Medicines and Healthcare products Regulatory Agency

Qualitative research with stakeholders on providing regulatory information about medicines online

March 2010
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1.1 Introduction

The Medicines and Healthcare products Regulatory Agency (MHRA) is the Government Agency responsible for making sure that medicines and medical devices work properly and are acceptably safe. The MHRA employs robust and fact based judgements to ensure that the benefits of medicines and medical devices to patients and the public justify any potential risks.

The MHRA holds a comprehensive database of Summaries of Products Characteristics (SPCs) and Patient Information Leaflets (PILs) for all medicines it licenses. Although, the electronic Medicines Compendium (eMC) makes SPCs and PILs available for most branded prescription products, currently patients and healthcare professionals cannot access this information on other medicines (including generic prescription and most over-the-counter products).

Opinion Leader was commissioned by the MHRA to conduct a scoping exercise to assess the desirability of providing basic product information about medicines online. The resulting research programme entailed a series of focus groups and depth interviews with a range of stakeholders including patients, members of the “well” public, carers and healthcare professionals (HCPs); the latter group included GPs, hospital doctors, nurses and pharmacists. This report provides the findings of these interviews and makes recommendations based on this evidence for how the MHRA may wish to develop its proposed website.

1.2 Aims and Objectives

The primary objective of the research was to explore the desirability of providing regulatory information about medicines online. Where there was appeal, the following considerations were discussed in-depth:

- Where patients and healthcare professionals expect to find this information (i.e. the MHRA website or another)
- What sort of questions the target audience might want answered and how they might want to search the data (e.g. by product name or disease area)
- The functionality required for the software to deliver
- The impact of making this information available
1.3 Approach

We established at the outset that it was important to interact with a range of stakeholders, identifying four key target audiences with which to engage:

- Patients with chronic conditions such as cancer, heart disease, diabetes, asthma, HIV and Arthritis, and patients who use certain medicines e.g. antidepressants
- The ‘well’ public
- Carers and
- Healthcare professionals including hospital doctors, GPs, nurses and pharmacists

Recognising the need to tailor our research method for each of the different target groups, our overall approach consisted of a mixture of interlinked activities.

**Patients, Carers and the Well Public**

Focus groups were the primary research method used to engage with patients, carers and the wider public. Participants were drawn from a variety of geographical settings encompassing three UK countries and a mixture of rural/suburban/urban areas to allow for potential variations in opinion according to location.

Two groups of eight members of the ‘well’ public were convened in Scotland, rural England and London. Three groups of carers were also held in rural England, Scotland and Northern Ireland. A strict recruitment specification was used to ensure a spread of participants according to gender, age and socio-economic group, and each group included at least one person from BME communities. For the two focus groups involving carers we ensured a spread of experience and background.

In addition to this, three further groups of patients were also held in different parts of the UK (Scotland, rural England and London), each consisting of patients with a specific chronic condition (arthritis, diabetes and/or asthma). These groups were slightly smaller (6 participants) to create the right environment for these participants to explore the issues fully.

The discussion guide used for these focus groups can be found in Appendix.

More tailored research solutions were provided for patients with more sensitive medical conditions and for those with mobility issues. Face-to-face interviews were felt to be a more appropriate setting in which to engage with patients with conditions such as Cancer, Heart Disease and Depression, as well as the best way to ensure an open and honest response. Visiting rather than calling these patients to conduct the interviews also meant we were able to show them examples of PILs and discuss these more effectively.
<table>
<thead>
<tr>
<th>Participant type</th>
<th>Type of Fieldwork</th>
<th>Location</th>
<th>No. of participants</th>
</tr>
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<tbody>
<tr>
<td><strong>Patients</strong></td>
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<tr>
<td>Mixed (Arthritis, Diabetes, Asthma)</td>
<td>Group</td>
<td>London</td>
<td>8</td>
</tr>
<tr>
<td>Mixed (Arthritis, Diabetes, Asthma)</td>
<td>Group</td>
<td>Glasgow (urban)</td>
<td>8</td>
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<td>Mixed (Arthritis, Diabetes, Asthma)</td>
<td>Group</td>
<td>England (rural)</td>
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<tr>
<td><strong>Carers</strong></td>
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<tr>
<td>Carers (mix of formal/informal)</td>
<td>Group</td>
<td>England (rural)</td>
<td>8</td>
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<td>Carers (mix of formal/informal)</td>
<td>Group</td>
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<td>Carers (mix of formal/informal)</td>
<td>Group</td>
<td>N. Ireland (urban)</td>
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<tr>
<td><strong>The 'Well' Public</strong></td>
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<tr>
<td>Public</td>
<td>Group</td>
<td>Scotland (rural)</td>
<td>8</td>
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<tr>
<td>Public</td>
<td>Group</td>
<td>London</td>
<td>8</td>
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<tr>
<td><strong>Number of participants</strong></td>
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<tr>
<td>Arthritis, Diabetes, Asthma</td>
<td>Depth Interview</td>
<td>National Mix</td>
<td>6</td>
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<tr>
<td>Heart disease</td>
<td>Depth Interview</td>
<td>National Mix</td>
<td>5</td>
</tr>
<tr>
<td>Cancer</td>
<td>Depth Interview</td>
<td>National Mix</td>
<td>4</td>
</tr>
<tr>
<td>HIV</td>
<td>Depth Interview</td>
<td>National Mix</td>
<td>4</td>
</tr>
<tr>
<td>Antidepressant user</td>
<td>Depth Interview</td>
<td>National Mix</td>
<td>3</td>
</tr>
</tbody>
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**TOTAL:** 82
A specialist health recruiter was used to arrange interviews with 50 HCPs in a range of different medical settings. As with the other participant groups, health professionals were recruited from three different areas across the UK (London, Scotland and Northern Ireland) and they included an even mix of the following groups:

- Hospital doctors (based in both large teaching hospitals and smaller general hospitals)
- GPs (from a variety of different-sized practices)
- Nurses (working in acute and community settings, including nurse prescribers and specialist nurses)
- Pharmacists (both community and hospital based)

It was agreed that depth interviews would be the best method to reach this group, allowing us to accommodate their busy work schedules/shift patterns and removing the need for them to travel. Conducting a proportion of these interviews by phone gave added flexibility for participants with limited availability. Given that health professionals are notoriously busy and difficult to reach a monetary incentive was offered to participants in return for their time.

The discussion guide used to interview health professionals can be found in Appendix. Please see Appendix for further details of the healthcare professionals interviewed.

*Table 2: Breakdown of interviews conducted with HCPs*

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<thead>
<tr>
<th>Participant type</th>
<th>Number of Face-to-Face Interviews</th>
<th>Number of Telephone Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Hospital Doctor</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Nurse</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Pharmacist (retail)</td>
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<td>3</td>
</tr>
<tr>
<td>Pharmacist (hospital)</td>
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<td>5</td>
</tr>
<tr>
<td><strong>Sub Total:</strong></td>
<td><strong>14</strong></td>
<td><strong>36</strong></td>
</tr>
<tr>
<td><strong>TOTAL INTERVIEWED:</strong></td>
<td></td>
<td><strong>50</strong></td>
</tr>
<tr>
<td>METHOD</td>
<td>SAMPLE</td>
<td>LOCATION</td>
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<td>--------------------------------</td>
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<tr>
<td>Qualitative groups</td>
<td>• Patients</td>
<td>• Rural England</td>
</tr>
<tr>
<td></td>
<td>• ‘Well’ public</td>
<td>• London</td>
</tr>
<tr>
<td></td>
<td>• Carers</td>
<td>• Scotland</td>
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<td>• N. Ireland</td>
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<tr>
<td>Depth interviews (face-to-face)</td>
<td>• Patients</td>
<td>• Rural England</td>
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<td></td>
<td>• Carers</td>
<td>• London</td>
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<td></td>
<td></td>
<td>• Scotland</td>
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<tr>
<td>Depth interviews (face-to-face)</td>
<td>• Hospital doctors</td>
<td>• Rural England</td>
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<tr>
<td></td>
<td>• GPs</td>
<td>• London</td>
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<td></td>
<td>• Nurses</td>
<td>• Scotland</td>
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<td></td>
<td>• Pharmacists</td>
<td>• N. Ireland</td>
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<tr>
<td>Telephone depth interviews</td>
<td>• Hospital doctors</td>
<td>Across all 4 nations and</td>
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<tr>
<td></td>
<td>• GPs</td>
<td>spread of settings</td>
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<td></td>
<td>• Nurses</td>
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<td></td>
<td>• Pharmacists</td>
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2. Healthcare Professionals (referred to as ‘HCPs’ in this report)

2.1 Provision of medical information in general

HCP-patient relationship
Most HCPs noted that their relationship with patients was variable and heavily dependent on the individual patient. For many it was an open and ‘confidant’ style relationship. In these circumstances, there was utmost trust between patients and HCPs and advice on healthcare and medicines was consumed without question. Some also commented that, in the past, this has especially been the case for those from poorer backgrounds and those who had known their doctor for many years.

