

Literature review: How evidence is used by the public to judge risks and benefits of medicines?

Melanie Smallman, Think-Lab Ltd

September 2015

Executive Summary

This literature review gives an overview of current research into how evidence is used by the public to judge risks and benefits of medicines. It presents a picture of how evidence has been talked about in previous dialogue exercises and in the science communication literature, to provide a backdrop against which the AMS's future work in this area can sit. Key points emerging from the review are:

1. GPs and medical practitioners are seen as the most important sources of advice about the risks and benefits of medicines.
2. People believe that evidence from large samples and gathered over a long time-frame is the most reliable.
3. Personal experience is seen as more valuable than statistics or probabilities.
4. After GPs, the secondary choice of information varied according to educational level, ethnic background, age and gender but includes advice from friends and family, the internet and charities or support groups.
5. Public dialogue and deliberation appears to be an important way for patients and researchers to interact, to improve one-another's understanding and to enable patients to get involved – for instance, in new healthcare models or in testing and regulatory regimes.

Introduction and Background

The Academy of Medical Sciences is undertaking a new workstream on “How does society use evidence to judge the risk and benefits of medicine”. The workstream sets out to explore issues around strengths and limitations of different sources of evidence, the impact of conflicts of interest on perceptions of validity, how society sees evidence and how evidence can be communicated to support informed decision making.

Underpinning this workstream will be a programme of public and stakeholder engagement, to ensure that discussions are informed by the views of the wider society.

Over the past ten years however, a number of public dialogue events have already taken place in the UK and worldwide. The subject of sources and communication of evidence is likely to have been considered and raised in these discussions. Furthermore, academic research in science communication is also likely to offer insight into these questions. This literature review gives an overview of this existing material, presenting a picture of how evidence has been talked about in previous dialogue exercises and in the science communication literature, to provide a useful backdrop against which the AMS’s future work in this area can sit.

Our approach

The literature review is made up of two elements:

- a) *An analysis of how evidence has been discussed in recent UK public dialogue events.*
This analysis has been based upon our own computer assisted text analysis of dialogue reports, to give an overview of relevant emerging themes. This has been supplemented with particular focus on any dialogue specifically looking at the question of evidence or biomedical issues.
- b) *An analysis of what has been written in the literature about how the public and patients view medical evidence, the effect of sources and the media on this.*
In this analysis, the focus has been on communications relating to medicine, especially around medicinal products (rather than medical technologies) but includes evaluations of other ‘scientific’ evidence where it is particularly relevant. We have looked at international literature, but with a strong focus on the UK, Europe and the USA as there are likely to be significant differences in countries with very different socio-economic circumstances.

Further details of search criteria and methodologies are given in appendix 1 and 2.

How evidence is used by public to judge risks and benefits of medicines – the review.

Part 1: The evidence from dialogue events to date

a. Analysis of Sciencewise dialogues 2002-2011

The following conclusions are based upon our computer assisted text analysis of the reports of all public dialogue events on science and technology, funded through the Sciencewise programme from 2002-2011, supplemented with a traditional text analysis of any further relevant dialogues taking place from 2012-2015. Further details of the computer assisted text analysis technique are given in (Smallman 2014). In summary, it is a process that provides a statistical map of texts which identifies the main themes being discussed, allowing you to look at large bodies of text without having to sample. It is very useful in providing an overview of a series of documents and in pointing you towards the parts that you are likely to find most relevant.

General points from text analysis:

- A commonly voiced view was that participants were suspicious that there is a tendency to use drugs and technologies as quick fixes rather than deal with underlying social problems. In the DrugsFutures dialogue, for instance, people talked about drugs being used as a 'sticking plaster' and expressed suspicion that in the case of mental health conditions, drugs were prescribed to make the lives of others, rather than the patient, easier.
- Industry was seen as a corrupting influence – diverting resources and effort away from social goods:

"Whilst participants generally did not consider academic scientists as doing research with profit as the main motive, the potential allure of private sector investments and the relative inexperience of researchers in brokering effective business deals could mean that ideas and innovations get taken in directions that are much less socially beneficial."

