

Report on the MHRA Medicines Information Online Discussion

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Main conclusions

The online dialogue process itself worked well, and produced highly engaged and detailed contributions to the proposition, 'The Government's medicines watchdog want to put their comprehensive and up-to-date drug information online. Is this a good idea? How would you use it?' Overall participants made it clear that they thought having a comprehensive online medicines database is definitely a good idea. It would allow patients more freedom to be truly informed and take an active role in their healthcare and would help health professionals in their roles. The main issue was whether the online database should be created by the MHRA or if pre-existing databases, namely the emc, should be added to, in order to save duplication of effort and money. Any MHRA led database must justify its cost by demonstrating how it surpasses current databases, focusing on how the MHRA and only the MHRA can provide this database effectively and prove they can meet the commitment of keeping such a database up to date.

The following themes are discussed in more detail in Section Three of the report:

- Public access to an online database
- Duplication of existing efforts (emc and others)
- Functionality/ 'the database should include this'
- Help Health Professionals in their job
- Patient Safety
- Up to date
- Collaboration
- Money

Introduction

From 8th February 2010 to 8th March 2010, Delib ran an online discussion for the MHRA to research whether a proposal to make MHRA's PILs and SPCs information available online was a popular idea, and what that database might look like.

This report is designed to primarily do three things:

- 1) tell the story of the process that was run

- 2) outline the participation metrics of the dialogue
- 3) highlight the key themes and insights that emerged from this discussion

We think the exercise was fruitful, valuable and successful – especially as a first venture into new waters for the MHRA. We hope that this report makes it easy to understand the process that was run, the factors in its success and the ideas that it produced. We hope, in turn, this will encourage more, similar exercises in future with an intent to continuously improve consultation and opinion research processes, particularly to take account of the possibilities and audiences that exist online.

N.B. Because of the nature of online processes, this discussion was never intended to be a definitively representative, closely controlled market research exercise. Rather, it was deemed a valuable complement to offline market research processes which could 1) ensure that online audiences were listened to (important for a project dealing with online) and 2) potentially turn up new ideas, opinions or voices. Both we and the client think the project was successful in accomplishing these aims and it is worth remembering this context in reading this report – these findings cannot be reliably extrapolated to say anything about the population of the UK as a whole, for example; they should be understood, valued and assessed in a different way to traditional market research exercises. Because of this, this report mostly attempts to tell the story of the Discussion, presenting the information in a comprehensible and digestible way which we hope will lead to actionable insight.

If you have any questions or comments regarding this report, please contact Michaela Dennis: michaela@delib.co.uk | 0845 638 1848

1. Process/methodology

The Medicines Information Discussion was run using Delib's Dialogue platform.

Delib's dialogue platform is an online tool for facilitating open-ended, consensus-building discussion on any topic. It has been proven as an effective method for gathering high quality ideas and comments from large numbers of diverse participants.

The dialogue platform has the following key elements of functionality:

- Allows the client or a public user to submit an initial idea or statement which is then published on the website
- Allows other site users to read ideas or actions submitted and post their own comments, thematic tags and star ratings on them
- Allows client representatives or administrators to join in the public discussion with site users and moderate inappropriate submissions
- Surrounding the debate platform can be other static pages presenting introductory information, background documents for those that want to learn more, and links to other resources, all stored within a distinct microsite for the consultation.

The use of such a methodology and platform achieves the following key project objectives;

- Opens up an online channel and opportunity for participation – vital for this project to ensure people who are happiest communicating online are not precluded from contributing to the discussion
- Allows for value beyond simply 'temperature-taking', providing an ongoing, asynchronous, opportunity for the generation and discussion of ideas – enabling elements of crowd-sourcing and collaborative design to be incorporated into the exercise
- Collects participant demographic and location information for monitoring purposes, through the use of a very simple registration system

- Demonstrates transparency and openness, as the conversation takes place in public, rather than the content submitted falling into a 'black box' and only emerging again once passed through the filter of analysis
- Shows that opinions submitted are valuable and being listened to as they are responded to by other site participants and MHRA figures themselves
- Provides simple mechanics for a large volume of sustained participation, not only writing ideas but rating other ideas with a simple click.

The real value of any dialogue comes from its participants and their contributions: adding ideas, comments, tags and ratings. The strength of the system is that it operates like a good chairperson would: providing a clear proposition and purpose for the discussion while giving just enough structure to help people make sense of the discussion, allowing it to flow freely. The dialogue platform is designed to support organic, participant-driven discussion, for example, two of the key drill-down filters – the tagging and rating systems – are entirely user-generated, with the best ideas bubbling to the top through continued high ratings or levels of commenting.

The dialogue platform requires participants to register and login; this potential barrier to entry is kept as low as possible but it does allow useful segmentation of results in the reporting stage and ongoing feedback to participants throughout the process.

