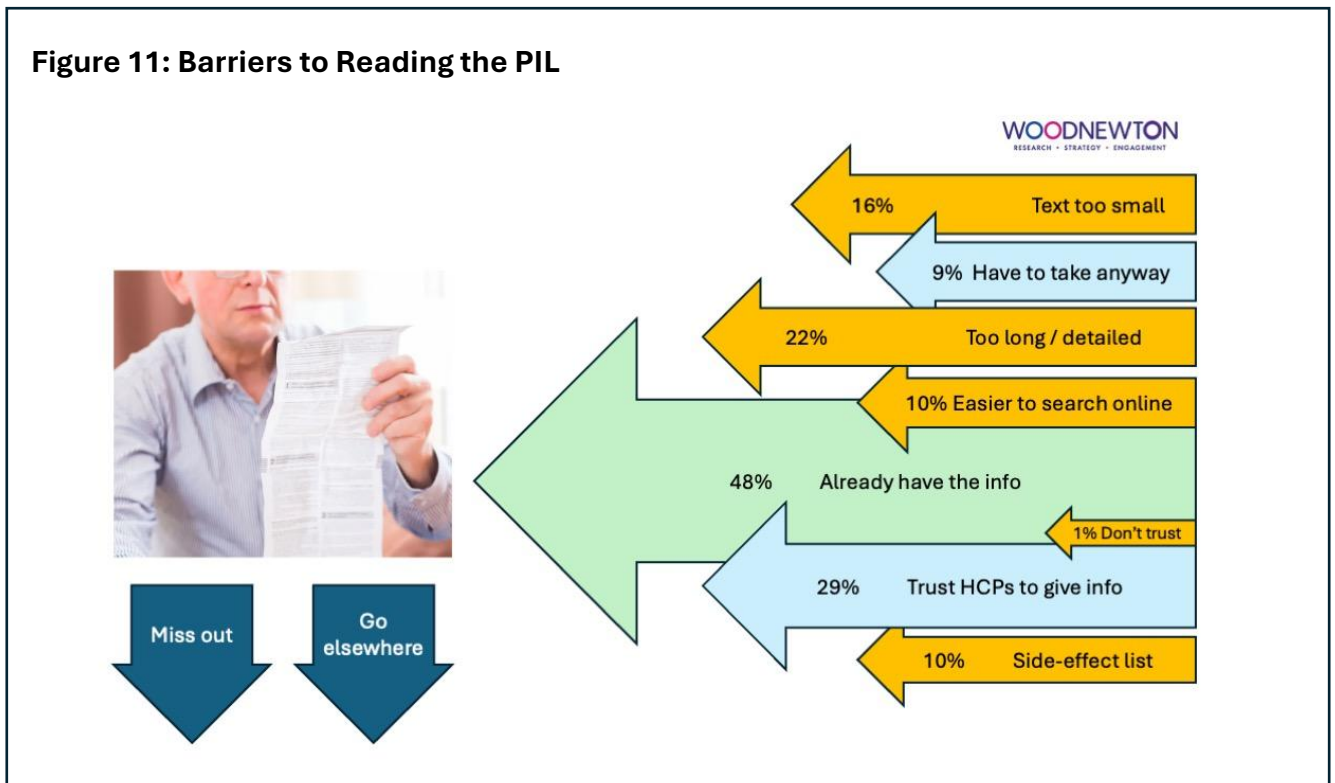
Even when patients had strongly negative views about PILs, they might well still use them. The factors or ‘barriers’ that would stop people using the leaflet overlap with the negative views, but form a distinct pattern. The most significant ‘barrier’ to use was the patient feeling they already knew enough about the medicine and so did not need to look at the leaflet. This was cited by 48% of survey respondents, with 29% also saying they would not read the leaflet because they trusted their doctor or pharmacist to give them the information they needed.

Poor design was still a significant factor, with 22% citing excessive length as a barrier, 16% small type, and 9% complex language. Being put off by the list of side effects was cited by 10%, and in the focus group discussion participants suggested that while side effects needed to be included, there would be ways of communicating the likely incidence or offering other reassurance to help ensure users were not put off reading the leaflet or taking the medicine.

In the focus groups, when asked to describe the things that would stop them using the PIL, participants tended to offer seven reasons.

- **Time and effort:** people were too busy and had other priorities.
“I never read the leaflet, but I’m the same with all instructions, like with a new TV or Ikea furniture.”
- **Trust in the medical profession:** if there was something they needed to know, they would be told.
“I feel when you are given a prescribed medication you trust the GP is giving it for the correct reasons. If unwell I just want to take the medicine to help me.”
- **The box provided what they needed:** it would show how to take safely and effectively, and anything really serious would be shown on the box or label as well.
- **No need:** if the medicine is familiar or low risk or if you already have the information from other sources or have read the leaflet already.
“If it’s a new med, I’ll take it out and have a read of it, but other than that I tend to take it out and literally bin it, because it’s a pain in the backside getting the tablets back in the box.”
- **Hard to read:** the design and language is off-putting.
- **Pointless:** it was just a legal disclaimer and even if you read it you’d still need to take the medicine anyway.
So if I know I’m going to get a drug for something, I’ll look at what the options are to see if there’s an alternative. If there isn’t an alternative and that’s the only medicine, you have to take it.”
- **Worrying:** the list of side effects could worry some and deter others from taking the medicine.
“Sometimes the side effects can sound very scary and although I know legally they have to tell you, they can be off putting for taking the medication.”

Figure 11: Barriers to Reading the PIL



5.7 Selecting Sections

Participants would usually refer to the leaflet to find specific types of information. The ones they mentioned most frequently were:

- What the medicine was used to treat.
- Any side effects, risks or activities to avoid.
- Any interactions with other medicines or health conditions.
- How to take the medicine, including frequency, time of day, the individual dose and any conditions such as taking before or after food.
- How to use any devices such as pumps or pens.
- How and when to dispose of the medicine.