BBSRC Synthetic Biology Dialogue 2010.

- A sense of nature and naturalness was very important in shaping people's views about technologies in general and in medical technologies such as stem cells. In the case of embryology and stem cells, this was expressed as a sense of naturalness, raising the moral question of whether it is right to 'mess with nature':

"It seems unsafe to carry out procedures which are unnatural, in the sense of being not possible by natural processes"

Human-animal Hybrids dialogue 2007

- Risks and benefits of new medicines (and other technologies) are seen as different sides of same coin – the challenge is about balancing these:

“Another view expressed was that the risks associated with the slippery slope argument are outweighed by the potential benefits”

Hybrids and Chimera 2006

- People were more positive towards medical technologies and prepared to take more risks than with environmental technologies:

“There was a view that there were inherent risks involved in developing new technologies but that if we were too careful with the development of nanotechnologies then this could lead to the field stagnating and losing impetus.”

Nanotechnology for Healthcare, 2009

b. Lessons from particular dialogues

Drugfutures – Sciencewise and AMS (2006)

Drugfutures asked participants what makes them trust a particular drug. The following factors were considered important in making that decision:

- Reputation – whether a drug has been around a long time and has been tested.
- Efficacy – personal experience of taking a drug and it working.
- Evidence of family members’ experience.
- Doctor or pharmacist’s advice.
- More likely to trust a consultant than a nurse.
- Assumption that if a drug is available over the counter it will be fine.
- Brands are important and convey a sense of trustworthiness.
- The side effects are acceptable (e.g. drowsiness, nausea or headaches).
- Weighing up the seriousness of the condition vs the side effects.
- Information from the internet – people were aware that the reliability depended upon who was writing, but were keen for personal stories and wanted as much information as possible.
- Support group information.
- Natural rather than chemically based treatments were preferred.
- Natural alternatives to prescribed medicines were seen as desirable.
- If its more expensive, more likely to trust it.
- Conflicting advice from trusted sources was a matter of concern and made decision making difficult – for example Doctors and pharmacists might say different things.
- Some circumstances made people more wary of drugs – for instance, when pregnant or breast feeding.

Discussions around advice on recreational drug use (specifically how to discourage young people from taking them up) identified a number of further trusted sources for such advice. In particular, peer to peer advice, and involving ex users and users in giving drug advice was seen as important, while information from teachers and doctors was not seen as trustworthy as they were seen as either being hypocritical or lacking in first hand knowledge. While this discussion was specifically

looking at discouraging people from recreational drugs, this is also likely to be relevant to discussions around sources of advice on pharmaceutical products – specifically around the value of peer to peer and user advice.

New Medicines for Serious Conditions: How patients would weigh the risks and benefits’ – The Genetic Alliance (2014)

The Genetic Alliance carried out research on ‘New Medicines for Serious Conditions: How patients would weigh the risks and benefits’, based on a Citizen’s Jury, two deliberative workshops and a Europe-wide survey, between 2011 and 2013.

The research was designed to explore how patients with rare and/or serious conditions (and their families) perceive the risks and benefits of new medicines, and how well decisions made at the marketing authorisation stage of medicine development reflect their preferences.

The following recommendations were made:

1. Regulators should include psychosocial factors in decision making.

The top factors participants recommended to be considered were:

- Autonomy/control - I want to feel independent and in control
- Fatigue – I do not want to feel tired all of the time
- Employment status – I want to be able to work
- Anxiety – I do not want to worry about the uncertainty of my condition

2. Regulators should be more permissive for those treatments for people with rare and/or serious conditions.

Patients affected by rare and/or serious conditions often have few or no effective treatments available to them. Because of their unique circumstances, such patients may well be willing to take greater risks than the system currently allows, and should be given that choice:

- Where it is uncertain how the medicine will work
- Where it has been tested on fewer people than normal
- Sooner than normal

3. Patients should be more involved in all stages of the process, from setting the research agenda, to post-marketing authorisation decisions.