The data collected in a dialogue process is a rich combination of qualitative and quantitative and can be combined, cross-sectioned and usefully analysed in all kinds of ways. To support this depth of analysis, the data is made available as an Excel export (see Appendix) which can be interrogated by simple or sophisticated queries.

Outreach

Throughout the process Delib conducted outreach to help drive traffic to the site. This took the form of contacting relevant sites, bloggers, Twitter accounts and social networking sites to drive people to the Med Info Discussion site. Evidence of this outreach can be found in Appendix 1. Alongside this MHRA spoke to their contacts to disseminate knowledge of the Dialogue, put up a press release on their website (<http://www.mhra.gov.uk/NewsCentre/CON071157>) and emailed their mailing list.

2. Participation overview

The data outputs of the dialogue consist of Excel exports of all ideas, comments, ratings, and tags, as well as the details of the registered participants (email and other demographic questions) and the date and time of all contributions to the site. In addition, Google Analytics was used to track traffic and user activity (i.e. what pages they visited). MHRA were updated weekly on participation levels and sent full data exports of all outputs. These can also be found in the appendices.

Users

There were 252 registered users, however of those 20 were admin users, either MHRA members of staff contributing to the dialogue, or Delib members of staff testing the dialogue to ensure it was technically sound.

An interesting point is that there were a high proportion of usernames which were actual names – suggesting trust and seriousness.

Ideas

There were 65 ideas from 60 different people, showing a healthy diversity in who contributed to the dialogue and not a discussion dominated by a noisy minority.

(Qualitative analysis of all of the ideas can be found in the 'Big Stories' section)

Comments

There were 149 comments (an average of 2.3 per idea)

(Qualitative analysis of all of the comments can be found in the 'Big Stories' section)

Ratings

There were 135 ratings (an average of 2.1 per idea)

The ratings feature was not heavily used – far less by ratio compared to previous similar exercises. This, combined with the high ratio of original ideas, suggests that most participants were highly engaged and participative, keen to articulate their own contribution rather than nudging or adjusting others.

Tags:

There were 70 tags in all (1.1 per idea).

The most popular tags and the counts for those are listed below, the most popular being accessibility, emc, safety and duplication (of the database) all of which are investigated further in the 'Big Stories' qualitative analysis section.

Popular tags

The most popular tags used throughout the dialogue and the number of times they were used.

Tag	Number of times added by user	Tag	Number of times added by user
accessibility	21	accuracy	7
emc	18	all medicines	5

Tag	Number of times added by user	Tag	Number of times added by user
safety	9	pils	5
duplication	9		

Infrequent tags

The most infrequent tags used throughout the dialogue and the number of times they were used.

Tag	Number of times added by user	Tag	Number of times added by user
printout	4	governance	2
side effects	4	medicine	2
other language	3	bnf	2
information standard	3	patient uk	2
joinedupthinking	3	prescriptions	2
life saving	3	adverse reaction	2
accurate	2	yellow card	2
powerful	2	mah	2
foreign drugs	2	health warning	2
funding	2	informed consent	2
spcs	2		

Single-use tags

Tags that were only used once throughout the dialogue.

Tag	Tag	Tag	Tag
gps	useful	disability	anonymity
alerts	complicated	patient care	availability
pil	updates	prescribing	dils
primary resource	emc misleading	knowing	websitelinks

Tag	Tag	Tag	Tag
compare medicines	pharmacists	embeddable data	copyright
clearlanguage	medicine pictures	science based	privacy
partnership	latex	herbals	internetpurchases
health websites	taxpayer	good idea	integrated
treatment options	medicine information	liability	pharmacy it
misleading,	advertising	adherence	definitive resource
interoperability			

Cost per engagement

As an exercise the value of each participation can be equated to £261 per idea; £67 per participant; which is £5 per engagement.