The leaflets use a standard set of nine headings for different categories of information. In the survey, respondents were presented with a list of the nine sections and for each asked whether they tended to read in full, skim/glance, or do not read at all. The results are presented in Figure 12.

Five sections were read or at least skimmed by at least 83% of respondents: What the medicine is and what it is used for, Precautions and warnings before you take the medicine, How to take the medicine, Possible side effects and how to store the medicine. The remaining four were read or at least skimmed by less than 60% of respondents.

Figure 12: How Patients Select Information from PILs by Section

Q) The patient information leaflet contains the following information.
Generally speaking, to what extent, if at all, do you read each of the sections of the patient information leaflet when you get a new medicine? Single code only for each option. RANDOMISE ORDER

A) What the medicine is and what it is used for
B) Precautions and warnings before you take the medicine
C) How to take the medicine
D) Possible side effects
E) How to store the medicine
F) Ingredients
G) What the medicine looks like
H) Who the manufacturer is
I) When the leaflet was last updated

(A)	(B)	(C)	(D)	(E)	(F)	(G)	(H)	(I)	
%	%	%	%	%	%	%	%	%	
54	59	69	55	42	22	22	13	15	Read in detail
33	31	22	34	41	36	36	33	25	Skim or glance at it
9	6	6	8	12	34	27	43	37	Don't read it at all
2	2	1	1	2	3	8	5	15	Did not know this information was provided
3	3	3	3	3	5	7	6	8	Can't recall

5.8 Different Ways of Using Leaflets

Participants were asked to describe what they would usually do with the leaflet. Although their behaviour varied greatly depending on factors such as the seriousness of their condition, they could still be placed with confidence into five distinct but over-lapping groups: Readers, Skimmers, Keepers, Bidders and Caregivers.

Readers

They would generally read the leaflet, either in full or to find specific information such as side effects or potential allergies. They might not read the leaflet for a familiar medicine,

such as a repeat prescription, or one they saw as low-risk, such as Paracetamol, but the leaflet formed a significant part of how they obtained their information about the medicine.

Skimmers

As with Readers, their use of the leaflet would vary depending on familiarity and perceived risk. Some would glance at the leaflet in case it highlighted any relevant but unfamiliar information, For this group, the leaflet was a check or backstop, not a significant source of information. Others would skim it to find specific information they wanted. For them, summaries and clear headings were particularly welcome.

“The bits that I tend to skim are time recommendations when you talk about does it need to be taken with or without food or is it a morning thing or a night thing, and very lightly skim side effects. Particularly the ones where it's 1 in 10 people so it's quite a common side effect, I don't tend to go right into 1 in 100 because it's so rare.”

“Make it more skimmable.”

Keepers

Whether or not they had read or skimmed the leaflet, some kept it in case they wanted to refer to it in future. For them, the PIL was a potential source if they had future information needs, such as side effects or a question about their medicines from an HCP.

“I usually just scan it in case there's any information I want, but I always keep it with the medicine in case I want to refer to it again later.”

Bidders

A few participants said they routinely and intentionally disposed of the leaflet. Sometimes this was because they did not see a need to keep it, often because they were on repeat medication and felt familiar with the information in it. Some even found it annoying.

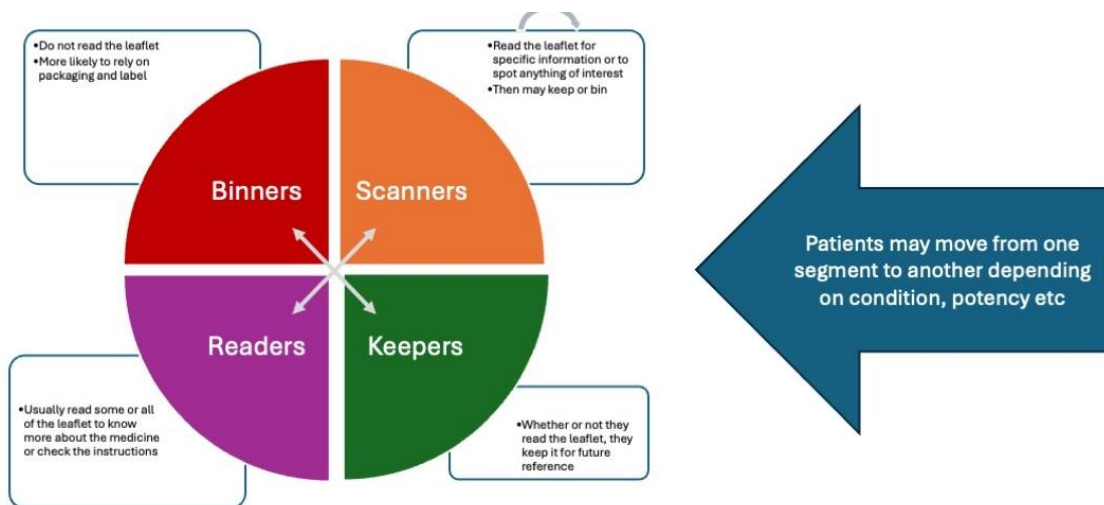
“Because most of the medicines I'm on, I've been taking them for some time, I don't read it, I throw the leaflet away.”

Patients might move from one behaviour-group to another, depending on other factors such as the nature of the condition the medicine was intended to treat, the level of prior familiarity with the medicine, and the perceived potency of the medicine. They might also respond differently depending on their perception of each individual leaflet, and particularly the extent to which they saw it as providing valuable instructions or was more providing legal cover as with contractual terms and conditions. Some participants

thought that these different ways of absorbing information reflected wider trends in society, such as people becoming used to scrolling on their phone rather than reading a reference book or paper leaflet.

“I don't think people are used to doing that anymore, like reading the full manual of anything. I think people scan, because that's like how people maybe consume information now.”

Figure 13: Fluid Behavioural Segments



Participants frequently said that their use of the PIL would be different if supporting someone else to take a medicine, such as a child or elderly parent, or someone with cognitive impairment. They would be much more likely to review the leaflet in detail and to retain it afterwards.