This, participants argued, would ensure that the benefits which really matter to patients, and the levels of risk they are prepared to tolerate are considered in the decisions. This is particularly important for serious and rare conditions, where the stakes are so high. Patient representatives (such as patient group members) should be supported as joint decision

makers, alongside clinical experts, throughout the process. There was no appetite for a 'patient decides' or an unregulated system. Instead, participants and survey respondents, in the main, argued for joint decision making across the research and regulatory system. Jurors and workshop participants also called for greater support for patients to get involved.

4. Patients should be better supported to make their own decisions regarding which medicines they take, reflecting their individual circumstances, beliefs and preferences.

Participants also recognised that:

- A more permissive regime would give more choice and hope to patients
- Patients would need more information and support if regulators were more permissive
- Patients and doctors should work together to make complex decisions.

5. Deliberation appeared to reduce the frequency of 'don't knows'.

Particularly around questions relating to the permissiveness of regulation, those taking part in the citizens juries discussions were less likely than those being surveyed, to say 'don't know'. The report authors argue that this is a methodological matter and that the process of deliberation helps participants form clearer views.

Stratified Medicine – Sciencewise and Innovate UK (2012)

In the stratified medicine dialogue the importance of information was reported as a key issue in the dialogue – as well as the need to communicate the concept in non-technical and consistent ways. Participants identified the importance of healthcare information being communicated through trusted channels. GPs were identified as a particular group to whom the public turn for impartial advice.

Participants also made a variety of recommendations about the media that could be used to increase awareness and public understanding of stratified medicine, including TV and newspaper ads and social media. Some mentioned specific examples such as episodes of Horizon that they had enjoyed or popular presenters like Brian Cox. Others suggested that more events where the public and patients could interact with researchers would be useful – often citing their experience with this dialogue as valuable. This was tempered with concern that the media might sensationalise coverage, but nevertheless, participants thought that it was inevitable that much of the information reaching the public will come from news media.

Case studies were seen as especially useful for explaining the idea of stratified medicine – highlighting a video in which a patient explains his own experience of stratified medicine as bringing the idea to life and suggesting that more of these would be valuable. Participants also felt that honesty and realism was crucial to get the message across effectively – stratified medicine needs to be presented in a balanced way including the advantages and the risks, and its success and failures, so that neither false expectations and hope, or unwarranted fear and scepticism, result.

Young people in particular were concerned that the media might misrepresent issues and had a stronger focus on social media. Some also favoured documentaries and information leaflets to educate people about stratified medicine.

Participants were also keen to be involved, as citizens, in the development of new healthcare models – they did not want to be just passive recipients of information communicated via the media. This was at odds with the views of some of the medical professionals involved in the stakeholder discussions, who believed that the priority should be on explaining individual treatment options to patients, the report notes.

Participants also believed that more stratified approaches would increase the amount of information with which clinicians and patients need to deal, but they had different views about the level of information they would want, particularly when testing would give results in terms of probability.

The role of the private sector and its potential to profit from research at the expense of improving outcomes for everyone was also raised.

The initial findings of the dialogue were reviewed at a stakeholder workshop and a series of recommendations were developed, in collaboration with the TSB. These recommendations could be of value to the AMS's current project:

- 1. Developing a coherent message**

Communication about stratified medicine has to be based on a single, cohesive description that is used consistently in public and among researchers and funders. Stratified medicine might not be the right term for this task.

- 2. Being realistic about what can be done and when**

Managing expectations is vital; communication about stratified medicine must not raise hopes which cannot be met. This means not presenting the approach as a radical new method, but as an evolving practice, with different rates of progress in different diseases. Giving the pros and cons is necessary to avoid perceptions of bias.

- 3. Finding trusted channels for communication**

Trust is crucial when communicating with people about healthcare - people are more likely to trust information given to them by their GPs and other healthcare professionals, patient groups and charities. Other bodies such as industry are less trusted, but there is scope to improve this. A caveat: people are astute about messaging - if information isn't balanced then it won't be trusted regardless of who delivers it.

- 4. The need for publicity on 'stratified medicine' versus specific stratified treatments**

While public participants were often keen to see widespread publicity about stratified medicine, stakeholders tended to think that it was more important to inform people about specific treatments or about the workings of the medical research industry more generally as background before they could engage with the concepts of stratified medicine.