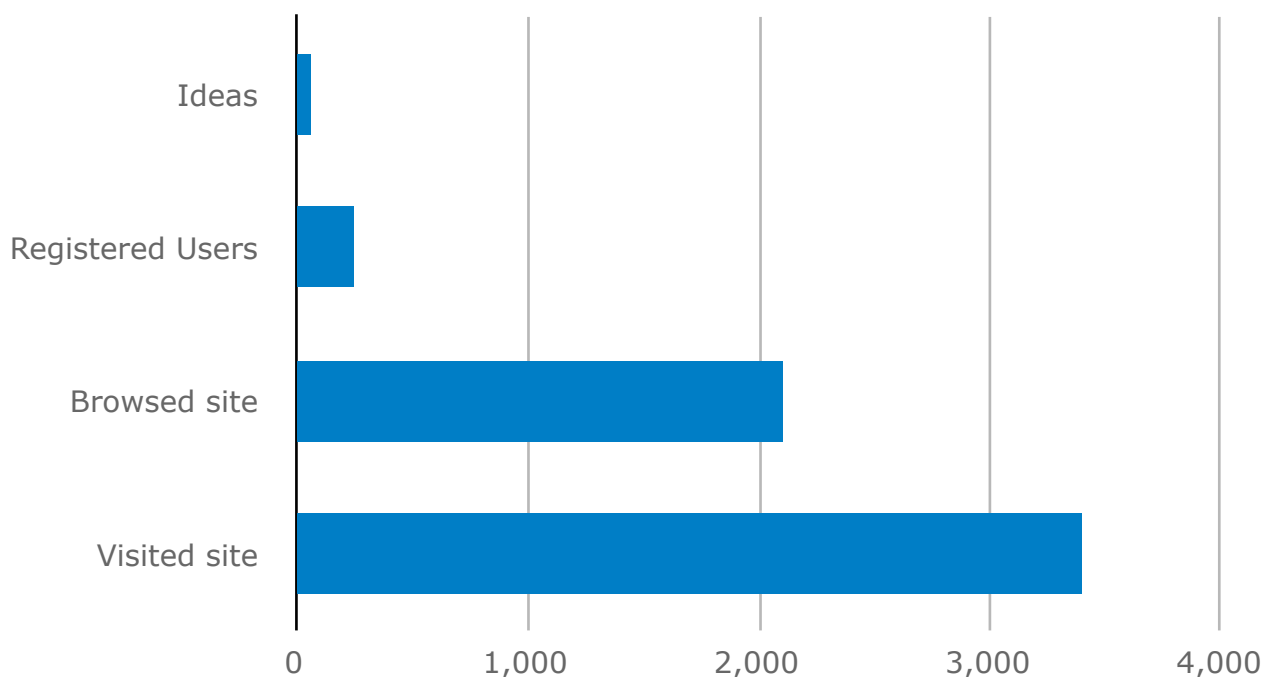
Conversion rates

Terminology used in this section:

- **Conversion rate:** The conversion rate is the ratio of visitors who did something on the site, expressed as a percentage. This metric indicates the number of visitors that came to the site and found it valuable enough to firstly look around, then register and finally join the conversation.
- **Unique site visitors:** The number of unique visitors represents the number of individual users that visited the website over the course of a specified time period, in this dialogue 2,306
- **Site visits:** Number of times the site was visited, including multiple visits by the same unique visitors

The conversion rate for the Medicines Information Online Dialogue is shown in the graph below.

Conversions



So out of the 3,398 people that chose to visit the site (visits), 62% of people chose to stay on and browse the site. Of those people, 12% chose to register as a user (so 7.4% of all site visits equated to sign up). Of those that registered, 63% went on to take some action on the site (either adding an idea, commenting, rating or tagging). From those that registered on the site and took action, 26% of people added an idea, the most intensive form of contribution. These are very impressive conversion rates, especially from registration to participation—essentially only 37% of registered users did not take action on the site. This is a testament to the engaging content which clearly motivated people to sign up and then contribute to the dialogue.

Analytics

The analytics of the site focuses on the amount of traffic the site received and is taken from Google Analytics. The MHRA were provided with a password to view their account on Analytics.

Overview of Google Analytics - site visits

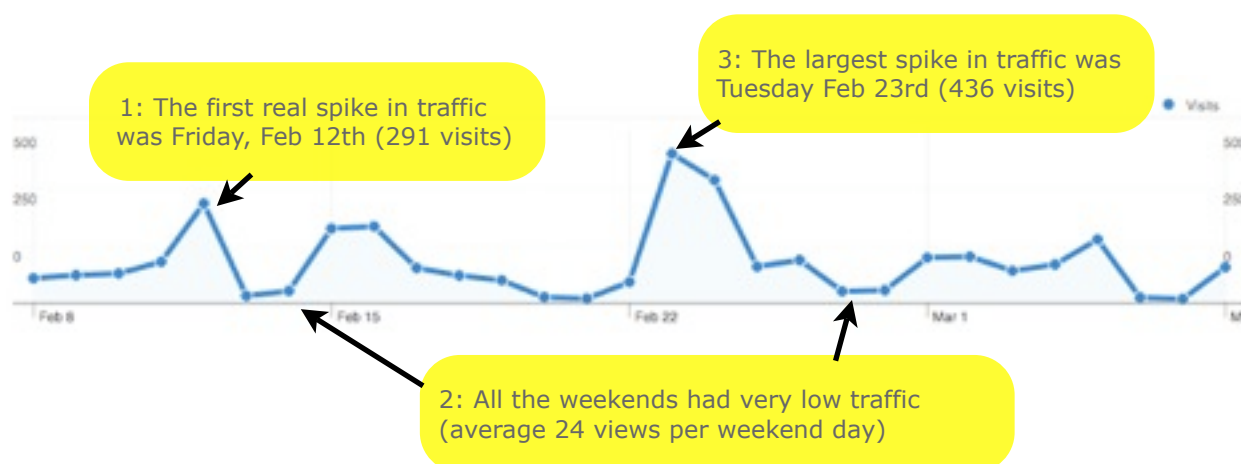
Week 1 (8th Feb - 14th Feb):	712
Week 2 (15th Feb - 21st Feb):	725
Week 3 (22nd Feb - 28th Feb):	1163
Week 4 (1st Mar - 8th Mar):	798

Week 3 was the peak of the Dialogue's traffic, with nearly 1200 visits compared to a fairly steady 700-800 visitors for the other weeks. Quite a lot of visits over the course of the week happened over about 2 days each week, with the exception of Week 4, which had fairly steady traffic through every day on the final week (although Friday March 5th did represent a small spike for that week with 186 visits).