“I've only ever read it for if my daughter's got a medication or something. I don't read it for myself because I've got no allergies and I don't really have side effects, but I'd read it for someone else. Let's say my nan – she's concerned about it and she can't read it, I'd read it to her or something.”

“So for me, I'm looking at the dosage, how long you should take it, what are the side effects, how much of it should you take, and things like age, because I've got children, so I'd be looking at stuff like that.”

5.9 Keeping and Reading the PIL

Insights from the qualitative discussions informed the design of questions for the general public survey. This set of questions aimed to understand how many people would

read/not read and keep/throw away the leaflet depending on the type of medicine they would take. The results are shown in Figure 13a.

Respondents were provided with five scenarios (A-E) where they might take medicines, for example a new medicine or a medicine to treat a serious health condition. For each scenario, respondents could select one answer option that best reflects how they would typically use the PIL.

In most cases, the most popular response was that patients would read some or all of the leaflet before taking the medicine and keep this for future reference. But the likelihood of reading and/or keeping the leaflet varies considerably.

Where patients are taking a medicine for the first time (A), the vast majority say they are likely to read the patient information leaflet (84%). Similarly, four in five (79%) say they would read leaflet if they take a prescription only medicine (C). In contrast, around three in five patients (58%) would not read the patient information leaflet for a medicine they feel familiar with (B).

Figure 13a: Keeping and reading the PIL in different situations

Q) Every medicine available in the UK (prescription and non-prescription) should come with a patient information leaflet. This is usually found within the medicine box.
Which of the following statement best applies to what you would do with the information leaflet for the following types of medicines

(A) A new medicine you have not taken before
(B) A medicine you feel familiar with (e.g. something you’ve taken before or take regularly)
(C) A medicine that is available on prescription only
(D) A medicine to treat a serious health condition
(E) A medicine you have obtained for someone else (e.g. a child or elderly parent)

	(A)	(B)	(C)	(D)	(E)	
	%	%	%	%	%	
	6	32	7	5	6	I do not read the leaflet and throw it away before I take the medicine
	6	26	8	6	6	I do not read the leaflet before I take the medicine, but I keep it for future reference
	24	17	26	19	18	I read some or all of the leaflet before I take the medicine and then I throw it away
	60	20	53	55	41	I read some or all of the leaflet before I take the medicine and keep it for future reference
	3	3	4	4	6	Don’t know
	3	2	2	11	23	Not applicable – I’ve never had this type of medicine

12	58	15	11	12	before
84	37	79	74	59	Do not read
					Read

5.10 Absence of a Leaflet

Participants were asked how they might react if they received a packet containing medicine and there was no leaflet included. The most common response was that they would be concerned that the medicine had been tampered with in some way, or was counterfeited or a 'grey import'. Some also thought they might assume that it had been dropped to save paper.

"I think if it was known worldwide that they're doing this to save paper or whatever, then it'd be ok. But if it was just random, I'd be like what the hell is going on?"

"It also needs to remain in physical copy. That is essential so that everyone who has that medication can read it regardless of their technological ability."

5.11 Demographic Differences

Figure 13c shows the demographic analysis of the proportion of different sub-groups of the public who say they would typically read the PIL for both a new medicine and for a medicine they feel familiar with.

There is some consistency in answers: all types of people are significantly more likely to read the leaflet where it is for a new medicine rather than a medicine they feel familiar with. There are also some differences in stated behaviour, especially between men and women for a new medicine. Fewer men would read the leaflet (77% vs. 89%), although still more than three in five men say they would.

Figure 13b: Reading the PIL demographic analysis

% who would read the PIL for "a new medicine you have not taken before"

84%	Overall
77%	Male
89%	Female
77%	18-34 years
82%	35-54 years
88%	55+ years
84%	White
75%	Non-white
83%	Less than a university degree
85%	University degree or above
83%	Based in England
84%	Based in Northern Ireland, Scotland or Wales

% who would read the PIL for “a medicine you feel familiar with (e.g. something you’ve taken before or take regularly)”

37%	Overall
38%	Male
36%	Female
37%	18-34 years
34%	35-54 years
39%	55+ years
36%	White
49%	Non-white
37%	Less than a university degree
37%	University degree or above
37%	Based in England
35%	Based in Northern Ireland, Scotland or Wales

Figure 13c shows key demographic analysis of how different types of people engage with three parts of the PIL. The demographic patterns are similar as to those observed previously with gender and age accounting for most variability: men and younger adults typically less likely to read in detail key sections of the PIL.

Figure 13c: Engagement with the PIL demographic analysis

% who “read in detail” the following sections of the PIL

Precautions and warning	How to take	Possible side effects	
59%	69%	55%	Overall
53%	64%	50%	Male
64%	73%	59%	Female
53%	59%	47%	18-34 years
51%	65%	49%	35-54 years
69%	78%	65%	55+ years
58%	69%	54%	White
64%	62%	60%	Non-white
59%	68%	57%	Less than a university degree
59%	71%	55%	University degree or above
59%	68%	55%	Based in England
57%	69%	53%	Based in Northern Ireland, Scotland or Wales

6. Making Leaflets More Effective

Key Findings Participants thought the single most helpful change would be to have **a summary of key information at the start of the leaflet**, as they sometimes found on the medicine packaging.

They felt the design could be improved with **more diagrams, bold text, bullet lists and spot colour** (such as red for warnings).

All agreed the **text should be larger**, though views were mixed on whether the text could or should be simplified.

There was **support for using a QR code** to link to further information. This would also facilitate more accessible versions (audio, alternative languages) without making the PIL even longer.

There was **support for using the NHS App** to provide more (and personalised) information.

Participants thought that if the PIL were significantly updated, this should be **flagged on the external packaging**.

6.1 The Need for Improvements

In the focus group discussions many participants initially felt that the PIL could be substantially improved and could be presented in ways to encourage them to engage with it. These suggestions primarily focused on the design and layout of the leaflet (see below) and also the amount of information the leaflet conveys. However, on reflection, many participants recognised the inherent difficulty in using a standard leaflet to provide information about a medicine that might be used for different types of patients with different needs (and potential reactions).