5. **Continuing to engage with the public and patients**

This dialogue highlighted a number of areas where the public and patients are cautious about the development of stratified medicine, and where further dialogue is needed to understand those concerns. This project was a starting point in a much longer conversation with the public and patients.

Attitudes to antimicrobial resistance (a Sciencewise review or research, 2015)

Despite high levels of knowledge about antimicrobial resistance and the correct use of antibiotics, many survey respondents reported poor concordance with prescription instructions. This implies that the respondents in these surveys are taking into account other external pressures when making decisions about their use of antibiotics, and a review of the literature suggests that the body of current research is insufficient to explain this. For instance, although 78% of respondents in Nesta's survey and 88% in PHE's survey reported trusting their GP to accurately diagnose their condition, a small number of respondents said that they had insisted on a prescription of antibiotics, even if their clinician was reluctant to prescribe them. One study (Office for National Statistics - Department of Health, Don't Wear Me Out--the Public's Knowledge of and Attitudes to Antibiotic use) found that a greater level of understanding and knowledge about antibiotics is associated with poorer compliance with disposal guidelines and a greater likelihood of non-prescription use of antibiotics. This indicates that any future communication campaigns would need to be sensitive to the opinions of individuals and understand their motivation. It is clear that further engagement is required to clarify these complex attitudes.

c. Other comments on impact of dialogue from the literature

Looking at the literature, there appear to be a number of further insights gained from public dialogue into healthcare issues.

Carman et al (Carman, Mallery et al. 2015), looking how public deliberation methods affect people's input of health related information found that participating in deliberation increased participants' knowledge of evidence and comparative effectiveness research and shifted participants' attitudes regarding the role of evidence in decision-making, regardless of the deliberation method employed. They conclude that "Public deliberation offers unique potential for those seeking informed input on complex, values-laden topics affecting broad public constituencies".

Similarly, (Zorn, Roper et al. 2012), looking at the impact of dialogue on public attitudes towards human biotechnology found that as a result of participation in dialogue, participants' attitudes toward scientists were more positive and that scientists' and participants' attitudes toward human biotechnology tended to converge.

Part 2: What the current literature says

1. How do the public use scientific evidence?

The key paper we found in terms of how the public use scientific evidence in decision making was (Schapira, Imbert et al. 2014) titled 'Public engagement with scientific evidence in health: A qualitative study among primary-care patients in an urban population.' This study looked at public attitudes to clinical research evidence, through a series of four focus groups. They found that patients were more interested in new research if it was relevant to their health or that of a family member. They identified three themes that informed the level of patient awareness and interest in scientific evidence in health: firstly, their scientific literacy; secondly, medical decision making style; and thirdly the influence of culture and community.

In terms of types of evidence, Schapira (2014) found that people understood that evidence produced from large samples was better because such studies produced more reliable statistics and more generalizable data. The participants also had the view that studies should be conducted in people of a similar race or age to those people considering the intervention. The length of the study was also important because of the possibility of side effects from new medications – they often gave examples of drugs that were taken off the market because of unexpected effects becoming apparent.

In addition to basic elements of scientific study design, Schapira et al also explored the perceived value of statistical information about the efficacy of medical interventions. Some focus group participants said that quantitative risk estimates of benefit would be important to their decision-making. The following quote from the paper illustrates this point:

"I think it is important to know because it increases your confidence to know how many people it worked and didn't work on and I have to have a level of confidence before I take a medication and then I need to know what possible adverse effect it is going to have. That information would therefore allow me to make a more informed decision."

Quote from focus group participant, Schapira et al. 2014.

In contrast, others expressed the view that probabilities lacked personal relevance and were not important for personal risk estimates and decision-making. Again, this point is illustrated by the quote below:

"For me, personally, it doesn't make a difference. It's meaningless. You don't know if you are going to be one of the forty percent. It's shooting crabs."

Quote from focus group participant, Schapira et al. 2014.