“Most patients treat what I say as gospel without questioning the prescription. Many of these patients have known me for a long time and trust me to give them clear and accurate advice.”
- GP

“I have a great relationship with my patients. Sometimes they ask for an explanation, but in the end they mostly are happy with the medicines I prescribe them.”
- Practice Nurse

However, many HCPs also spoke of patients who are less accepting of the ‘doctor’s word’ and required further reassurances, especially when visiting a GP. When such circumstances arose, the GPs would usually explain things using leaflets, specialist websites and Patient Information Leaflets (if available). However, this was by no means standard practice and was only employed when initiated by the patient.

“A few patients are much keener to know everything about the medicine they are taking. I tend to reassure them by showing them websites that they can visit or if they have the medicine to hand, I’ll go through the patient leaflet with them, not the whole thing though, just the relevant sections, mainly side-effects.”
- GP

Provision of information on medicines to patients
Generally speaking, some HCPs have noticed that patients are demanding more information and advice, especially amongst those from wealthier and more educated backgrounds. This was most common at those times when a patient was receiving a medication, especially an unfamiliar one, for the first time. The key explanations and clarifications sought after by patients are related to side effects (both short & longer term), dosage and compatibility with other medicines.
“For some people the doctor’s advice on its own is no longer enough, they need to justify what they say and provide evidence.”

- Hospital Doctor

“Patients really want to know about side-effects above all else.”

- Practice Nurse

A number of GPs noted that those patients that asked questions about their treatment were also the ones that had pre-conceptions about medicines, mainly around its side-effects, based on findings from personal research. This was said to be through Google searches in particular and through having read it in advice and comment pages in magazines and newspapers such as the Daily Mail. GPs in particular viewed this as a barrier to proper treatment as it causes unnecessary anxiety and confusion amongst patients through seemingly contradictory diagnosis. Some HCPs also spoke of inaccurate information that many patients had on medicines and conditions more generally, including information from untrustworthy sources or those linked to the US where drug trials and medical protocol differ.

“I get people coming to me and saying ‘oh I read in Take A Break’ that this causes rashes on my body’ for example. For the most part they can be reassured that this is rare, but it does prove difficult at times to go against what they have been told else where.”

- GP

“There are so many dubious websites out there, American sites or chat room forums that make the patient feel anxious.”

- Hospital Nurse

Some HCPs mentioned that those on repeat prescriptions and/or with long-term conditions were more informed about the medication they were taking. However, they were also less likely to ask questions as they had got used to the medicines they were taking and in the majority of cases had seen its positive effects. Amongst these patients questions only arose when their medication was changed, increased or decreased.

“I have patients with conditions stretching back several years and they barely ever ask questions, although in the half-yearly catch-ups they tend to question why the medication has been increased or decreased.”

- GP

When HCPs were asked for more information by the patient, they would go through the relevant sections within the PIL (if available) and discuss any queries and in some instances provide them with
a print out (from the EMC). Other useful methods mentioned included promoting specialist websites such as Arthritis Care, Patient.co.uk or referring them to local or in-hospital pharmacists.

“There are times when I need to give the patient some more information, sometimes I would just refer them to a website or just talk them through it carefully.”

- Practice Nurse

Provision of information on medicines for HCPs
The interviews revealed that GPs as well as specialist doctors and nurses were in the best position to receive accurate and consolidated information about medicines. GPs, for example, have their own internal digital systems that they use (e.g. Mentor), whilst specialist HCPs were naturally more informed about the medicines that they were prescribing. Some had specialist resources produced for them by external organisations. PILs or other stimulus were used only when the patient was leaving the hospital and had to treat themselves, whereas in-hospital treatment was dealt with without such resources.

“I feel that I am well catered for at present, but it’s always good to have more information, especially for the patients.”

- GP

“There is more of a paternalistic approach to hospital treatment and patients rely on us much more. As they are usually more gravely ill they are less in a position to question what they are being given.”

- Hospital Doctor

When asked, HCPs did not see huge gaps in the current provision of information about medicines. However, there was not said to be a single place where one could go to find all the information that they needed. Current sources of information on medicines were seen to be disparate.

“I visit numerous sites online, I just got to Google a lot of the time, can’t remember exactly what comes up every time, but it’s quite random, there isn’t one place I go to, I mix it up with the BNF.”

- Practice Nurse

HCPs highlighted a variety of sources that they use, and had used in the past, to inform their decisions on prescriptions and medicines. Still most commonly used, especially by GPs, are monograph-based resources, including the BNF (also used online), Stockley’s Drug Interactions and the Oxford Textbook of Medicine. Although the BNF was seen as the authoritative text on medicines that was referred to heavily pre, during and post consultations, it was at times seen to be out-of-date concerning new medicines that had just come into the market.
“I use the British National Formulary as a point of reference, it is the holy bible for information on medicines. But I have a brilliant system, I think it’s called Mentor, which tells me what I want without having to go online, it’s already part of the computer login.”

- GP

A number of participants also mentioned personal relationships as a continued method of finding out about medicines, including pharmacists and drug reps. Hospital Doctors and Nurses in particular used pharmacists as they usually had access to one in-hospital and with whom a close working relationship had been established. Some GPs also spoke of the continued relationships with pharmaceutical representatives, who although seen to be partisan, were still perceived to be a useful resource in finding out about new medicines.

“If I have any problems or queries I can always call or go to the pharmacist, he’s only down the corridor. A face-top-face explanation from me is better than going online or to a book, but there isn’t always time for that.”

- Hospital Doctor

“Drug reps still come round and see me. To be honest I know they have an agenda but they definitely serve a purpose. There isn’t anything at present that can replace them.”

- GP

However, online was also widely mentioned as a medium through which information about medicines was gathered. This ranged from more general ‘Googling’ to the use of more specific online resources with the most commonly cited including NICE, Clinical Knowledge Summaries (especially by Pharmacists), SIGN guidelines (for Scotland), Royal Pharmaceutical Society website and Oxford Clinical Mentor (by GPs). If necessary, many participants also mentioned referring to condition-specialist leaflets and websites such as Diabetes UK, Arthritis.org and the British Heart Foundation.

“I carry out Google searches, but end up on websites specific to the condition, like asthma or diabetes.”

- Practice Nurse

A number of pharmacists in particular mentioned using the Electronic Medicine Compendium to look up PILs and print them off when necessary. However, HCPs currently find it incomprehensive and not up-to-date. It was noted that as the website was both a commercial entity and relied on pharmaceutical companies uploading information onto it, it could not be relied upon wholeheartedly to provide information about medicines. Those who are using the EMC website, find the printing / downloading functions useful as they help them to address most patient queries and concerns directly and provide documentation for the patient to take with them or reference at home.
“The EMC website is really useful as you can print and download PILs, which I can then give to my patients. It means that there is always a back-up.”

- Retail Pharmacist

“You can already access patient information leaflets from the EMC. I use this quite regularly. At times the medicine isn’t on there, but all I all it is a useful resource and quite user-friendly.”

- Hospital Pharmacist
2.2 Usage and views of Summary of Product Characteristics and Patient Information Leaflets

Usage of SPCs and PILs vary across different types of HCP and amongst individuals as well. It is also influenced by individual patient needs and personalities. All HCPs had heard and used PILs before whereas SPCs were not widely used and some did not even know what they were. However, some specialist nurses said that they referred to SPCs during more complex in-hospital treatments.

“There are invaluable to both myself as a professional and to patients.”
- GP

“There is an issue at times when I send patients home and they’re already on a course of treatment with lots of random medicines and then we expect them to carry this on. They really need tutoring and hand-holding in how to take the medication.”
- Hospital Nurse

In terms of PILs, some HCPs would refer to a PIL during a consultation with a patient who needed careful instruction on taking the medicine and to alleviate concerns. However, only pharmacists were seen to have access to the PILs at all times whereas other HCPs would only have them to hand if the patient came with their medication box. As a result, pharmacists are more likely to refer to PILs than any other HCP, followed by in-hospital doctors and nurses who have access to in-hospital pharmacies. The latter were more likely to go through the PIL more carefully when sending the patient home with a specific treatment plan rather than during in-hospital treatment, especially if it required mixing different medicines and dosages.

“I only use it for those patients that have fears or anxieties about medicines. They are really useful, especially for more complicated treatment.”
- Hospital Doctor

When PILs were used, the exercise was seen as useful in informing the patient, explaining the treatment to them and calming any anxieties about side-effects that are listed on the PILs or that had been heard through word of mouth. Others said that they just signposted the patient to the PIL within the medicine box and did not use it as Standard Operating Procedure (i.e. they did not use them if the patient had no questions or concerns).

“Many patients hear things through the grapevine and so I use PILs to inform them about the realities, especially around side-effects, which can be intimidating.”
- Hospital Nurse

“I don’t use PILs very often as I don’t have them to hand so I refer to the BNF or other websites instead. But when a patient has brought one in then it is useful. We also
keep some common ones in a folder, but we can’t aim to have all of them like in the pharmacy.”

- GP

“I regularly use the PIL to explain things to a patient. I just open the box and guide them through it.”

- Hospital Pharmacist

GPs, hospital doctors and nurses actively referred to PILs during certain critical junctures, such as when prescribing new medication or when increasing dosage as this is when patients had the most queries. For patients with long-term conditions there was less need to do so.