Further, participants tended to accept that even if they did not read or feel some information should be provided in the Leaflet (for example, ingredients or name of the manufacturer), they accepted that other patients might find this information useful or vital. Therefore, it was not uncommon for participants to conclude with two competing views: “the leaflet should be shorter, but I don’t know what to cut”.

The survey respondents were asked to respond to the following question:

How, if at all, do you think the patient information leaflet could be improved to encourage you to read it?

The respondents wrote in their answers and these were then coded into six common themes. The results are shown in Figure X and explored in more detail below.

Figure 14: proposed improvements to the patient information leaflet

- 1) **Increase Font Size:**
Address readability issues, especially for older patients or those with vision impairments.
"The fonts are too small to read, end up taking photos to be able to read it, even with glasses on."

 - 2) **Simplify Language:**
Use plain English and avoid jargon to make content accessible to a broader audience.
"Simpler language. Less medical and more practical."

 - 3) **Shorten Content:**
Condense information to focus on essential details like dosage, side effects, and storage.
"It's just too much information, if it were seriously condensed to bullet points... that would be better."

 - 4) **Improve Structure**
Use bullet points, clear headings, and a summary section to enhance scannability.
"Clearer Structure: Use headings, bullet points, and short paragraphs for easier scanning."

 - 5) **Add Visuals and Colours:**
Incorporate diagrams, icons, and colour coding to make PILs more engaging and easier to navigate.
"Less words – more diagrams."
"Colour code important information - possible traffic light system."

 - 6) **Offer Digital Access:**
Include QR codes or links to online versions for interactive or larger-text formats.
"QR codes could be used to provide digital information for more details or links to videos."
-

While the majority of survey respondents provided suggestions on how the PIL could be improved, it is also noteworthy that a significant proportion felt that the leaflets worked well or that they suited their needs and preferences.

“I think they are absolutely fine as they are.”

“I’m happy with patient information leaflets. I like a lot of detail.”

Some were concerned that if the leaflets were shortened, valuable information would be lost.

“I don't think there's much you can do. You can't make it shorter or simpler because there is a lot of information that has to be given. I would say spread it out more but that would make it even longer and use more paper.”

Feedback from the focus group participants matched that provided by the survey respondents. The overall sense was that the patient information leaflets did not encourage people to read them because of their layout and formatting. In particular, participants reacted most negatively to leaflets that were considered to be “compressed text”.

Overall, there was broad consensus among participants that the following three enhancements would improve patient information leaflets for everyone and especially for those who would struggle reading small print:

- More effective summary of key points.
- More visual elements, such as icons, bold text and colour.
- Make the text larger.

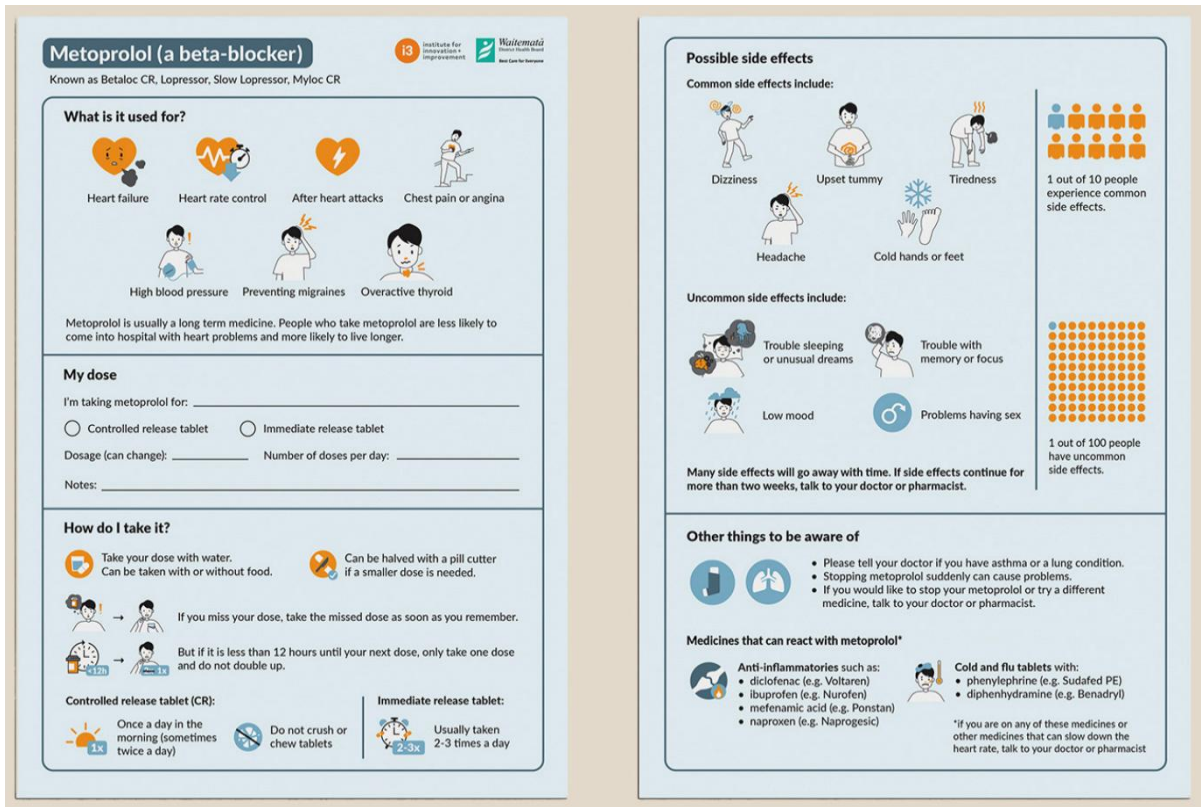
These suggestions have informed the **‘ideal’ leaflet set out in 6.4 below.**

“Simplify the layout so that it’s easy to understand - something like calorie information on food or washing instructions on clothes labels.”