The study also asked participants if an overall quality score for scientific studies – for instance a grade (i.e. A to E) or star system (i.e. 1–5 stars) - would be of interest to them when dealing with information about a new scientific finding in health. Some thought that a higher grade would increase credibility. Others said that such a score would not be of personal relevance as the grades wouldn't deal with their specific case.

Schapiro et al report that the nature of the funders of research was an issue that many of the participants raised an interest in, in recognition that the motivation for conducting a study could lead to biases in study design and interpretation.

Finally, they report that participants in their focus groups described how aspects of their community or culture had an impact on the value placed on scientific evidence in the context of medical decision-making. For instance, attitudes toward 'traditional' medicine appeared to have an influence and family traditions were mentioned as important – specifically, those brought up in cultures that valued non-traditional medical remedies influenced engagement in scientific evidence. Participants did however recognise that traditions change over time and generations, and that the younger generation may be more open to new interventions than their previous generation.

In another study, (Robinson, Kerr et al. 2004) looked at patients' attitudes to clinical trial procedures and found that most participants found it unacceptable to suggest allocating treatment at random in clinical trials, and that the scientific benefits of doing so were not recognised – they did not judge that more certain knowledge would be gained about which treatments worked best by allocating treatments at random, rather than by patient/doctor choice. Around half of the participants were also loathe to accept that a clinician could be completely certain – whether in a treatment or research context.

(McMurray, Cheater et al. 2004), looking at parental decisions around vaccination in the wake of the MMR controversy found that in this particular case, evidence of science and medicine plays very little role in the decision of whether or not to vaccinate their children for most parents. Instead, the primary determinant of whether or not parents decided to vaccinate was prior parental experience of autistic disorders or the mumps, measles or rubella diseases. Such experience informed parents' judgments of the acceptability of alternative outcomes, and the perceived likelihood of a given outcome. There were exceptions, however - where parents, or those known to them, were employed in medical or scientific fields, they acted as informal experts capable of weighing the evidence and informing decision. The authors argue however that in these instances, some parents felt a need to apologise for making a rational rather than emotional response to the controversy that surrounded MMR, with one parent commenting that at some level it 'sounds awful' to be reliant on scientific information, the implication being that as a mother she should just know what is best. Although GPs were trusted sources of information, few parents cited

them as influencing their decisions, suggesting that they were too willing to 'toe the party line' on MMR.

Adding to that, (Cornwell, Hu et al. 2014) found that active healthcare consumers were also more likely to use evidence in decision making.

In terms of attitudes to drugs for disease prevention, risk and efficacy again only appear to be part of the equation for patients. Looking at drugs to prevent cardiovascular disease in particular, researchers have found that there is little enthusiasm for drugs such as statins to be prescribed to anyone over a certain age, with concerns being expressed at the idea of people taking a pill unnecessarily and over possible side effects. As a secondary prevention measure (to those in high risk groups) there was slightly more support, but people expressed similar concerns about possible side effects and inflexibility (Virdee, Greenfield et al. 2015). Many preferred lifestyle changes (Mann, Allegrante et al. 2007). In terms of the acceptability of new drugs, such as the 'polypill', most saw little clinical benefit in changing from an established, effective and tolerable drugs regimen to one that is less flexible and may not reflect their current dosages. Some would however be willing to try a new combined pill if it was suggested by their doctor (Williams, Shaw et al. 2005).

2. Where do people get information?

The overwhelming conclusion of the literature is that the most trusted source of health and medical information is local GPs. For instance, (Rokade, Kapoor et al. 2002), looking at ear, nose, throat (ENT) patients in Wigan found that while 57% attempted to get information before a visit to the clinic, GPs were the source of health information for 64% and was the most trusted source. Likewise, (Dart, Gallois et al. 2008) found that the GP was considered the most trusted important and preferred source of information across three communities of different socio-economic makeup. Similar results have been found in surveys of women seeking information about the menopause (Huston, Jackowski et al. 2009); parents seeking children's health information (Khoo, Bolt et al. 2008); low income HPV positive women (McCree, Sharpe et al. 2006); and patients in clinical trials (Appelbaum, Grisso et al. 1999), for instance.