Points of interest

Pointers 1 and 3 (shown in the graph below) can be traced to a mass email out to the MHRA mailing list (which holds in excess of 20,000 addresses) and the concentration of the Delib outreach campaign, which was sent out at the same time.

Pointer 2 shows the site had very little traffic over the weekends, which is to be expected in dialogues of this kind, with most online activity generally being from Monday - Friday. This has been the case for many dialogues and is not unusual.



Site Usage

Terminology used in this section

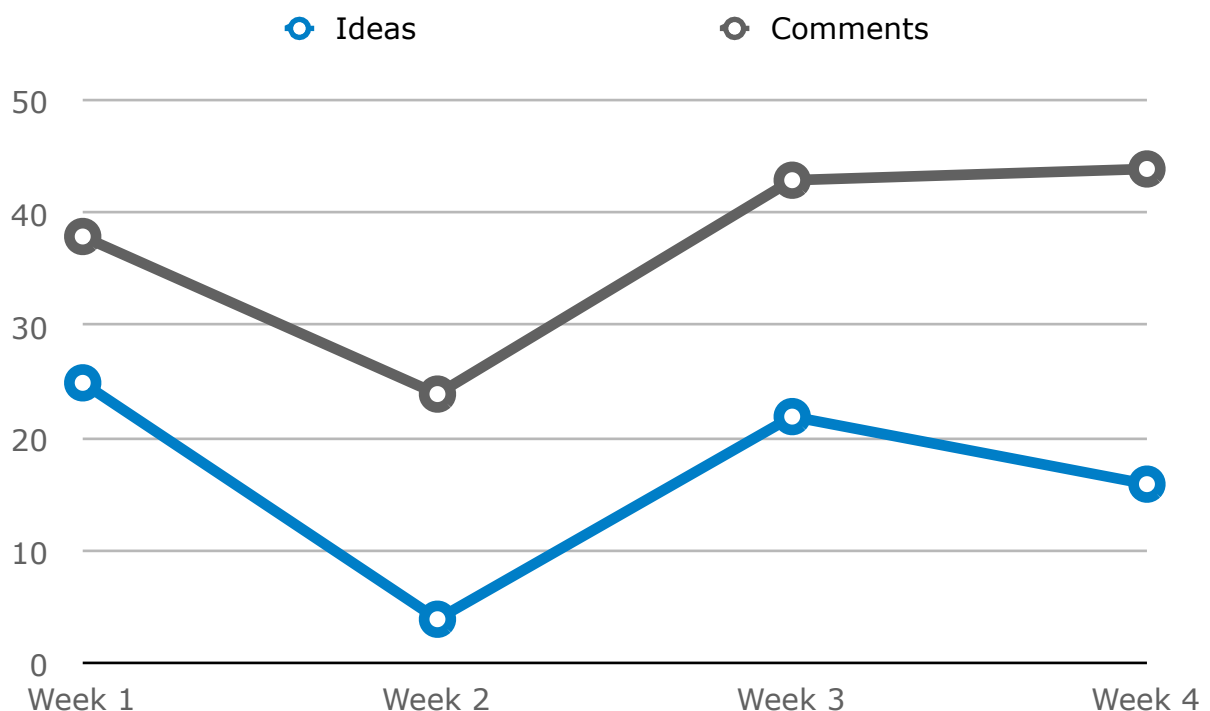
- **Bounce rate:** Bounce rate is the percentage of single page visits or visits in which the person left the site from the first page
- **Page Views:** This is the number of times pages are viewed over a given date range. A visitor can see multiple pages on a single visit. Each page they view in the site is counted separately.



Overall from the site usage we can see that there is a combination of low bounce rate (38.82%), a high amount of time spent on the site (5.07 minutes) and high page views (20,622). This indicates high engagement with the material on the site, and this is further supported by the high quality of contributions to the site.

Engagement over time

Participation in the dialogue correlated largely with the engagement work done, with no discernible tail off towards the end. In fact, there were some ideas received after the close of the discussion suggesting that had the dialogue been open longer, more contributions were likely to have been added. Ideas and comments were received in a consistent ratio to each other, suggesting that 1) ideas were still worthy of discussion throughout and 2) there were still new ideas coming through.



3. Big Stories - Key themes from the discussion

What follows is qualitative analysis of all of the ideas and comments broken down into 'Big Stories' which outline the key themes prevalent throughout the dialogue.