“I use them [PILs] when increasing a dose or changing medicine for those with a long-term condition such as asthma or diabetes. As they are so used to taking the old medication, they usually ask why I need to do so.”

- GP

Apart from pharmacists, most HCPs had a relatively low understanding of the MHRA role/remit. As a result, most were unaware about the recent work to improve the content and layout of PILs. However, this was perceived very positively and often encouraged as part of best practice. Some had already noticed improvements in PILs, possible due to this work, which has included simpler and clearer information.

“I’ve heard of the MHRA vaguely. I think they’re responsible for regulating medicines and the like, but I don’t know much more than that...If they’re going about improving PILs that’s great, I would have expected this to be part of their remit.”

- GP

When asked about their views on the layout and content of PILs, the feedback was generally positive. Information on side effects, dosage, directions of use and ingredients were seen to be most of use. There was also an underlying recognition that PILs are a statutory document that can vary due to the array of medicines and producers involved (e.g. pharmaceutical companies, hospitals, pharmacies).

“I think they’re good, some are obviously better than other in terms of the level of detail and readability, but all in all they serve the patient’s needs well from my experience.”

- Hospital Doctor

Where criticism was noted, this centred around the level of detail being provided, especially in relation to listing potential side effects without providing a clear account of the risks of them
occurring. There were also comments made about the need to maintain clarity of language and consistency in terms of shape and length.

“There is such a thing as too much information. It can really cause anxiety among patients.”

- Practice Nurse
2.3 Perceptions and ideas for the MHRA online offer

**Benefits of the online database**

There was overwhelming support for an online database from HCPs both from a professional and a patient perspective, particularly if it draws together information which is already out there but found in disparate locations. First and foremost, participants thought it would provide them with a trusted, robust and up-to-date source to find and reference PILs, especially as most HCPs already used the internet as a primary source of information. However, many also noted that this database would be potentially more useful to patients in order to signpost them to reliable information during and after the consultations.

“*That’s a great idea, a one-stop-shop to all the information that you need about medicines. If it was updated regularly that would make it even more useful.*”

- Hospital Nurse

“*There are certain times when this would come into play such as when I’m seeing a patient and they are looking for a second opinion or something that they can look at themselves.*”

- GP

A common perception was that, although information was out there, this would fill a big void insofar as there is no one current online source offering this information. Some of those who were in contact with pharmaceutical companies and drug reps specifically thought that they were still an invaluable part of every day life, but also felt that they would have less reason to contact and oblige them if such a database existed. Overall, there was a healthy demand for such an online database to be used to research privately and interactively during consultations.

“I *definitely think it’s a good idea, why not shake loose of those drug reps. I have a good relationship with them, but I do sometimes doubt their intentions. I would assume that this website would be independently updated and objective in the information that it provides.*”

- GP

GPs were less keen on the system as many thought they were already catered for by internal offline systems such as the Oxford Clinical Mentor, as well as more traditional resources like the BNF. However, they did support it as a resource for patients, which would keep them informed throughout the treatment process and act as a reference tool to recommend to their patients.
“I have a system that gives me information about medicines, diseases and so on without having to login or go online. All I do is highlight the medicine name or condition and it shows me the information I need.”

- GP

“I think it would prove to be useful when a patient comes to me and says ‘I want more information’ or they ring me up and say I want to know if I’m having a side-effect. In these cases, it would nice to refer them to a guaranteed an authoritative back-up.”

- GP

Pharmacists in particular mentioned that it would be useful at times when prescription boxes were split and resulted in the PIL not accompanying all medication given out. In such cases the ability to download and print out a PIL or otherwise guide the patient to it was seen as invaluable. Some retail pharmacists also mentioned they were only able to visit certain websites that were authorised by the company and that if this resource became available it would need to be approved and cleared for access.

“Sometimes, especially with repeat prescriptions, the medication is split up and so both packs can’t get the PIL. If I could print off another copy that would be excellent.”

- Hospital Pharmacist

“There’s only one snag that I can see and that is what we call a ‘white list’, which is a selected number of websites that we are allowed to visit. This new website would not automatically be on it.”

- Retail Pharmacist

**Drawbacks of the online database**

There was a lot of concern from across the HCPs surrounding the anxiety that a lot of people face about side-effects. Although most noted that this corresponded to a select type of patient, they also foresaw an impending problem of unleashing too much information.

“You must be really careful with a platform like this, I know that patients get really anxious about medicines, especially their side-effects.”

“There is a real danger that it could back-fire and create paranoia amongst patients. You need to ensure that this does not happen.”

There was some caution noted about older people and those without access to the internet reinforced the need for PILs in paper format to continue being available with all medicines. However,
many of the same HCPs qualified these comments with a projection to the future when most people would have the skills to access the internet.

“Of course not everyone has access to the internet; plenty of older people can’t use computers so this may cause problems in terms of getting wider uptake. But I guess looking to the future most people will be computer-savvy, my 75 year-old mum is.”

- Hospital Doctor

Views on location

Most participants wanted the database to be hosted on the MHRA’s website. This was because the licensing of the PILs, and hence the development of the website, was seen to be part of its remit. The MHRA was viewed as an independent government organisation and, therefore, more trustworthy and reliable in updating the website than, for example, pharmaceutical companies. It was also felt that the MHRA should have the ongoing responsibility to regularly update the website with new and modified medicines.

“Having it as part of the government would make it more trustworthy, which is crucial when there are so many websites out there that purport to tell you the right answer. But it needs to highlight this through the web address.”

- GP

“I know the MHRA and having it as part of their website would be fine, it would ensure that the information is updated and reassure me that it’s all legit.”

- Hospital Pharmacist

However, this view was not unanimous as some respondents noted the need to link it with a more recognisable NHS location (such as NHS Direct, NHS 24 and NHS Choices) because few patients would have heard of the MHRA. There was also mention of it having the .gov domain name as a reassurance to users of its link to an official government body and not a pharmaceutical entity.

“This website will be accessible to all people and its main goal should be to espouse trust in it and make it the number one authoritative website for information about medicines. People already trust and visit the NHS websites, so linking it to them or even having it as an offshoot would work well.”

- Hospital Doctor

Views on marketability

An array of options were put forward for marketability. These included leaflets sent directly to HCPs as well as print based advertising, especially in medical journals like the BMJ, HSJ and the BNJ. Utilising hospitals and GP surgeries was also widely recommended, especially leaflets in common rooms. More innovative ideas centred on using the NHS/PCT intranets as well as using GPs, nurses
and pharmacists as word of mouth spokespeople to disseminate and encourage uptake. Respondents also thought that it should be marketed digitally with direct links to the website from emails sent to HCPs.

“I think digital communication is best so people can just click on the link. If I was to receive a letter I wouldn’t necessarily follow it up. It needs to be direct and make people experience the website to then come back to it.”

− Hospital Doctor

“We have an intranet for nurses that they could post a message and a link on, otherwise staff common rooms would be good.”

− Practice Nurse

Views on content

There was a consensus amongst respondents that the online database should have the same information as is currently on the PILs but with added information around the medicines’ benefits, ingredients and price. The latter was seen as useful in determining treatment plans, but caution was erred in having this information available to the general public who would question why they were being given cheaper medicines. Although, nobody mentioned it spontaneously, most participants thought that having an FAQ page would be useful.

“Access to a medicine’s price would be useful for me. It’s always good to know what the NHS and my practice is paying, especially when the same medicines have different brandings.”

− GP

Most HCPs saw no need for two distinct areas/formats for HCPs and the public as it would make it seem as though something was being hidden from the public. The most common way to get around the problem of too much information was thought to be a ‘Wikipedia’ style template that allows users to expand certain sections at their leisure or less just read the brief synopsis. HCPs were keen to have more detailed information such as composition, results from previous drug trials, compatibility with other drugs and usage, which patients would treat on the whole as irrelevant. There was a concern that providing too much information on side effects would cause unnecessary anxiety and paranoia amongst patients.

“I don’t think you should ever hide anything from patients, being open with them is my mantra, which will naturally lead them to trust you more. When you hide things, suspicion takes over.”

− Hospital Doctor
However, others thought that a better way to approach the concerns was through a more ‘guided’ website that allowed patients to access the same information as HCPs but ‘caveat’ it with the probabilities of getting certain side-effects and with contact numbers recommending referrals to a HCP in case of any misunderstandings.

“There should always be some provisos in something like this. The proviso for this is that you go to a doctor or a nurse with anything is not totally clear.”

- GP

“The patient needs to be spoon-fed the information carefully with web-based annotations.”

- Hospital Pharmacist

**Views on functionality**

When discussing preferences for the functionality of the website, the spontaneous reaction was to suggest an advanced search facility by medication name as well as side effects and condition. A particular problem commonly cited was the prevalence of several names for the same medicine and that this resource should take this into account when creating search terms.

“Being able to search for all manner of things, side-effects, all the medicines’ names and other things should be a given.”

- Hospital Doctor

A number of participants also sought to have a website that could be tailored to their needs. This meant being able to save previous searches and in getting quick access to medicines that relate to their specific condition. Adaptable saving, printability and downloading functions were also seen to be essential.