(Cutilli 2010) reports that older individuals make decisions based on information provided by healthcare professionals even more than younger people do – even when they have access to information from a variety of sources.

Looking at parents gaining medical advice about their children, (Sciberras, Iyer et al. 2010) found that parents preferred to receive verbal information from a health care professional. In contrast however, (Shea-Budgell, Kostaras et al. 2014), looking at information needs and sources of information for patients during cancer follow up, found that patients preferred

personalised written information from their healthcare provider. In this instance, the least trusted sources of information included television, radio and newspapers.

Factors such as health and literacy have been found to affect the sources of information used by individuals. After healthcare professionals, Cutilli (2010) found that the next popular source of information was not consistent in different populations. In groups such as BAME groups the next source of information was friends and family, while the internet was more popular amongst young people. Overall, they found that the white population was more likely to use the internet than those from BAME backgrounds and that those with less education and literacy were more likely to use TV and radio.

(Maloney, D'Agostino et al. 2015), looking at breast cancer patients, found that patients read information most frequently from websites of the cancer organisations. In particular, they turned to these sites for information about side effects, alternative therapies and proven or traditional treatments. Patients planned to discuss fewer types of information with their doctor than they read about, suggesting they were exercising some judgment over the information they had consumed.

Kutner et al (Kutner, United States. Department of Education. et al. 2006) found that individuals with below basic health literacy were less likely to obtain health information from written sources such as books and magazines. Instead they sought 'a lot' of health information from television and radio but overall sought information from less sources than those with higher health literacy. Supporting this finding, in work to profile those individuals with cancer who do not seek health information in the US, (Ramanadhan and Viswanath 2006) found that non-seekers tended to come from the lowest economic and education groups.

3. How do people decide where to get information?

Trust appears to be the key factor in deciding where to get information (Huston, Jackowski et al. 2009). For instance, trustworthiness and knowledgeability were among the most frequently mentioned factors influencing perceptions of medical information source reliability (Tio, LaCaze et al. 2007). (Rains 2007) found that distrust in traditional sources (i.e. healthcare providers) was associated with the use of the web for health information.

Perceptions of helpfulness and knowledgeability were found to be most influential in predicting trust in pharmacists and other health care professionals, along with perceived bias (Huston 2009).

Other factors do appear to be at play in certain instances however. For example, low-income women seeking information about HPV preferred sources that were trustworthy but also accessible and convenient, could be viewed in a private locations and were written in easily understood language. While medical practitioners were the most trusted sources, women also preferred obtaining information from other women with HPV (McCree et al 2006).

On the other hand, uncertainty, frequent shifts in expert opinion and controversy appear to leave people less trusting of medical advice. For example, Huston et al (2009), looking at women making decisions about menopause argued that frequent shifts in expert opinion makes it difficult for women to decide where to turn for trustworthy information. (Dixon, Scully et al. 2009) argue that health consumers may be better able to negotiate conflicting medical information if different sides of the argument are plainly noted and a clear distinction is made between opinion and evidence.

4. How does the media affect views on medicines and healthcare?

The consensus of research echoes the earlier point that information from healthcare professionals has the most impact on patient views – regardless of wider media coverage.

(Passalacqua, Caminiti et al. 2004) carried out a survey across 2600 patients with cancer to see the change in patients' opinions and attitudes at the peak of a media campaign promoting a particular unproven cancer treatment. They found that although the media changed the way patients feel, it did not affect the doctor-patient relationship, nor the decision making process. Similarly, (Chew, Palmer et al. 1995) looked at the impact of a television programme on people's consumption of health information. They found that knowledge levels increased after television viewing, but that the consumption of other media and the use of doctors as health information sources remained the same.

More recently, (Hong 2015) looked at audience responses to television news coverage of medical advances – specifically the role played by emotion. They found that news stories with a human example were more likely to intensify the audience's positive emotions than those without, which in turn influenced favourable perceptions of the medical advance being described. In addition, the extent to which the audience identified with a human example (in particular, sympathy) mediated the relationship between the audience's involvement in the news story and its perception of the portrayed medical advance. They did not however look at how this affects medical decision-making or information consumption.