There was a large amount of detail and specialist knowledge which fed into individual ideas/comments - as far as possible these have been included within the analysis, however there is a limit to fine grain detail which can be included whilst drawing out the main themes.

Theme 1: Public access to an online database

One of the clear themes was that the principle of public access to an online database was desirable. Within this large theme some of the more discrete thoughts can be broken down as follows:

'It's a good idea'

Throughout the discussion, participants overwhelmingly thought that having public access to an online database of PILs and SPCs is a good idea.

In a modern culture of openness it is unusual that this doesn't exist already. ”

Access/ease of having online

People would be able to see at a glance whether a particular medicine is suitable for them, and there was an indication that participants thought people more likely to read PILs rather than from in the box.

Overall, there was a clear advantage in access with an online database, with participants pointing out that healthcare is not 'Monday-Friday, 9-5'. Considerations such as remote access for healthcare professionals not working in an office/surgery, healthcare being administered in the home and people wanting to check medicines while they are on holiday, all contributed to this.

Right to information

- Should be a legal requirement
- Should be freely available
- Trustworthy and definitive

Access to both PILs and SPCs for all

There were some contributions which stated that SPCs should just be accessible for the professionals, to prevent confusion with patients, but there were also contributions which strongly suggested everyone should have access to ALL information. One argument was that Doctors currently hold all the information and this is elitist; patients should be more informed and involved in their treatment if they want to be and this resource should aid that.

Ultimately individuals are responsible for their own health and should take an active role in decision making, with an important point being made that many patients with critical conditions are more expert with their condition than a GP, and giving them access to this information can give them more insight into what and why they are being prescribed certain drugs.

Theme 2: Duplication of existing efforts (emc and others)

Another frequent concern was duplication of effort. There are already databases in existence which does the job that the MHRA is describing to some extent, and they should either be extended or the MHRA must justify strongly why what they will be doing is significantly different or better.

Mainly participants identified the emc (Electronics Medicines Compendium) found at <<http://emc.medicines.org.uk/>> as a database that, to some extent, meets the needs MHRA is describing. However other participants mentioned the BNF, and linking the emc and BNF together to solve the issue, or the DM+D. Other known databases (as part of regulatory bodies) include IMB, EMA, FDA.

It is worth noting that there were a small amount of participants who thought the service the emc already offered was useful and fit for purpose and it being adequate as it was. However most people agreed that as it currently stands, the emc is not enough to provide the benefits of public access to a PILs and SPCs database.

Main topics of interest which led the conversation:

- The database must be comprehensive - i.e. it must include all PILs and SPCs information, as well as information for generic medicines.
- The database must be in one place - in order to be definitive and easy to access/find for both the public and HPs

There are a proliferation of unconfirmed generic and commercial information which tends to obfuscate rather than inform the end-user.

- Whether the MHRA should/must be involved in some way.

“Build on the success of the EMC” - a viable option?

Participants’ biggest concern was saving time, money and duplication of effort. Unless the MHRA plan to do something radically different or add in new pieces of functionality compared to the emc, perhaps they should build on what is already there.

The main problem with the emc - it is not comprehensive

There was a general consensus that whilst the emc contains a lot of information related to PILs, it was far from comprehensive, especially with regards to SPCs and generic medicines. The emc themselves recognise the need to have a comprehensive database and even though they currently offer a lot of information, it is not currently comprehensive, and repeated on several contributions their desire to work with the MHRA to make such a database.

A clear priority for participants was outlining that the:

True benefit of an online database only comes when it is comprehensive.

It would be appropriate to use the emc if...

- It was made obligatory for drug companies to put PILs and SPCs on the emc
- If effort was put into publicising the EMC - for example changing its URL to something more appropriate for the public.

Not appropriate to use the emc...

The MHRA are in the best place to provide such a database because they have the best source of data and it must be seen as a non commercial venture. The general risk associated with drug companies having to pay the emc to be listed, and as such limit it to those who can afford to do so was mentioned repeatedly.

Specific failings of the emc for this database include it not being well-known outside the medical profession and that after a recent site design, the emc is not technically as good as it was. Further to this point, a participant suggested it would be:

Better to have a new system that to adopt an old one

”

But MHRA involvement would be needed...

Participants definitely felt MHRA had to be involved, for example, owing to the of the nature of the web, there is lots of invalidated information available which could be misleading. Un order to be a successful and useful online database, it needs to be the regulatory agency behind it.

The MHRA were seen as:

Highly trusted

”

The main quandary the participants identified with any MHRA involvement in improving the emc is the complexity in the MHRA's public role, and even though the emc is "not for profit", obvious commercial interests in any such database, and how dealing with the drug manufacturers in such a relationship should work.

Theme 3: Functionality/ 'the database should include this'

Lots of participants outlined specific pieces of functionality of the database or things that they would really like it to include.