“It would be wonderful if I could back to it and be able to access what I had already searched for previously, especially when I work within a specialist field and I tend to want to know about the same kinds of medicines.”

- Hospital Nurse

“Being able to print and download the information would mean you could use it offline and download those bits that you want rather than everything under the sun.”

- GP

As the website was seen to have a largely narrow remit in terms of purely providing information on medicines, links to other NHS and trusted/specialist disease websites (e.g. NHS Direct, Diabetes UK and other specialist websites) was seen to be important, especially to drug trial information and
medical papers. Some even suggested having links to lifestyle websites that could provide a holistic overview of what was needed for a healthy lifestyle.

“Directions to other sites would be good, other NHS-related or health-related websites. The more connectivity that we have between different areas of health management the better.”

− Hospital Doctor

Furthermore, some participants also wanted to have regular (email/RSS) updates on new developments about current and new medication, products, drug trials and licenses with an option for them to be tailored to the area in which the HCP operates. A lot of them are currently receiving MHRA updates by email, and view this very favourably.

“I would obviously add this to my favourites but if there was a regular update by email then I could have it top of mind and access it through a link on it without wading into the internet.”

− Practice Nurse

Many participants noted the issue surrounding ‘polypharmacy’ and the need to show how contraindications work across medicines. A feature that allows the comparison of different medicines, their side-effects and their suitability in being taken together was seen to be a valuable addition for patients and HCPs.

“In today’s world where people take numerous medicines to treat various conditions, we call it ‘polypharmacy’, there is an increased need to know what medicine can be taken with what.”

− GP

A couple of the more innovative HCPs also suggested that they would like the additional feature of a mobile interface with the database being easily accessible via their mobile phone. Further innovations included having a recognisable desktop icon that directs you automatically to the database as well as a metatag, both of which were thought to increase the ease and speed of access as well as ease of navigation around the database.

“A mobile phone apps on the iPhone wouldn’t go amiss in today’s high-speed world where people have little time to do things. I’ve already seen a medical-related app on the phone.”

− Hospital Pharmacist

When probed, most HCPs were unsupportive of the idea of a networking facility and patient forums on the website, with most participants saying that they never used professional networking sites.
With regards to patient forums, most HCPs thought that only negative comments would be posted, which would in turn, detrimentally affect their patients and the decisions that they make. A couple of participants suggested that a website of this nature should be clean and simple and concentrate on the specific remit of providing authoritative and legal information on medicines.

“I never use these forums, but anyhow they would detract from the point of the website.”

– Hospital Doctor

Having images and diagrams on the site were seen to be a useful feature largely because patients would find it easier to make sure that they are taking the right medication, as they can vary in shape, size and colour. It would also be an added aid for both patients to use at home and HCPs to use during consultations on how to take a certain medication and the ‘dos’ and ‘don’ts’ for each medicine.

“My dad for example keeps his pills in a small black film container without any identifiers to which pill is which. If there were pictures of the pills then if he got confused he could on the website and check it.”

– Practice Nurse
2.4 Wider benefits to patients, HCPs and the NHS

The number of HCPs thought that the website would enable them to signpost patients to a reliable website that could answer their questions without the need for needless phone calls and face-to-face time. However, some did think that it would result in different rather than less questions being asked of them. A large section of the HCPs also saw it as a useful ‘back up’ resource for HCPs in case patients needed reassurance either at home in the consultation room.

“Many patients will be able to look things up at home and come to me more informed. This kind of information should always be qualified by a healthcare professional, but patients having access to it would allow me to answer questions with a back up than reassured the patient...Many of their questions will also be answered prior to coming to me, especially around side-effects.”

– GP

“It could unleash a different can of worms in terms of the types of questions being asked.”

– Practice Nurse

It was also considered that a more informed public were more likely to accept a treatment plan and for there to be ‘concordance’ between patient and HCP, with the wastage of medicines being the resultant benefit. It was felt that, if used, patients would have a more in-depth knowledge and understanding of what they are taking and the reasons for it, empowering them to have more confidence in taking responsibility for their own health.

“Although some patients ask obscene questions, I still prefer the patient to care about their health and medication and ask the questions. The plain and simple fact is that greater understanding result sin what we call ‘concordance.’ The patient is more likely to take the medication.”

– Hospital Doctor

A further benefit envisaged by some HCPs was reduced trial and error due to a greater awareness of contraindications, although most also acknowledged it to be part and parcel of the medication process, in that unforeseen side-effects would always be apparent for different individuals, especially with more complex drugs such as anti-psychotics. It was thought that the website could also potentially create greater clarity around contraindications, especially with the highlighted concern around ‘polypharmacy’ especially for the elderly.

“There needs to be trust between a patient and a doctor so that they understand why they are taking the medicine and thus actually take it. This issue of ‘concordance’ is
vital in healthcare. I’ve been round people’s houses and opened up draws stuffed with medicines that have not been taken, it’s such a waste!”

− Hospital Doctor

A couple of participants thought that the HCP-patient relationship and consultation dynamic would improve as the latter would be more informed and aware leading to a more open and collaborative approach to treatment.

“I believe in a truly open relationship with my patients. A website like this would add to the transparency that I advocate and this can only be for the better. If a patient is more informed he is more likely to follow what is advised, leading to a stronger relationship going forward.”

− GP

Overall, HCPs felt that the database should in no way replace the relationship between the patient and the HCP who were there to act as the ‘mediators’ and ‘qualifiers’ of the information. The dangers of treating the information out of context were noted by a number of participants. However, the database was viewed as a desirable aid to make the interaction more meaningful.

“As a doctor, I need to contextualise the information, otherwise my patients will jump to unfounded conclusions and that would cause all manner of problems.”

− Hospital Doctor
3. Patients, ‘well’ public and carers

3.1 Provision of medical information in general

*Current need and usage of information on medicines*

At the beginning of the focus groups and depth interviews patients, carers and the ‘well’ public were asked about the kind of information on medicines and related products they need or use. Overall, patients and carers wanted more information about medicines especially when they are prescribed or for a longer term condition. The importance of this information for these individuals tended to be high as it increased their awareness - of compatibility, dosage and side affects – and also allowed them to manage their health.

“It is really important for me as I want to know how it will work, when I need to take them in the day and if I need to know any side affects.”

- Patient, Scotland

“Knowing the ingredients of new medicines is crucial form me as I need to be 100% sure about compatibility.”

- Patient, England

Carers tend to need similar information but also want more clarity around directions of usage for those they are caring for. A number of parents who care for their children have raised the need for more information about the long term effects of medicines on the health and wellbeing of their children.

Across the three audiences, there was relatively less demand for (and use of information) for over the counter and non-prescribed medicines and products. Similarly, for repeat prescriptions and/or medicines that they know well, little or no information was required.

“I only need and read the information the first time I take a medicine.”

- ‘Well’ public, England

*Access to current information*

When asked about how they currently access this information, the majority cited advice from health care professionals (HCPs) especially their GP. A number of participants also mentioned hospital consultants, pharmacists and specialist nurses. It was apparent that relatively older respondents were more likely to trust their HCP’s recommendation.

“I never think about looking at the box because my GP knows what I need to take for what. That is why I go to him in the first place.”
Patients with long-term conditions were especially knowledgeable about the medicines that they are taking and had done a lot of prior research in and around their treatment plans. Personal experience throughout the years was seen to have made them more aware of the different medicines available.

A significant number of people mentioned that they carry out research personally and/or via a family member or friend - both before and after purchasing - into medicines and related products. Most of this tends to be through internet searches, reading the Patient Information Leaflets (PILs) and/or referring to medical encyclopaedias. A few stated that they frequently ascertained details from newspapers; the Daily Mail was the most common. The following participant cohorts were relatively more likely to carry out such research:

- Higher socio-economic groupings (i.e. B and C1),
- Carers,
- ‘Well’ public,
- Parents,
- 35-50 year olds, and
- Rural participants

It was interesting to note that while some with long-term conditions did carry out research, most were very trustful of their GP, specialist nurse or consultant.

Those undertaking online searches often begin their searches by typing in symptoms or names of medication into search engines; Google was the most popular. The participants then navigate through the results offered, which tend to be medicine guide sites such as Medguides. A small number had visited chat forums, pharmaceutical companies and American websites (such as Family Doctor). Most of those using this medium were unsure about the authenticity and credibility of such websites. Several said that the details on side effects, directions of usage and compatibility were not always easy to find.

“I would say there are gaps online {in terms of the information} as you don’t always find everything you need on the same site.”

- Carer, N. Ireland

The majority of participants deemed NHS and government sources to be most trustworthy as compared to corporate sources and/or personal recommendations.

“You don’t know how accurate the information is or if the medicine is properly licensed in the UK.”

- Carer, N. Ireland
3.2 Usage and views of Summary of Product Characteristics and Patient Information Leaflets

During the focus groups and depth interviews, the participants were informed about the role of the MHRA. There was little awareness among the target audiences about the organization or its role. However, the participants were unanimous in their opinion that the MHRA had a unique and important remit.