“Make things as simple as possible, if possible giving a visual explanation (diagram?) on the understanding some people may not be that literate or may be scared by medical jargon.”

The desk research identified some examples of leaflets that addressed some of these areas for improvement. There were also examples of good design being applied to explore how a leaflet could be made more effective through design (for example, see Figure 15).

Figure 15: Example of a design exercise in repurposing the information in a PIL developed by Good Health Design in New Zealand⁷



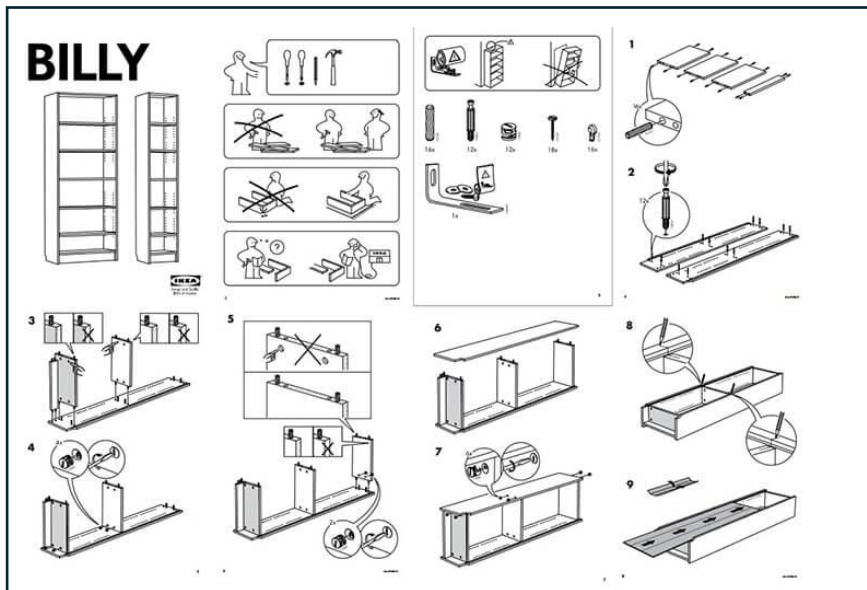
Participants also saw a great of value of linking enhancements to the leaflets themselves to other changes, such as **accessibility and inclusion, integrating the leaflet more with the rest of the packaging**, using **QR codes** and putting the information in the leaflet online, including using the **NHS apps** to make the information they contain easier to access and assimilate,

6.2 Expectations and Comparisons

Several participants drew comparisons between PILs and instruction leaflets, such as those provided by IKEA for self-assembly products. Although the challenges each faced were very different, IKEA’s emphasis on using visuals including pictograms to convey information was seen as something PILs should emulate.

⁷ <https://www.goodhealthdesign.com/projects/metoprolol-medical-information-leaflet>

Figure 17: Example of an instruction leaflet for flatpack furniture



Participants also compared PILs to passenger safety cards on airliners, and particularly their high design values and use of images in place of text. The comparison is instructive in three ways:

- They have been mandatory since 1965 (See Figure 18)
- There are intended (in the words of a 1977 FAA Advisory Circular to airlines) to be ‘...as appealing and interesting as possible to obtain passenger interest.’ (Figure 19).
- They can be more inclusive than text-only versions, for example when incorporating multiple languages. (Figure 20).

Figure 18



Figure 19

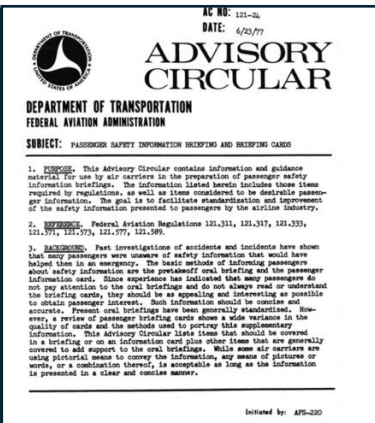


Figure 20



6.3 An Ideal Leaflet

Most participants felt there was a great deal of value in the current content of leaflets, and a reluctance to cut specific sections. Doing so risked losing one of the strengths of the leaflet, which was it was generally comprehensive (if not always comprehensible). The ideal leaflet would retain the same content, and this should be arranged in consistent headings to help them to go easily to the sections they were most interested in. The written content should always be checked to ensure it was as easy to read and digest as possible, without losing the clarity and accuracy, and recognising that some medical jargon might be inevitable. Above all, the text should be larger.

Every leaflet should have a ‘Quick Guide’ or summary at the start, setting out the key information needed for it to be taken effectively and safely. This would be similar to the summary information often printed on the medicine packaging. It might include:

- Warnings about who should not use the medicine, such as children or pre-existing conditions.
- Warnings about needing to consult a doctor before using.
- Warnings about activities you should avoid when using the medicine, such as driving.
- Warnings about potential side effects, highlighting any that are particularly serious or high incidence, and suggesting the user checks the full list in the leaflet.
- The dose, including any limits on how often or for how long it can be taken.
- Instructions for taking the medicine.

This summary box or page would use pictograms or symbols such as warning triangles to emphasise the messages. It would end with a message encouraging users to continue to the full leaflet if they have any questions or concerns. It would also include the QR code (see below) explaining this is to allow users to access the leaflet information and any supplemental information online.

The main leaflet would have a contents list repeating the standard headings, again using symbols to make it more visually appealing and accessible.

Ideally, this would be followed by a brief introduction reassuring users before they get into the detail, particularly of potential side effects. This would respond to the view expressed by many participants that the leaflet can be ‘scary’ and they can be put off reading it, or even put off taking the medicine. (This reflects the finding in the literature that a high proportion of prescribed medicines are never taken, though the patient does not inform

their HCP about this, so reducing health outcomes and increasing the risk of more serious conditions and emergency admissions.)