Database could cover more than just PILs and SPCs

Some participants thought the database should include information on medicines not licensed in the UK but commonly prescribed in the EU and USA. Similarly, herbal products and alternative therapies should be included, showing evidence of their effectiveness and what they affect if they are taken with conventional medicines, e.g. St John's Wort. The main argument for these things is that one of the key objectives of this database would be to promote patient safety, and to do this it must include other reliable information not just on UK licensed medicines.

Reporting adverse reactions, which emc added through an 'email to the MHRA' button, one participant suggested that improving the reporting of this as part of any new MHRA database. However some participants thought linking to such a form is all that is required (like the emc) and that this database is not the place to include this service.

A few participants saw the database as an opportunity to do something really interactive, such as renewing prescriptions online which updated your chemist or using the database to integrate with the summary care record, allowing doctors to know what other drugs patients use (assuming Pharmacists or patients update this information).

Design

- Easy interface.
- Make it like an online version of the old MIMs but for the general public.
- Colours and icons should be used to make it more user friendly.
- Build the database so that data is stored in an open format, so it can be converted into useful formats.
- Should not require cookies or use randomly generated URLs which change over time.

Searching

- Intuitive searching.
- Sort by disease (like the BNF categories) as well as alphabetically.
- By product name and by license number.

Pure functionality

- The most important piece of functionality would be to show contra-indications of different medications when taken together, with one person suggesting there be a red alert function which appears when an adverse reaction occurs.
- No registration required to be allowed to use database.
- Include pictures of drugs, as colours of the same drugs of drug may vary depending on manufacturer.
- Some way of being able to search by scanning in barcodes.
- Clear distinction of what is an SPC and what is a PIL, making it clear that SPCs are designed for HPs.
- Be able to print out the SPC or PIL of your choice and for it to be available in a special large font. They should be able to be printed as a single page.
- The ability to embed the data in other sites.
- The ability to sign up to follow a medicine so that if there's an update to the information on that product you are notified by SMS or email.

Accessibility

- The database should be able to be available in large fonts.
- Must be usable with a screen-reader.
- Provide more common medicine information in different languages, especially for high risk drugs.
- Use clear language.
- Provide audio information.
- Have British sign language translations.

Security

- Ensure that none of the information can be manipulated on the screen.

More information

- Package inserts for injectable medicines.
- There should be a way for people to be able to find out if a product contains latex, because it is hard and time consuming for a patient to find this out.
- There should be information available around drugs for long term conditions which effect the contraceptive pill.
- Cost per normal prescribed item should be indicated on the PIL to raise awareness of the cost of medicines.
- All potential limitations of any information in the site should be made clear (for example differences in drug brand).
- There should be a glossary of common concepts in layman's terms.
- There should be an explanation of side effects, but also consequences of NOT taking a certain medicine or stopping taking the product and the risks associated with that.

Theme 4: Help Health Professionals in their job

The dialogue outlined certain benefits that an online database would bring to members of the healthcare profession, especially Pharmacists. These are expanded upon below:

Access to the latest (common standard) information was obviously important to HPs, especially with side effects and the changes in medicines being so frequent.

It is clear from the contributions to the discussion that a large amount of health professionals' time would be saved if a comprehensive PILs and SPCs database was available online. The main example mentioned many times was the frustration in chasing the drug company or time consuming internet searches for SPCs.

The ability to print out PILs appears very useful for HPs but most notably for Pharmacists, who could then provide a PIL for every prescription which they currently have trouble doing due to splitting packets. An example in support of this is that in Australia, pharmacists are provided software with PILs information which they can print out when needed. It would be good for the public to know that they can request a PIL from a Pharmacy as well.

An MHRA suggested idea centered around whether having this database available could help HPs discuss treatment options with patients. This idea was refuted by the emc, as PILs are not designed to be used in this way. However one contribution thought this would be useful for looking up contra-indications and informing the prescriber to avoid a wasted prescription, and another participant highlighted that patients could look up at this information beforehand to see if a particular brand suited them before seeing the Doctor.

Theme 5: Patient Safety

Contributors to the dialogue quite clearly outlined that a free and open database would contribute to both patient safety and patient choice.

Patient safety

- Reduce medication errors.
- Prevent misinformation.
- Make clear contra-indications of different medications being taken.

Patient choice

Other contributions also called for the need to have more information about ALL options available, including:

- EU and US licensed but not UK licensed drugs.
- Alternative medicines.
- Herbal medicines.

Patients need to have choice of treatment and may feel better on one particular type of medication not manufactured in the UK. Some people require medicines they can't get here. So there were some contributions that saw the database as an extension of a patient's right to have reliable information on all medicines they take.

In addition, there were a few contributions that also mentioned the possibility of this database being used worldwide if the quality and breadth of the information was unrivaled. This would be especially useful in developing countries.