Perceptions of PILs

Focus group attendees and interviewees were given copies of PILs and asked if they had seen and used these before. Almost everyone engaged in the fieldwork had seen a PIL before. The majority had come across a PIL inside the packaging of medicines. Most had read a PIL for directions of usage and side effects: only a very small minority said that they read PILs regardless of their familiarity or the number of times they had taken the medicine before.

“Once I have read them, I don’t read them every time I get a new prescription. What’s the point, the tablets look the same...I just throw them in the bin.”

- Patient, England

The analysis of the feedback generated from the fieldwork with patients, carers and the ‘well’ public, suggested no discernable differences between who tends to read PILs more often. It seems to be dependent on the individual and their inherent attitude and behaviour. For instance, while some patients with long term conditions referred to PILs regularly others said that they didn’t read them at all. At the same time, participants with HIV were the most concerned and proactive in terms of reading PILs to minimise/eradicate potential contraindications.

Views on the content, layout and language of PILs varied. A large number of participants felt that the information they needed or wanted was provided on these leaflets. However, there was an overwhelming consensus that PILs can be difficult to read for a number of reasons. Firstly, the participants across the fieldwork locations were particularly critical of the long list of side effects listed for most medicines. They thought that this can create unnecessary anxiety and raise further questions.

“You have to worry about all those side effects even from an aspirin.”

- ‘Well’ public, Scotland

“Why can’t there be a clear description of how likely each of those side effects is?”

- Patient, England
Spontaneously, participants were also critical of the font size and different layouts employed. Many commented that they were put off by the different sizes and shapes employed by the PILs in circulation. Not surprisingly, they preferred PILs with bigger fonts, clear headings and imagery/symbols (such as the warning one).

“I like the symbols as they make it easier for me to find my way around all that text.”

- Carer, N. Ireland

When told about the recent work carried out to improve PILs, all participants were unaware of this. However, when asked if they had noticed any changes only a small number felt that the layout and font size had improved somewhat.

It is important to note that participants, in general, perceived PILs to be comprehensive in terms of content; they thought that if any specific information was needed then the leaflet would most likely have it. Indeed, apart from the suggestion of making the side effects section more meaningful, there was no other idea put forward to improve current content.
3.3 Perceptions and ideas for the MHRA online offer

Views on the online database

The focus of the qualitative research with patients, the ‘well’ public and carers was to determine the desirability for an online database of PILs, and then to seek their views on its appearance, functionality, location and marketing.

A large majority of those engaged in the fieldwork were in favour of the online database being proposed by the MHRA. This was mainly due to a number of perceived benefits. Firstly, there was a common feeling that the online database would fill the void of a lack of credible online resource on medicines and related products.

“I do worry about how accurate the information is online….a centralised website would make be more confident about the advice and support available.”
- ‘Well’ public, Scotland

Secondly, a large number of those engaged mentioned that the internet was ideally suited for hosting such an online database. This was not only because it was seen to be easily accessible but also in sync with the growing role and influence of the internet. Quite a few of those who were not currently using the internet (due to either lack of interest or knowledge) thought that the current trend in the medium’s popularity will result in “everyone using it for all kinds of things in the future.”

Thirdly, several participants from the carer target group (and some patients who were receiving care from families and friends) thought that the online database would enable carers to fully understand the medicines and related products being taken by those receiving their care.

“I am not always present when my wife sees the GP. This website would be a good way for me to get answers to the questions I often have but cannot ask.”
- Carer, Northern Ireland

“My children are always trying to ask me about the medicines I get prescribed…the website will let them read about that.”
- Patient, England

It was also asserted that having an online database of all PILs in circulation would allow the public to refer to it whenever they needed to. Many thought that the paper copies were difficult to store over a period of time.

“You can lose them and then you are really stuck if you need ‘em!”
- ‘Well’ public, England
“When you are ill or in pain, you can’t be bothered to read the information in the boxes. But this website will let people read up the details after they get better.”

- Patient, Scotland

Potential benefits
Some participants agreed that the new website might make it easier for them to manage their health. The explanation provided was that they would be able to use the website to better understand the medicines that they were taking or could take. They stated that the provision of any additional information in this regard can only be a good thing for patients and the public.

“If I found something on the website that was different to what I was being told by my doctor then I could challenge them more confidently. At the moment, it is not always easy to ask questions or to ask for clarification.”

- ‘Well’ public, Scotland

On several occasions, it was mentioned that the website could be particularly useful for patients with polypharmacy. The main explanation provided was that they would not only be able to understand how each medicine actually works but also the potential risks and benefits of using other medication at the same time.

“The website could be useful in guiding patients in knowing how and when to take more than one medicine. It can be very confusing even after being on so many pills for 4 years.”

- Patient, England

A couple of the patients with polypharmacy went as far as to say that they would be more likely to take all their medicines if they knew about what the medicine did and its importance.

Potential drawbacks
When asked, the participants could not think of any potential drawbacks of the website. They felt that because this was an initiative by a credible government agency, the website content would be accurate and unbiased. Indeed, about 70% of all the engaged participants (patients, carers and the ‘well’ public) raised their hands when asked if they would actually utilise this online database.

The ones who were reluctant to use it often cited their dislike and/or unfamiliarity with the internet as well as deference to the advice and support provided by their GP or other HCP.

“I don’t need or want extra information. That is what my doctor is there for. What’s the point of having a doctor then?”
Carer, N. Ireland

“If the PILs are still going to be in the boxes, I don’t see why we need them online as well?”

- Carer, N. Ireland

“Views on location”

During the focus groups and interviews, participants were asked to decide on the location of the online database and the most appropriate mediums by which to market it to the wider public. In terms of location, the vast majority wanted an independent website with NHS accreditation and branding. There was consensus that the address of the site would need to be memorable. It was also stated that the address should directly convey the primary focus of the website.

“We think it should be called: ‘knowyourmedicines.gov.uk’”

- ‘Well’ public, England

As already outlined, those engaged wanted the website to have NHS or government accreditation. This was both in terms of the content style and the web address. They strongly believed that this would reassure the visitor of its authenticity. A few thought that the database should be located on an existing NHS website that caters for patient and public information need. They tended to be adamant that existing websites - such as NHS Direct and NHS 24 - are well established, and would therefore, provide the most appropriate location.

Interesting debates took place between participants in focus groups on the need to have links to other websites. While some thought that the primary focus of the website should be to provide information on medicines and related products, a sizeable majority thought that additional information on health and wellbeing issues could be imparted to visitors. Some of these individuals were favourable to the website itself hosting such information; others thought links to other sites could be provided on the side banners.

“As a lot of people would be coming to the website, it would make sense to give information on quitting smoking, eating healthy and exercise.”

- Carer, N. Ireland

“Potential marketing and communication strategies”

Patients, carers and the ‘well’ public proposed an array of marketing techniques to increase awareness and usage of the website. The most common suggestions were TV, radio and press campaigns. Many had seen the NHS Direct and the Swine Flu awareness raising drives and felt that something similar needed to be invested in. It was interesting to note that most of these individuals recognised the potential cost of such mediums.
“We know it will cost a lot but this is a matter of life and death. People need to know about this website. There may be a lot of people on the wrong medication who don’t know anything about what they are taking.”

- ‘Well’ public, England

Participants were keen on the role that HCPs could play in encouraging the public to frequent the website. In particular, they viewed GPs as an important partner in ‘getting the word out’ to patients. Similar to the feedback provided by HCPs, leaflets and posters in surgeries and pharmacies were also commonly cited. A few of the innovative ideas centred on printing adverts on the packaging of medicines. The individuals who put this forward said that pharmaceutical companies could be called upon to print this mandatorily.

**Views on content**

During discussions with participants from the differing target audiences, the content of the online database was ascertained. Generally, the feedback suggests that details on how the medicine works, directions of usage, side effects and compatibility with other medication are the most needed. A few of the participants wanted wider information on health and wellbeing to be available as well; simple narratives on different health conditions were also mentioned.

It was felt by a large number of people that patient forums and reviews of medication should also be a feature of the online database. The latter was especially popular with patients, carers and the ‘well’ public. However, there were occasions where other participants felt that this would dilute the focus of the website and would also be difficult to administer.

“I think only negative comments will be left for medication.”

- Carer public, N. Ireland

“What works for one person may not work for another. This is why getting advice from a qualified health professional is so important in guiding patients.”

- ‘Well’ public, England

There was widespread support for having two distinct sections – one for HCPs and the other for the public – among the participants. It was felt that due to the varying needs and understanding between the two cohorts, the information would need to be presented in a targeted manner. It was evident that participants wanted the same site to cater for both, rather than having an entirely separate location for the HCPs.

In terms of the amount of detail, there was a consensus that the website should offer simple and concise information. Overall, participants wanted basic information to be provided with the option to delve in to more detail.
“The reader should not be overloaded with information as they will probably have more concerns than they did in the first place.”

- ‘Well’ public, Scotland

The majority wanted the same level of information to be presented in the paper PILs. Ensuring consistency was important for most of these individuals. However, there was a consensus that the layout of the information should be different: the key information (i.e. directions of usage and potential side effects) should be at the top and eye-catching.

“Anything on side effects and dosage should be right at the top. Everything else should follow.”