However, looking at the effect of social media on patients undergoing plastic surgery treatment, (Montemurro, Porcnik et al. 2015) found that almost all (95%) of the 500 patients surveyed had used the internet to collect information prior to consultation and for 65% this was the first search method. 46% used social media and 40% of these were strongly influenced by this when choosing a specific doctor.

5. Influence of the internet

There is wide evidence of increasing use of the Internet as a source of medical information, but in many instances this appears to be as a secondary or preparatory source compared to the advice of medical practitioners (for instance Rokade (2002); Cutilli (2010); Maloney 2015 – already mentioned above; (AlGhamdi and Moussa 2012). Nevertheless, others argue that the fact that individuals do not report the Internet to be an important source of information does not necessarily mean that the information obtained in their Internet searches is not influential in their decisions (for instance (Betsch 2011).

So with that in mind, (Allam, Schulz et al. 2014) conducted an experiment that changed the relative rankings of search engine results. They found that the selection and sorting/ranking criteria of search engines play a vital role in online health information seeking. Search engines delivering websites containing credible and evidence-based medical information have a positive impact on internet users seeking health information, whereas sites retrieved by biased search engines create some opinion change in users and these effects are apparently independent of the way in which users judge the credibility of the websites. The authors argue that website users are affected beneficially or detrimentally but are unaware, suggesting they are not consciously perceptive of indicators that steer them toward the credible sources or away from the dangerous ones.

Conclusions and Questions for Dialogue

From the research to date described above, a number of general conclusions can be drawn:

1. GPs and medical practitioners are seen as the most important sources of advice about the risks and benefits of medicine
2. People believe that evidence from large samples and gathered over a long time-frame is the most reliable
3. Personal experience is seen as more valuable than statistics or probabilities

4. After GPs, the secondary choice of information varied according to educational level, ethnic background, age and gender but includes advice from friends and family, the internet and charities or support groups.
5. Public dialogue and deliberation appears to be an important way for patients and researchers to interact, to improve one-another's understanding and to enable patients to get involved – for instance, in new healthcare models or in testing and regulatory regimes.

For the planned AMS public dialogue events, this last point is possibly the most important – rather than using this as an opportunity to test public knowledge and attitudes to expert perspectives and information, it could be an interesting opportunity to use the dialogue as an opportunity for patients/the public to coproduce knowledge and understandings with the experts themselves. For instance, working together to describe what a mutual vision of what the role of drugs in future healthcare might look like; or developing advice for GPs on how to better support patients in making medical decisions, or a set of guidance for encouraging patients to become more active in their own healthcare.

Appendix 1: Methodology for the Literature Review

Step 1: Identification of relevant literature (UK and internationally)

Relevant literature will be identified in a number of ways to ensure comprehensive coverage:

- (i) A keyword search (see appendix 2) of Google, Google Scholar, SCOPUS and Web of Science databases.
- (ii) Searches of shared lists on academic social media groups such as those on Mendeley and Academia.edu
- (iii) Recommendations from our own bibliographies.

Step 2: Select literature for inclusion in the review

All of the papers and reports identified in Stage 1 were included in a spreadsheet. From this long list, the most relevant papers were identified, to create a focused spreadsheet of papers to be reviewed.

Step 3: Reviewing the literature

Each of the papers in the focused corpus was read and reviewed and key points summarised.

At this point, the quality of the reports was also considered. While we were not seeking to only include peer-reviewed papers, we aimed to exclude, or at least note the shortcomings of any particularly low quality or biased reports (e.g. reports which are clearly setting out to push a particular agenda).

From here, themes and patterns were identified and the literature grouped accordingly. We also identified any possible questions worthy of further exploration in public dialogue.

Step 4: Reporting

Lessons and learning have been summarised into this report, based around key themes and questions emerging from the literature.

Appendix 2: Search terms used in the Literature Review.