This introduction would make clear that the medicine will be safe and effective for most people when used according to the instructions, but to minimise any risks the leaflet contains warnings and potential side effects. It would encourage anyone who is still worried about taking the medicine to go back to their doctor or talk to a pharmacist, and further reassure them that healthcare professionals understand illness and medicine can be very worrying and they will be happy to advise. (This should help reduce the proportion of patients who avoid taking their prescribed medicines.)

6.4 Accessibility and Inclusion

Participants thought the improvements they were suggesting for the leaflet, notably on the clarity of the design and the use of images and summaries, would also make a substantial contribution to making them more accessible, particularly for those less comfortable with the English language or with learning difficulties.

They were also strongly in favour of the information in the leaflet being made available in a range of alternative formats (such as Braille or simple English) and languages, but largely because they felt the leaflet itself was already too long and unwieldy. They thought the alternatives should be made available online, in a format that could also easily be printed out (to help address digital exclusion), with a link included in the leaflet (including using a QR code).

6.5 Integration

Some participants gave examples of how the leaflet and the rest of the medicine packaging could be combined to give a better presentation of the information. For example, a well-known brand of hot lemon cold remedies containing paracetamol had information on the box and on the sachet as well as within the leaflet, and this was seen as a good way to serve both those seeking a quick reference and those wanting more in-depth information. Putting more key information on the outside of the packaging would also help those wanting to check the active ingredient or for potential allergies before buying, given few people would think it right to open the packaging to read the leaflet before they had actually bought it.

If the QR code were shown on the outside of the packaging, this would have the further advantage that a potential user could check the medicine before buying it, and so not run the risk of taking the medicine home and finding they could not use it. In contrast, the leaflet would only be accessible once the medicine was paid for and opened.

Even when participants said they wouldn't know how to use a QR code themselves, or would prefer another route, they thought a QR code made sense. It was particularly seen as a way to give people additional information without overloading the leaflet: for example, by providing versions in a range of languages or more accessible formats. But they were also clear that a QR code could not replace a paper leaflet, at least for now. In part, this was because of digital literacy or exclusion.

“I think it needs to be added rather than replaced, because my mother-in-law doesn't do internet at all in any way shape or form, so I think you perhaps exclude the older generation.”

“It's the same as I can't rely on digital boarding passes on my phone. Even though they say you don't need a paper printout, I always take a printout. What about if I lose my phone?”

6.7 NHS Apps

There was clear support for using NHS apps or other health apps to provide people with information specific to their personal situation for all medicines they are prescribed, with 27% of survey respondents strongly in support, and a further 39% tending to support (66% support overall). Just 5% tended to oppose and 4% strongly opposed.

For the focus group participants, the main positives of linking PILS and the NHS Apps were that this could be linked to an individual's prescription, so the information would automatically be on the App and not need to be searched for. Users could also receive a message via the Apps if the information in the leaflet were updated. Some also suggested the Apps could spot any potential interactions between different medicines that a patient had been prescribed, and give an automatic caution or warning. Similarly, it could be linked to their patient record, potentially highlighting automatically if there were the risk of an allergic reaction or a contra-indication because of a separate health condition.

“Your prescriptions are listed within the NHS app so there's a way to actually just tap on it and say ok let's have a look, I can see what they've prescribed, what's the info on it, so if it was within the NHS app that would be a bonus.”

However, some participants were less enthusiastic. They thought the NHS Apps clunky and lacking in functionality. Some also preferred the idea of having access to this

information and potential integration with their prescriptions or patient records through another health app.

It appeared as if those who had used the NHS Apps more recently, or whose version of the Apps had more functionality, tended to be more positive about integration within the Apps.

6.8 Retaining the PIL

While there was strong support for both adding a QR code and linking PILs to the NHS Apps or other health apps, there was also a strongly held view that these should be alternatives, and not replace the paper PIL – at least for now.

“Not everyone's maybe got access or is good with the internet, you know, or in like an emergency situation, if they were having adverse effects, they're not going to feel like going onto the internet and looking for information.”

In the survey, respondents were asked their views about stopping automatically providing a paper patient information leaflet and instead guiding people to find the information online, for example through a QR code. 30% were strongly opposed to this, and a further 25% tended to oppose (55% opposed overall). Only 7% strongly supported this idea, with a further 15% tending to support it.

In the focus group discussions, participants generally felt that ending the automatic inclusion of PILs would disadvantage many people, particularly those who were less confident with technology or were digitally excluded. Some felt that there may be a point in the future where ending the inclusion of leaflets would be appropriate, but this was some years away.

6.9 Limits of the PIL

Some survey respondents and focus group participants recognised that there were practical constraints to what the Leaflets could do. For example, they could not include versions in multiple languages without becoming many times longer than at present, and they could not personalise information for individual patients. As medicines would often work differently for different people, there would often be a good reason to use other sources as well as or instead of the Leaflet, including online searchers or hearing from others with the same condition or with experience of taking the same medicine.

Some also felt that while leaflets could be improved, there was also a responsibility on individuals to engage with the material and recognise that it might be long, complex or off-putting.

“It's up to the person taking it to choose not to be an uninformed dipshit about stuff they're taking.”

“They contain all necessary information now. No changes required. People are just too lazy to read them.”

Some respondents said there were roles that the leaflet could never perform well or at all, including hearing from other users about their experiences with the medicine, and having advice on dose or interactions with other medicines or conditions tailored to their specific circumstances.

7. Conclusions

The Patient Information Leaflet is usually used in conjunction with a range of other sources of information. For some users, it is irrelevant, as they would expect to gain all the information they need either from formal sources such as their prescriber or dispenser, or from their own researchers, most likely on the internet. For others, it is a helpful additional and authoritative source of information which they might refer to for a specific query (such as checking for side effects). Others who take a very ‘hands-on’ approach to their healthcare may be motivated to read the leaflet in detail or keep it for future reference. In practice, most of the time, the Leaflet is just one part of a process by which patients learn about their medicines.