- Patient, England

Those who preferred the online database to offer additional content to the paper PILs tended to want supplementary information on the medication (i.e. who manufactures it, how long it had been in usage, previous issues with/expiry of the license and the results of clinical trials that it had undergone). The price of each medication to the NHS (as well as the private patient) was also cited a number of times. Some thought that knowing relative prices of the medicines would help them to understand the prescribing behaviour of their local HCPs (particularly GPs).

“Anything on side effects and dosage should be right at the top. Everything else should follow.”

- Patient, England

**Views on appearance**

In terms of appearance, the analysis of the feedback indicates that participants would like something similar to Wikipedia. They asked for a contents page that would help them to navigate between sections such as dosage, directions of usage and so on. They also wanted Meta tags for medical terminology and other jargon.

“It would be good if the definition of a word would come up in a box as the mouse cursor was hovered on top of it.”

- Patient, England

In addition, a large number of participants encouraged the use of images and symbols to supplement text. Having photographs of the pills and/or the packaging was seen to be important because pharmaceutical companies employ different shapes, sizes and colours for the same product.

**Views on functionality**

To maximise the usefulness of the online database, participants were asked about the kind of functions they would expect from the site. The most commonly mentioned was the search facility.
The vast majority wanted a detailed search function, which could help them to access information according to condition (i.e. symptoms) and product name. Most thought that the latter would have to recognise the official brand name as well as the generic one. On a couple of occasions, an Ask Jeeves kind of interface was suggested.

“There could be a space where you would type in your question and it would bring up the most relevant results or answers.”

- ‘Well’ public, Scotland

Participants would like the ability to compare and contrast the characteristics of more than one medicine at a time. They thought that the screen could be split so that you could have each of the medicines on either side and could compare them on a standard template. In the event of any of the medicines being reviewed being incompatible, the participants wanted the website to alert the user. They also thought this function was critical in making sure patients do not misdiagnose themselves.

The option of emailing a particular section to a family or friend (similar to recommending an article on the Guardian’s website) was also quite liked. It was felt that this could be useful for the patient to share information with their loves ones in a very simple manner.

A Frequently Asked Questions (FAQ) page and an update facility which could clearly provide latest information on a medication or condition were popular requests. The former was seen to be a main prerequisite as it would provide answers to the user’s questions quickly. Similarly, a number of participants stated that medicines (and science as a whole) are advancing rapidly. Therefore, it would be important to alert current and potential users of a medicine or a product of any change in its constitution.

“A box should pop up to notify you that something has changed. It would have to be really direct or else it could be missed.”

- ‘Well’ public, Scotland

Some participants also suggested that users of the online database should be able to save their searches from previous visits. A few even thought that a personalised space could be created if users wanted to save the information they had referenced before.

Being able to increase the text (font) size and print off the whole PIL or a section of it was also frequently mentioned. The former was seen to be important for those with visual impairments. The idea of an iPhone application was also advocated by a number of participants.

It was interesting to note that a small number of individuals perceived the role of the website to not only provide information on medicines, but also to offer advice on their overall health concerns and issues. For example, it was put forward that a ‘chat window’ could be provided for visitors to seek
answers from qualified professionals to user concerns in real time. This was challenged spontaneously by other participants who believed that this would not only cost a lot but would also dilute the primary focus of the site.
3.4 Wider benefits to patients, HCPs and the NHS

At the end of the focus group and interview discussions with participants, it was asked if the online database would offer any wider potential benefits to the public, HCPs and the NHS as a whole.

Potential benefits for non-HCPs

When thinking about the possible benefits to the public, there was a widespread belief that they would have a more detailed understanding of their medicines and why they were taking them. Greater ownership and responsibility for their own health was perceived to be a potential outcome in this regard.

“Those who don’t complete their medication or just stop would be able to see the risks of their behaviour.”

- ‘Well’ public, England

Participants also thought they would be able to have a greater choice and say in the most appropriate medicines for their condition(s). Indeed, it was stated by a few that they believed the HCP-patient relationship and consultation dynamic would improve as the latter would be more informed and aware (both before and after seeking advice from qualified HCPs).

A number of individuals felt they could challenge the advice or prescription of HCPs more meaningfully and confidently if they had the content of the website to refer to. Such respondents felt the risk of being misdiagnosed or being treated through trial and error could be mitigated. Some who had had negative experiences before were most likely to put this view across.

Comments were also made about the possibility of reducing barriers that can sometimes discourage patients from seeking medical advice and support. It was believed that they could do the research on the website beforehand to allay any concerns.

“Going to the doctor can put people off...after all who likes to think about getting some bad news? Sometimes knowing that you can be treated without needing an operation or hospitalisation can be uplifting.”

- Carer, N. Ireland

Potential benefits for HCPs

It was more difficult for participants to outline potential advantages for HCPs and the NHS. However, it was stated that patients would be less likely to feel rushed in consultations as they could have a more meaningful discussion about medicines and treatment plans with the HCPs. The option to read
the information before, during and/or after the interaction with the HCPs was seen to be especially advantageous.

With the assumption that patients would be more likely to take their medication as well as to self-diagnose for minor ailments, a reduced burden (financially and capacity wise) was expected as a positive result of the database.

“A lot of needless appointments that are made by over-concerned people could be reduced.”
- ‘Well’ public, England

At the same time, it was interesting to note that many asserted that nothing could compare (or replace) the importance of direct contact between the HCP’s and the patient. However, the database was viewed as a desirable aide to make the interaction more meaningful.
4. Key conclusions and recommendations

As outlined, patients, carers and public participants felt that nothing could compare to the benefits of direct contact between the HCP’s and patients. However, the database was viewed as a desirable aide to make the interaction more meaningful. The findings emanating from the interaction with various HCPs and patients, the ‘well’ public and carers suggests that there is significant support for an online database.

In exploring the reasons behind this, it is evident that even though HCPs can identify professional benefits, they largely focused on the potential benefits for their patients. This is a key learning as it throws up a number of considerations. Firstly, it will be important that the site is patient focused and accessible for their needs and expectations.

Secondly, even though there is consensus that the information needs to be different (in terms of detail) for HCP and non-HCPs, it is imperative that all sections are perceived to be open and accessible. Any “hidden sections” may inadvertently create suspicion amongst users.

We would propose that the content of the online database includes (as a minimum) all the information currently on offer on PILs. At the same time, supplementary information, as discussed in the report, needs to be provided as well. This would help in ensuring that the database caters for the needs of different patients, with varying preferences for the level of detail. At the top end of the spectrum, there should be added information on the following:

- Background information on the medication (length of license)
- History of drug and clinical trials
- Composition (ingredients) of medicines
- Price

Such added information would not only fulfil the expectations of certain patients but would also provide advantages to healthcare professionals.

In order to be seen as independent, credible and trustworthy the online database should be part of and/or linked to an already established NHS information portal. The views expressed by those engaged indicate that NHS Direct or NHS 24 may by suitable options. Moreover, having an NHS logo and generic branding on the site would be advisable. We also suggest that the URL of the online database includes either ‘NHS’ or ‘GOV.UK’ as this would aid in conveying credibility.

Another key learning from the research is that the functionality and appearance of the online database has to be similar to other popular websites used for information collation i.e. Wikipedia. In particular, the option of being able to navigate between the different sections and accessing the exact information through indexing would need to be a key feature.
We would strongly advocate that the online database offers some inherent intelligence in highlighting potential risks (contraindications) of using two or more medicines at the same time. This is pertinent as many participants experiencing ‘polypharmacy’ felt that they would use the site if it offered such a feature. The database should also be developed so that it provided up to date information and news alerts in a timely and direct manner.

In order to increase the perceived utility of the website and its contents, we recommend that links to other websites imparting information on health and wellbeing (i.e. eating, exercise, smoke cessation and so on) are hosted. The added facilities to increase font size, print information and invite others to look at a particular medicine also need to be considered.

The marketing strategy required to raise awareness about the new site needs to convey a number of messages. Firstly, that it is UK based and caters for information needs on medicines and related products in current circulation. Getting this across is crucial as engaged participants are adamant about having an information portal for the UK. Secondly, the images or text in the messages need to get across the following impressions about the online database

- Authoritative
- Objective
- Credible
- Up-to-date
- User-friendly
- A one-stop shop for information on medicines

Potential benefits of using the website – such as informed choice, empowerment and personal control – need to be the core messages. This will help in raising the perceived appeal and utility of the information and the website in the user’s perspective.

In terms of the possible mediums that could be used, the onus should be on ‘word of mouth’. In particular, getting GPs, pharmacists and other HCPs to inform patients about this website could be a very effective method. Additionally, using eye-catching posters and leaflets in NHS buildings and hospitals could also be a cost-effective route. Digitally, having links to the database from already established NHS and health-related websites and HCP intranets would be recommended.