Better informed patients

This follows on from theme one that generally patients should be more involved in their healthcare, reiterating that ultimately individuals are responsible for their own health and should take an active role in decision making. Giving them access to this information can give them more insight into what and why they are being prescribed certain drugs.

Theme 6: Up to date

Participants in the dialogue outlined a general concern about making sure that any database contains the correct and most up to date information, mostly based around the regular changes/variations to products and delays in releases of leaflets (SPCs and PILs) after drug approval from the MHRA.

The emc themselves highlighted that the updating of the database was the bulk of their work, and some participants noted the large amount of responsibility the MHRA would be taking on (as well as all their other responsibilities). This formed a basis for the questioning whether MHRA were the best organisation to do this.

Theme 7: Collaboration

Participants added joined up thinking, partnership and website links as specific tags to the dialogue, indicating the need for the MHRA to include other people in making any online database, in order to make it a success.

Whatever the site turns out to be (emc + MHRA or just MHRA) it has to be the reference site of choice for the NHS and other important sites. There must be widespread linking with sites, especially patient sites, the BMF and DM+D.

The involvement of PCTs, Royal Pharmacological Society (specifically named), HPs and important websites is vital, especially around sharing information widely about the database and increasing awareness.

Finally there should be some form of toolkit to let other sites use the MHRA database information, which links in with making data embeddable (the potential to charge for this might be pertinent).

Theme 8: Money

As with any government department or government agency proposing to spend money on such an IT project, money came up as a recurring theme throughout the dialogue.

There were contributions on both sides regarding the funding of any such database, with some thinking it would be a waste of money (especially if it duplicated the emc) and others saying arguments over costs are short sighted. Compared to the public accessibility and safety benefits which are clearly a priority:

Cost of implementation should be secondary

”

There was some support for the idea that it should be paid for by the manufacturer as part of the fees they pay to license products. In addition, because of the value of the data (as mentioned in the collaboration theme), other websites would possibly pay to use the data on their sites.

Another interesting string of thought was a concern about ensuring the MHRA will have enough long term budget in place to maintain the database, and there is a large risk that is if the emc

ceases to exist because of the MHRA database, which itself might be difficult to keep running, that there would then be no database available at all.

Additional points

MHRA set out in their brief document information which would be of use in informing other improvement activities, namely the MHRA website and the re-design of PILs. Some participants made reference to these in the dialogue and they are laid out below:

PILS re- design

- The current PILs are too comprehensive and have too much background information.
- The PILs are currently designed as pack inserts - which is the main problem.
- They should include more diagrams.
- The only important information that should be in a PIL is: Dose, How to use, Side effects, Contra-indications and Ingredients.
- Adverse reactions should be clarified to: 1 in 100, 1 in 500, 1 in 1,000, 1 in 10,000 and very rare.
- Cost per normal prescribed item should be indicated on the PIL to raise awareness around the cost of medicines.
- There should be explanation of side effects, but also consequences of NOT taking a certain medicine or stopping taking the product and the risks associated with that.
- Should be suitable for those with learning difficulties.
- I actually think that the current statement on PILs (Like all medicines, XX may cause side effects...) is about right.

If this central database was created, it would be a good opportunity to standardise SPCs to ensure consistency, and to ensure terminology between SPCs is similar ”

MHRA website

- The current MHRA site is difficult to navigate and as such, the new database should not be put there.
- The MHRA site has lots of useful relevant links of reports etc., so the database should be on the MHRA site.

MHRA

During the dialogue, certain mentions were made of the MHRA (sometime contradictory assertions). A selection are shown below:

- MHRA have other important responsibilities in their agenda and resources are stretched already so should not take a database on as well.
- They are the regulatory agency and as such, trusted to provide such a database.
- Must demonstrate clear justification that they are the appropriate body to be doing this.
- Need to re-market themselves - the public do not know who they are.

The most popular idea

Response on behalf of UKMi Executive

Only one idea attracted more than 5 ratings, collecting 20 votes – and, remarkably, they were all 5 stars (this is pretty much unprecedented).

These ratings are anomalous. They don't necessarily mean this idea is four times better than any other, or worthy of more attention in and of itself; we can't really infer that because of the pattern of ratings elsewhere. It wasn't the community saying 'we like this best by a mile' so much as this idea attracting its own microcosmic discussion – it's like a mini-Dialogue. That said, the idea does seem very well-liked by the audience it attracted and nobody felt the need to reduce its high rating.

One comprehensive repository is required

A comprehensive collection of all SPCs and PILs is needed. In the modern culture of "openness", it is a curious anomaly that this doesn't already exist, and we would encourage and support the MHRA to address the issue. Lack of information is a key factor inherent in medication errors, and a key tenet of the NPSA's safety alert about injections was that there is no single place where professionals can go to get administration information about all UK licensed injections. ”

NHS pharmacists, especially those working for UKMi, spend a lot of time chasing companies for such info - it is needed for patient safety, therapeutic decision-making, and formulary work. Online access would save considerable time and enable patient-centred problems to be resolved more quickly. Some generic companies are loathe or very slow to provide copies of SPCs. The eMC is an extremely valuable and reliable resource, and we would like to see any development building on their success, rather than have an additional place to look for SPCs and PILs. The eMC is easy to use, well-presented, has been responsive to the needs of users, and offers a rigorous audit process. The new search facilities are especially commendable.