Nevertheless, the Leaflet is intended to be a stand-alone resource that **provides the patient with the information they need to take the medicine safely and effectively**. This is a complex and challenging role. For example:

- It has to provide comprehensive information on the medicine across a range of categories, from side effects to the product licence-holder, but also allow those taking the medicine to extract the specific information they are seeking easily.
- It has to be precise in its language, and communicate complex concepts such as risk, but also comprehensible to the general population and, as far as practical, to those with a range of disabilities or who are not confident in using English.
- It has to make the risks of medicines clear without scaring users to the extent they do not take it.
- It may have to educate users about risks or effects they may not have encountered before, without assuming too much basic knowledge of health or medicine.

The way patients think of the Leaflet reflects these tensions. For example, they think it is too long and detailed, but they also struggle to suggest what should be left out, because they see that someone else might want information that they themselves do not.

But patients also see that the Leaflet could be made much more effective even within these constraints, above all by:

- Including a short summary of how to take the medicine safely at the start of the leaflet
- Making more use of design elements such as symbols and pictograms, spot colour and bold text.
- More standardisation in headings and layout to help users navigate more quickly to the information they want.

- Better ways to show the comparative risk or incidence of different side-effects.
- Using a larger text to make it easier to read.

These kinds of enhancements would make the leaflet more effective. Critically, they would also make the leaflet look like the kind of document they could be expected to take out and read. At the moment, the leaflet presents more like ‘terms and conditions’ that are included as a legal requirement, which does not encourage patients to read it. Making the leaflet more visually attractive would move it closer to an ‘instruction manual’ users are encouraged to read.

There is a strong expectation amongst the public that the wider move to digital channels should apply to patient information leaflets. The inclusion of a QR code on the packaging was seen as an obvious development, as it would help those who would never or rarely read a paper leaflet to be directed to a trustworthy and regulated source. A QR code could also link the user to additional formats or versions – for example, an audio or video summary of the medicine for those who struggle with written documents, or versions in other languages.

There was also an expectation that technology will in the future provide users with a more integrated and tailored approach to providing them with information about their medicines, their medical history and up-to-date personalised guidance. This could be provided through the NHS apps and potentially through other health apps.

Annex A: Topline results from the survey

- Topline results of a survey of 2,091 UK adults (aged 18+)
- Survey conducted using the YouGov general public Omnibus platform
- Fieldwork conducted 30th September – 1st October 2025
- All questions required single code responses unless stated otherwise
- Results may not add up to 100% due to rounding or multiple choice answers
- Open ended (“write-in”) responses are analysed separately

Q1) Which, if any, of the following applies / has applied to you over the last 12 months (i.e. since September 2024)? Multicode

%

- 55 I have been prescribed medicine from elsewhere, for example from a GP or dentist (including repeat prescriptions)
- 42 I have bought non-prescription medicine from a supermarket or local shop
- 35 I have bought non-prescription medicine from a pharmacy (including from a pharmacy counter in a supermarket)
- 22 I have been prescribed medicine from a doctor in a hospital
- 10 I have obtained prescription medicine online
- 5 I have obtained non-prescription medicine online
- 1 I have obtained medicine in another way
- 20 None of these

Q2) Thinking about the last time you obtained medicines in the following way, did you feel you had enough information to take that medicine safely and effectively or not?

- A) Prescription medicine from a doctor in a hospital
- B) Prescription medicine from elsewhere, for example from a GP or dentist (including repeat prescriptions)
- C) Non-prescription medicine from a pharmacy (including from a pharmacy counter in a supermarket)
- D) Non-prescription medicine from a supermarket or local shop
- E) Prescription medicine online
- F) Non-prescription medicine online

(A)	(B)	(C)	(D)	(E)	(F)	
464	1198	759	908	208	112	<i>Base: those who have obtained medicines in this way</i>
%	%	%	%	%	%	
77	83	82	82	87	74	I had all the information I needed
18	12	14	15	10	18	I had some of the information I needed
3	1	1	1	2	6	I did not have any of the information I needed
2	3	2	2	2	2	Don't remember / can't recall

- Q3) Please imagine you were prescribed a medicine from a GP or dentist
Which, if any, of the following would do to get information about how to take the medicine safely and effectively? Multicode
- %
- 55 Talk to the GP or the person who prescribed the medicine
 - 53 From the information leaflet included in the medicine packaging
 - 46 From the specific instruction label normally printed on the bottle or package containing your medicine
 - 42 Talk to the pharmacist who dispensed or supplied the medicine
 - 40 From the general information on the bottle or package containing your medicine
 - 21 From a specialist online resource such as NHS Online or a health charity website
 - 20 From a general internet search, such as Google
 - 9 Talk to family, friends or carers
 - 6 Use an AI tool, such as ChatGPT
 - 3 From social media or online community, such as Reddit or a Facebook group
 - 1 Other
 - 6 Don't know
- Q4) Now thinking about buying non-prescription medicine from a supermarket or local shop.
Which, if any, of the following would you do to get information about how to take the medicine safely and effectively? Multicode
- %
- 49 From the information leaflet included in the medicine packaging
 - 47 From the general information on the bottle or package containing your medicine
 - 36 Talk to a pharmacist at the store / location you buy the medicine from
 - 21 From a general internet search, such as Google
 - 18 From a specialist online resource such as NHS Online or a health charity website
 - 16 Talk to a GP who can prescribe medicine
 - 10 Talk to another healthcare professional, for example in a specialist clinic
 - 11 Talk to family, friends or carers
 - 6 Use an AI tool, such as ChatGPT
 - 3 From social media or online community, such as Reddit or a Facebook group
 - 2 Other
 - 8 Don't know

Q5) Every medicine available in the UK (prescription and non-prescription) should come with a patient information leaflet. This is usually found within the medicine box.