The idea of advertising the website on the PILs and the packaging of medicines and products is worth pursuing. Of course, if resources permit, TV, radio and print advertising are other methods that have been used successfully in the past by various Department of Health and other government departments.
Appendix 1:
Focus Group Discussion Guide (Patients, Carers and the ‘Well’Public)

Medicines and Healthcare products Regulatory Agency
Qualitative research with stakeholders on providing regulatory information about medicines online

‘Well public’ focus group agenda – 1.5 hours – 7.45 pm start

<table>
<thead>
<tr>
<th>Timing</th>
<th>Item</th>
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<tbody>
<tr>
<td>19.30 – 19.45</td>
<td>Arrival and registration</td>
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<tr>
<td></td>
<td>• Participant badge</td>
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<tr>
<td></td>
<td>• Tea/coffee/refreshments</td>
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<tr>
<td>19.45 – 19.50</td>
<td>IN PLENARY: Welcome and housekeeping (Opinion Leader lead facilitator)</td>
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<tr>
<td></td>
<td>(5 mins)</td>
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<tr>
<td>Facilitator to:</td>
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<tr>
<td></td>
<td>• Welcome and thanks for attending</td>
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<tr>
<td></td>
<td>• Briefly explain what the focus group is all about (presence of MHRA observers, if any)</td>
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<td></td>
<td>• Reassure confidentiality: explain the role of facilitator and independence</td>
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<td>• Rules of the session:</td>
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<td></td>
<td>• No right or wrong answers</td>
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<td></td>
<td>• Please respect each others views</td>
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<td></td>
<td>• Make time to hear from everyone</td>
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<td></td>
<td>• Details of refreshments</td>
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<td>• Toilets, health and safety regulations</td>
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<td>• Mobiles off</td>
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<td>• Ask permission to record the group</td>
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<tr>
<td>Timing</td>
<td>Item</td>
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<tr>
<td>19.50 – 20.05</td>
<td><strong>Introductions (ice breaker) and general discussion: (15 mins)</strong></td>
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<td></td>
<td><em>Ask participants to get into pairs and task them with recording the following about each other:</em></td>
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<tr>
<td></td>
<td>• Introductions – Name, where do they live, what would they be doing if they were not here</td>
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<td></td>
<td><em>After 5 mins::</em></td>
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<td></td>
<td>• Each pair introduces each other in turn</td>
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<td>Timing</td>
<td>Item</td>
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<tr>
<td>20.05 – 20.25</td>
<td><strong>DISCUSSION SESSION: Ways in which participants currently find out information on their health, medicines and related products:</strong> <em>(20 mins)</em></td>
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<td></td>
<td>• Facilitator to ask and flipchart responses:</td>
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<td></td>
<td>• What are your health concerns? Who do you talk to about these? <em>(probe on family, friends, GPs, online, newspapers/magazines and also on whether it depends on the issues/concerns)</em></td>
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<td></td>
<td>• What is a trustworthy source of such information? <em>(probe corporate vs. government sources of information vs. personal recommendations from friends and individuals’ reviews online)</em></td>
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<td></td>
<td>• Are your needs around the provision of such information being met? <em>(probe on any gaps)</em> How much of an issue is this for you?</td>
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<td>• What sort of medicines do you buy at the pharmacy and supermarket/other shops? <em>(probe on differences in the kind of items being purchased between the two locations)</em></td>
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<td></td>
<td>• In relation to medicines, where do you get advice and information?<em>(GP, pharmacy, nurse, hospital doctor, friend, internet, insurance companies)</em></td>
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<td>• Does this change depending on the type of health problem that you are experiencing? <em>PROBE on level of seriousness and sensitivity of the health problem</em></td>
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<td>• Before buying a prescription or over-the-counter medicines/products, have you ever carried out any research in to product(s)? If so, describe your experience?</td>
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<td>• What sort of information are you looking for? Do you find it? Is this easy or difficult?</td>
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<td></td>
<td>• Has anyone ever used the internet to carry out such research about medicines? <em>(For those who have, probe on what kind of information were they seeking, did they find it, overall satisfaction: positive and negative aspects of their experience)</em></td>
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<td></td>
<td>• <em>(For all)</em> Where would you expect to find such information online?</td>
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<td>Timing</td>
<td>Item</td>
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| 20.25 – 20.40 | **IN PLENARY/DISCUSSION SESSION:** Explain the role of the MHRA/provide detail on the objectives of the current project and collate attitudes/top of mind views on desirability for an online database. *(15 mins)*

- *Facilitator to: (5 mins)*
- Explain the role of the MHRA
- Set out the aims and objectives of the overall project, and the focus group specifically
- Hand out a copy of a Patient Information Leaflet (PIL). *(seek spontaneous reactions and then probe if they have seen these before? Do they find content, layout and language useful?)*
- *Explain that PILs are regulated and the MHRA reviews the information on them before companies can use them*

*Facilitator to probe top of mind views on an online database and desirability: (10 mins)*

- Have you come across PILs? Where do you usually come across them? In what circumstances would you need to access it?
- Do you usually read them? If yes, probe which bits do they read (all of the PIL, just the ones prescribed by pharmacists, for new medicines only)
- If no, why don’t you read them?
- What do you think about the idea of having patient information leaflets on medicines online for the public? *(probe on whether they think there is a need for this kind of information online and whether the internet is an appropriate place to access this information)*
- What would be the benefits and drawbacks? *(flipchart feedback-inform participants we will come back to this in a later session)*
- Do you currently use any online sources of medicines information? What are your thoughts on them – strengths/weaknesses/anything missing? PROBE NHS Direct Online, NHS Choices, DIPEX, patient.co.uk, BUPA, BBC health pages
  - Do you feel that they already provide you with the information that you need? Why/why not?
- Would you use such an online database? *(Ask for a show of hands and record; probe on what circumstances they would use it and would it fulfil their information needs)*
- If not, why not? What would hold you back from using it?
### DISCUSSION SESSION: In-depth views on the online database (25 mins)

- Facilitator to introduce the session as an opportunity for everyone (regardless of their overall view on the desirability) to feedback on the key features of the database?

- Ask participants to work in groups of three and provide them with a template to design/draw their ideal online database with the following considerations in mind (7 mins): “If you were in charge of developing this what would you do in relation to...”:
  - **Website location** - would it be independent or part of another existing site i.e. MHRA with links to other websites?
  - **Marketability** – how would the wider public be informed about the existence of the new website

Each individual group to present their ideal website to whole group (6 mins); After completion facilitator to pick out similarities and differences (2 mins).

**Facilitator to probe whole group on:** (10 mins)

- **Content** - what kind of information would be most useful to you? *(probe on dosage, side effects and so on)*;
  - What level of detail should the information offer? *(probe on whether similar detail/less to the PIL)*

- **Functionality/appearance** – What kind of functions should the website offer? *(probe on a search facility, an online forum, a FAQ page, links to other websites, news and updates and so on)*
  - How would you like to access/search for the information? (product name or disease type or other)?
  - How should the information appear on your screen (text only or images)?
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<th>Timing</th>
<th>Item</th>
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<tr>
<td>21.05 – 21.15</td>
<td><strong>DISCUSSION SESSION: Overall benefits for the public and NHS (10mins)</strong></td>
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<tr>
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<td><em>Facilitator to re-introduce earlier question on the benefits of having an online database</em></td>
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<td></td>
<td>• If members of the public and patients are able to carry out more research into medicines and their health conditions, what kind of benefits will the following see:</td>
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<td>o Individual patients</td>
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<td>o GPs, nurses, hospital doctors and pharmacists</td>
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<td>o The NHS</td>
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<td></td>
<td><em>(Seek spontaneous views first, and then probe on potential benefits such as patient empowerment and choice, more informed patient/health care professional discussion, reduced trial and error, matched medicines, treatment by proxy, greater ownership/responsibility of personal health, larger focus on prevention, reduced burden on HCP/NHS system)</em></td>
</tr>
<tr>
<td>21.15</td>
<td><strong>FINAL THINGS: Thanks, next steps and incentives</strong></td>
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<td>Ask them to complete MHRA re-contact form</td>
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</table>
Appendix 2:
Focus Group Handout (Patients, Carers and the ‘Well’ Public)

Online database exercise sheet

Date of focus group/interview: ..........................
Location: ..........................

“If you were in charge of developing this online database what would you do in relation to...”

Website location:
(would it be an independent standalone website or part of an existing one such as the MHRA?)

Marketability:
(how would the wider public be informed about the existence of the new website? What methods would you use?)
Appendix 3:

Interview Discussion Guide (Patients, Carers and the ‘Well’ Public)

Medicines and Healthcare products Regulatory Agency

Qualitative research with stakeholders on providing regulatory information about medicines online

Patients’ discussion guide

- What kind of information on medicines and related products do you need/use?
  - Does this change depending on the type of health issue/concern? PROBE on level of seriousness and sensitivity of the health problem
- How important is this information for you?
- How do you find this information? Who do you talk to about this? (family, friends, carers, colleagues, GPs, online, newspapers/magazines and also on whether it depends on the issues/concerns)
- What is a trustworthy source of such information? (probe corporate vs. government sources of information vs. personal recommendations from HCPs, other patients, friends and individuals’ reviews online)
- Are your needs around the provision of such information being met? (probe on any gaps) How much of an issue is this for you? (probe on the barriers and frustrations they may encounter)
- Before buying a prescription or over-the-counter medicines/products, have you ever carried out any research in to product(s)? If so, describe your experience?
  - What sort of information were you looking for? Did you find it? Was it easy or difficult?
- Has anyone ever used the internet to carry out research about medicines? {For those who have, probe on what kind of information were they seeking, did they find it, overall satisfaction: positive and negative aspects of their experience}
- {For all} Where would you expect to find such information online?
Explain the role of the MHRA/provide detail on the objectives of the current project and collate attitudes/top of mind views on desirability for an online database.