There is also perhaps the opportunity to present further new information, such as pictures of each product. This would allow pharmacists to see how products are presented and labelled, which often has important risk implications. It would be particularly welcome if the package inserts for injectable medicines were made available at the same time because these often include information not contained in the SPC which health professionals rely upon for administering injections safely. We would welcome an opportunity to work with the MHRA and eMC, if our input could help to make this comprehensive database possible.

Why the contribution is important

It will reduce medication errors, save health professionals' time, and make the eMC comprehensive. It fits with the prevailing culture of "openness" and offers an opportunity perhaps for eMC, MHRA and UKMi to work together.

Who took part

This section will take a look at identifying the participants that took part in the dialogue, in order to get a better understanding of whose opinion the common themes derive from.

As participants signed up to become a registered user on the site there was optional information/ demographic questions they could choose to fill out. All but one participant answered all the optional questions, an incredibly high figure, which once again indicates a level of trust in the dialogue. The questions asked and the answers are listed below:

Q.1 Please check this box if you would like to be contacted by the MHRA to test an online trial of the database if it is created.		
Yes	98	42%
No	134	58%

A surprisingly large number of participants were happy to be contacted in the future to be involved in further database development, which shows a clear interest from users, and will obviously be useful to the MHRA in taking any plans forward.

Q.2 Which of the following options best describes you?		
General Public	73	31%
Pharmacist	74	32%
Doctor	11	5%
Nurse	7	3%
Pharmaceutical Industry	29	13%
Other	38	16%

A good amount of the general public took part in the discussion, however from the general types of the discussions on the site, it can be put forward that the 'General Public' may mean someone who is involved somehow in healthcare because of the technicality of some of the discussion. Conversely, 16% of participants choosing 'Other' outlined some kind of involvement in healthcare, which suggest perhaps that those denoting themselves as 'General Public' were in non healthcare/ lay participants.

A very large proportion of the participants were Pharmacists. This is probably in part due to the subject matter of the discussion, medicines directly falling into their remit, but also because of outreach to that group, particularly the mention of the dialogue on the popular Pharmacists news website Pharmiweb.com <http://www.pharmiweb.com/pwToday/default.asp?row_id=1448>.

Others included:

Academic, Activ Kent LINK and PPI member, carer, carer representative, Charity, Charity co-ordinator, Clinical Researcher, Datapharm, Datapharm CEO, ex-pharmaceutical industry, Head of Governance, Health Information Service, Info specialist, Lay member HMAc, Local INvolvement Network, Medical student, HCA medical writer, Medical Writer, Medicines

information, Medicines information designer and user tester, NHS Patient Representative (8 years), Patient Charity, Patient experience forum, Patient led charity, Patient Support Group, Pharmacologist, Pharmacy regulator, Policy, Psychologist lay committee member, Publisher, Regulatory consultant, research, residential manager, retired doctor, Student.

Q.3 Do you currently take medicines for a chronic illness?		
Yes	53	23%
No	179	77%

Illnesses specified:

Angina, arthritis, asthma, Bi-polar and personality issues, breast cancer, CFS?Statin Damage, Coronary artery disease (sic), Depression, Diabetes, Diabetic, Eczema, Familial hypertension, Fibromyalgia, Hypercholesterolaemia, heart disease, high blood pressure, hypothyroidism, hypertension, M.S, Parkinsons, Polymyalgia rheumatica, Post ca pancreas. Diabetic. Insulin allergy, no spleen, Post oesophagectomy, I need ppi drugs every day, peripituitary lack of ACTH, psoriatic arthritis, Recovering from septic arthritis and avascular necrosis, ongoing cervical spondylosis, rheumatism, high cholesterol, salbutamol, Type 2 Diabetes, UC.

Interesting Registered users:

Datapharm (emc)

Official bodies:

UKMi
PIPA
TEVA UK

Pharmaceutical industry

Abbott
Bayerhealthcare
BeaconPharma
Daniels Pharmacy
Hameln
HCS-UK Ltd
Lilly

Who didn't take part:

Interestingly, one idea - "Perspectives from PIPA, the Pharmaceutical Information and Pharmacovigilance Association" noted that, "Some individual pharmaceutical companies have not been able to interact with this style of open-access discussion/consultation due to corporate communication policies."

Appendices

The appendices can be found in separate files attached with this report.

- Appendices:
 - 1: Evidence of outreach
 - 2: All ideas, by date and by rating
 - 3: All comments
 - 4: All tags
 - 5: All registered users
 - 6: Google Analytics

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