Which of the following statement best applies to what you would do with the information leaflet for the following types of medicines? RANDOMISE ORDER

- (A) A new medicine you have not taken before
- (B) A medicine you feel familiar with (e.g. something you've taken before or take regularly)
- (C) A medicine that is available on prescription only
- (D) A medicine to treat a serious health condition
- (E) A medicine you have obtained for someone else (e.g. a child or elderly parent)

(A)	(B)	(C)	(D)	(E)	
%	%	%	%	%	
6	32	7	5	6	I do not read the leaflet and throw it away before I take the medicine
6	26	8	6	6	I do not read the leaflet before I take the medicine, but I keep it for future reference
24	17	26	19	18	I read some or all of the leaflet before I take the medicine and then I throw it away
60	20	53	55	41	I read some or all of the leaflet before I take the medicine and keep it for future reference
3	3	4	4	6	Don't know
3	2	2	11	23	Not applicable – I've never had this type of medicine before
12	58	15	11	12	<i>Do not read</i>
84	37	79	74	59	<i>Read</i>

Q6) Which, if any, of the following are reasons you would not read a patient information leaflet? Select all that apply. Multicode

%	
48	If I already know how to use the medicine and have all the information I need
29	I trust the doctor or pharmacist to give me the information I need
22	If the leaflet is too long / contains too much information
16	If the leaflet is difficult to read as the text is too small
10	Reading about side effects puts me off taking the medicine
10	It is easier to search for the information I need online
9	If the leaflet is difficult to understand as the language is too complex
9	There is no point reading the leaflet as I have to take the medicine anyway
3	Other
1	I do not trust what the leaflet says
9	Don't know
8	Not applicable – I will always read the patient information leaflet

Q7) The patient information leaflet contains the following information.

Generally speaking, to what extent, if at all, do you read each of the sections of the patient information leaflet when you get a new medicine? Single code only for each option. RANDOMISE ORDER

- A) What the medicine is and what it is used for
- B) Precautions and warnings before you take the medicine
- C) How to take the medicine
- D) Possible side effects
- E) How to store the medicine
- F) Ingredients
- G) What the medicine looks like
- H) Who the manufacturer is
- I) When the leaflet was last updated

(A)	(B)	(C)	(D)	(E)	(F)	(G)	(H)	(I)	
%	%	%	%	%	%	%	%	%	
54	59	69	55	42	22	22	13	15	Read in detail
33	31	22	34	41	36	36	33	25	Skim or glance at it
9	6	6	8	12	34	27	43	37	Don't read it at all
2	2	1	1	2	3	8	5	15	Did not know this information was provided
3	3	3	3	3	5	7	6	8	Can't recall

Q8) How, if at all, do you think the patient information leaflet could be improved to encourage you to read it?

Answers provided separately

Q9) To what extent do you support or oppose the following as ways to improve how patients get information about medicines? DO NOT CHANGE ORDER

- A) Provide a QR code on the medicine box / packaging so people can find more information about the medicine via their smartphone / tablet
- B) Use medical apps such as the NHS App to provide people with information specific to their personal situation for all medicines they are prescribed
- C) Stop automatically providing a paper patient information leaflet and instead guide people to find the information online, for example through a QR code

(A)	(B)	(C)	
%	%	%	
25	27	7	Strong support
33	39	15	Tend to support
26	21	19	Neither support nor oppose
7	5	25	Tend to oppose
6	4	30	Strongly oppose
4	3	3	Don't know

D1) Which, if any, of the following apply to you? Multicode

%

- 4 I have a visual impairment
- 3 I have dyslexia
- 5 I have Autism or a similar condition
- 4 I have ADHD
- 37 I am taking medicines for a long-term health condition
- 10 I have previously had a serious side effect or reaction to a medicine
- 42 I use the NHS App
- 4 I use other medical apps
- 1 I am currently pregnant
- 1 My partner and I are currently trying to get pregnant
- 2 English is not my first language
- 33 None of these
- 2 Prefer not to say

D2) Which of the following best describes how easy it is for you to access the internet at home if you are looking up information or using everyday services online?

%

- 97 I have good online access at home (either through broadband or mobile phone)
- 3 I have poor online access at home (either through broadband or mobile phone)
- 1 I have no online access at home

Annex B: Sample profile

Qualitative Research

In total 105 participants took part in formal qualitative discussions as part of this project through a combination of online focus groups, in-person focus groups and one-to-one depth interviews. Qualitative research is never designed to be fully representative of a wider population, but the sample can be designed to ensure a broad spectrum of adults across the UK and to ensure key demographic groups are included.

Figure A shows the achieved profile:

Figure A: Profile of qualitative participants

105	Total
51	Male
54	Female
42	18-40 years
39	41-64 years
24	65+ years
75	White background
30	Non-White background
83	Live in England
22	Live in Northern Ireland, Wales or Scotland
50	Graduate education or above
55	Non-university education
24	No medicine user
36	Low medicine user
45	High medicine user
14	English not first language

In addition, Woodnewton conducted two further validation focus groups which involved 23 participants in two groups. Detailed demographic data on these individuals was not collected, but these participants were generally older (with one participant 100 years old!), more likely to be digitally excluded and had a range of health and visual impairments. Therefore, the total number of participants was 127.

Quantitative Research

The quantitative research was collected through utilising the YouGov general public omnibus survey. This is a well-established survey of a representative sample of the UK adult (18+) population. Data is actively sampled from YouGov’s panel of millions of potential respondents and final data weighted by age, gender, social grade and education. The profile of those taking part is shown in Figure B.

Figure B: Profile of quantitative participants

Unweighted base	Weighted base	Weighted %	
2091	2091	100	Total
975	1014	48	Male
1116	1077	51	Female
459	536	26	18-34 years
719	723	35	35-54 years
913	832	40	55+ years
1299	1192	57	ABC1 social grades
792	899	43	C2DE social grades
1762	1759	84	Based in England
329	332	16	Not based in England
1875	1852	89	White background
154	171	8	Non-White background
958	1024	49	Non-university education
1051	975	47	Graduate education or above
45	45	2	English not first language

Data does not always add up to 100% where respondent said “don’t know” or “prefer not to say”

Further and more detailed profile information about respondents, for example health conditions and experience of taking medicines, are available in the survey results (SPSS and computer tables) for additional analysis.