- Explain the role of the MHRA
- Set out the aims and objectives of the overall project, and the focus group specifically
- Hand out a copy of a Patient Information Leaflet (PIL). (*seek spontaneous reactions and then probe if they have seen these before? Do they find content, layout and language useful?)
- *Explain that PILs are regulated and the MHRA reviews the information on them before companies can use them*

**Probe top of mind views on an online database and desirability**

- Have you come across PILs? Where do you usually come across them? In what circumstances would you need to access it?
- Do you usually read them? If yes, probe which bits do they read (all of the PIL, just the ones prescribed by pharmacists, for new medicines only
- If no, why don’t you read them?
- What do you think about the idea of having patient information leaflets on medicines online for the public? (probe on whether they think there is a need for this kind of information online and whether the internet is an appropriate place to access this information)
- What would be the benefits and drawbacks? Would it make it easier for you to manage your health in any way? If so, how?
- Would you use such an online database? If not, why not? What would hold you back from using it?

**In-depth views on the online database**

- *Facilitator to introduce the session as an opportunity for everyone (regardless of their overall view on the desirability) to feedback on the key features of the database?*
- Ask participants to work in groups of three and provide them with a template to design/draw their ideal online database with the following considerations in mind (7 mins): “*If you were in charge of developing this what would you do in relation to...*”:
  - **Website location** - would it be independent or part of another existing site i.e. MHRA with links to other websites?
  - **Marketability** – how would the wider public be informed about the existence of the new website
  - **Content** - what kind of information would be most useful to you? (*probe on dosage, side effects and so on*);
    - What level of detail should the information offer? (*probe on whether similar detail/less to the PIL*)
- **Functionality/appearance** – What kind of functions should the website offer?
  (probe on a search facility, an online forum, a FAQ page, links to other websites, news and updates and so on)
  - How would you like to access/search for the information? (product name or condition type or other)?
  - How should the information appear on your screen (text only or images)?

**Overall benefits for the public and NHS**

- If members of the public and patients are able to carry out more research into medicines and their health conditions, what kind of benefits will the following see:
  - Individual patients
  - GPs, nurses, hospital doctors and pharmacists
  - The NHS

(Seek spontaneous views first, and then probe on potential benefits such as patient empowerment and choice, more informed patient/health care professional discussion, reduced trial and error, matched medicines, treatment by proxy, greater ownership/responsibility of personal health, larger focus on prevention, reduced burden on HCP/NHS system)
Appendix 4:

Interview Discussion Guide (Health Care Professionals)

Medicines and Healthcare products Regulatory Agency

Qualitative research with stakeholders on providing regulatory information about medicines online

Healthcare professionals depth interview discussion guide – 30-40 minutes

Interviewer to:

- Thank participant for agreeing to take part
- Introduce aims of research
- Emphasise informality of discussion and reassure about confidentiality
- Gain permission to record for Opinion Leader purposes only
- Ask participant to introduce themselves and their professional role

Provision of medical information in general

- What are the most common health concerns that you speak to patients about? Are you aware of anybody else that they speak to about their problems? *(probe on family, friends, GPs, online, newspapers/magazines).* Preventative vs. solutions?
- What is the process that you go through in discussing treatment and medicine options with patients? Is it different according to medical cases/conditions?
- How much do patients know about medicines? Do they self diagnose and come up with a suggested prescription? What information have they accessed? Does this tend to be accurate/correct?
- Do patients challenge you on your recommended prescription?
- Do you currently use any sources of medicines-related information, stimulus or aides when seeing/assisting patients? If so, which do you find the most useful/trustworthy?
  
  PROBE:
  
  - Traditional print media – e.g. British Medical Journal
• Online media (medical)
• Online media (consumer)
• Medical symposium / meetings
• Online / virtual meetings
• Online / virtual sales representative presentations
• Social / professional networking
• Pharmaceutical representatives

- Do patients want more information about medicines; do they ever ask for information/use it?
- Have you ever referred them to any websites for more information about medicines?
- Are your needs around the provision of such information being met? PROBE ON ANY GAPS. How much of an issue is this for you/does it impede on your interaction with patients?
- Before advising on prescriptions or over-the-counter medicines/products, have you ever carried out any research into product(s)? If so, describe your experience?
  - What sort of information were you looking for? Do you find it? Is this easy or difficult?
  - How did you use the information? PROBE: Did you use it in meetings with other professionals or when in contact with patients?
- What are the trustworthy and useful sources of such medicines information for you as a professional? (probe corporate vs. government sources of information vs. personal recommendations from peers)
- Do you talk about medicines information sources/provision with colleagues? What are the frustrations?

Use of online resources

- Do you currently use any online sources of medicines information? PROBE: what kind of information were you seeking, did you find it, overall satisfaction: positive and negative aspects of their experience
  - How did you use the information? PROBE: Did you use it in meetings with other professionals or when in contact with patients?
  - Do you feel that they already provide you with the information that you need? Or information that you could provide to the patient to refer to? Why/why not?

PROBE:

Hospital Doctors/GPs: British Medical Association, Electronic Medicines Compendium, Doctors.net.uk, NICE, Royal Society of Medicine, General Medical Council, PubMed, NHS National Library for Health, Bandolier, British National Formulary, Clinical Knowledge Summaries (CKS), Clinical Evidence, Best Treatments, Doctor Online, Intute: Health and Life Sciences, Royal College of Medicines sites, NHS Evidence
Pharmacists: [ask pharmacists if they refer to the PIL when talking to patients/customers]; Royal Pharmaceutical Society, Electronic Medicines Compendium, British National Formulary, Intute: Health and Life Sciences, TRIP Database, National Library for Health, NICE, FDA, National Pharmacy Association, NHS Evidence

Nurses: Internurse, Worldwide Nurse, Centre for Evidence-based Nursing, Nursing and Midwifery Council, Electronic Medicines Compendium, The MHRA online offer

- Are you aware of the MHRA? Do you feel that you understand its role and remit? Probe on what this role is? What could its potential role be? What benefits would there be for HCPs/patients?
  - Is the provision of medicines information part of their remit?
- What is your view of the SPCs and Patient Information Leaflet (PIL) (seek spontaneous reactions) Do you use these? Where do you get them from? PROBE:
  - What is its value and need?
  - Do you ever refer patients to the PIL?
- Did you know that PILs must now reflect testing with target users to ensure people can find and use the key safety information in them? Were you aware of this initiative? Do you think this could improve PILs?
- These new PILs are now coming through the supply chain.
  - Do you think PILs are improving?
  - Do you find the content, layout and language useful?
  - Strengths/weaknesses?
  - Might you use new PILs more with your patients? How? What for?
- Where would you expect to find this kind of information? In what circumstances would you need to access it?

MHRA are thinking about developing an online resource to provide such information.

- What do you think about the idea of having regulatory information on medicines and products online for healthcare professionals? PROBE:
  - Do you think there is a need for this kind of information online?
  - Do you think the internet is an appropriate place to access this information?
  - What would be the benefits and drawbacks?
- Would you use such an online database? What circumstances?
- If not, why not? What would hold you back from using it?

“If you were in charge of developing this, what would you do in relation to…”
  - Website location - would it be independent or part of another existing site i.e. MHRA with links to other websites?
- **Marketability** – how would the wider public/other HCPs be informed about the existence of the new website
- **Content** - what kind of information would be most useful to you? *(probe on dosage, side effects and so on)*;
- **Functionality/appearance** – What kind of functions should the website offer? *(probe on a search facility, an online forum, a FAQ page, links to other websites, news and updates and so on)*
  - How would you like to access/search for the information? (product name or disease type or other)?
  - How should the information appear on your screen (text only or images)?
- Are there any other features that you would be looking for? E.g. e-updates on new medicines and on those about to reach their patent expiration date, networking with other HCPs
- Do you think that there is a need for having differences in how the information is presented to the healthcare professionals and the public/patients? What difference would it make? *(probe on trust and simplicity)*
- If members of the public, patients and HCPs are able to carry out more research into medicines and their health conditions, what kind of benefits will the following see:
  - Individual patients
  - GPs, nurses, hospital doctors and pharmacists
  - The NHS

Seek spontaneous views first, and then probe on potential benefits:
- Patient empowerment and choice
- More informed patient/health care professional discussion and relationship
- Reduced trial and error and better matched medicines
- Treatment of patients who are too old or ill by proxy (by family and friends)
- Greater ownership/responsibility of personal health
- Larger focus on prevention
- Reduced burden on HCP/NHS system

**The future?**
- Do you think that the way HCP use online sources to find out about medicines will change in the next 5 years?
- Thinking about the information on medicines specifically, do you think that there will be a change in the ‘patient choice’ agenda in the coming years?
• What do you think are going to be the top three medicines issues affecting healthcare professionals in the next 5 years?