Scopus Search

Keywords	total	relevant
medical AND evidence AND public	14,000	too public health
evidence AND public	70,023	focused
"public dialogue" AND evidence	5	0
"public engagement" AND evidence	125	5
Public AND Sources AND Medical	1115	12
Lay conceptions medical advice	7	1
how the public judge evidence	66	3
patient AND information AND		
Sources	27,000	too generic
"public attitudes" AND "sources of medical		
advice"	0	
patients and trusted and sources	194	24
"media influence" And patient	70	9

Public Understanding of Science journal search

Keywords	total	relevant
trusted sources	87	22
patient information	199	7
		nothing not identified
patient sources	183	above
medical communication	427	15
public dialogue evidence	150	1
public attitude sources	500	5

References

- AlGhamdi, K. M. and N. A. Moussa (2012). "Internet use by the public to search for health-related information." International journal of medical informatics **81**: 363-373.
- Allam, A., P. J. Schulz and K. Nakamoto (2014). "The impact of search engine selection and sorting criteria on vaccination beliefs and attitudes: two experiments manipulating Google output." Journal of medical Internet research **16**: e100.
- Appelbaum, P. S., T. Grisso, E. Frank, S. O'Donnell and D. J. Kupfer (1999). "Competence of depressed patients for consent to research." American Journal of Psychiatry **156**: 1380-1384.
- Betsch, C. (2011). "Innovations in communication: The Internet and the psychology of vaccination decisions." Eurosurveillance **16**.
- Carman, K. L., C. Mallery, M. Maurer, G. Wang, S. Garfinkel, M. Yang, D. Gilmore, A. Windham, M. Ginsburg, S. Sofaer, M. Gold, E. Pathak-Sen, T. Davies, J. Siegel, R. Mangrum, J. Fernandez, J. Richmond, J. Fishkin and A. Siu Chao (2015). "Effectiveness of public deliberation methods for gathering input on issues in healthcare: Results from a randomized trial." Social science & medicine (1982) **133**: 11-20.
- Chew, F., S. Palmer and S. Kim (1995). "Sources of information and knowledge about health and nutrition: can viewing one television programme make a difference?" Public Understanding of Science **4** 17-29.
- Cornwell, D., M. Hu and D. Esposito (2014). "Public perceptions of comparative effectiveness research and use of evidence in healthcare decision-making." Journal of comparative effectiveness research **3**: 623-634.
- Cutilli, C. C. (2010). "Seeking health information: what sources do your patients use?" Orthopedic nursing **29**: 214-219.
- Dart, J., C. Gallois and P. Yellowlees (2008). "Community health information sources--a survey in three disparate communities." Aust Health Rev **32**(1): 186-196.
- Dixon, H., M. Scully, M. Wakefield and M. Murphy (2009). "The prostate cancer screening debate: public reaction to medical controversy in the media." Public Understanding of Science **18** 115-128.
- Hong, H. (2015). "Audience responses to television news coverage of medical advances: The mediating role of audience emotions and identification." Public Understanding of Science **24** 697-711.
- Huston, S. A., R. M. Jackowski and D. M. Kirking (2009). "Women's trust in and use of information sources in the treatment of menopausal symptoms." Women's health issues : official publication of the Jacobs Institute of Women's Health **19**: 144-153.
- Khoo, K., P. Bolt, F. E. Bahl, S. Jury and R. D. Goldman (2008). "Health information seeking by parents in the Internet age." Journal of paediatrics and child health **44**: 419-423.

Kutner, M. A., United States. Department of Education. and National Center for Education Statistics. (2006). The health literacy of America's adults : results from the 2003 National Assessment of Adult Literacy. Washington, DC., United States Department of Education ; National Center for Education Statistics.

Maloney, E. K., T. A. D'Agostino, A. Heerdt, M. Dickler, Y. Li, J. S. Ostroff and C. L. Bylund (2015). "Sources and types of online information that breast cancer patients read and discuss with their doctors." Palliat Support Care **13**(2): 107-114.

Mann, D. M., J. P. Allegrante, S. Natarajan, E. A. Halm and M. Charlson (2007). "Predictors of adherence to statins for primary prevention." Cardiovasc Drugs Ther **21**(4): 311-316.

McCree, D. H., P. A. Sharpe, H. M. Brandt and R. Robertson (2006). "Preferences for sources of information about abnormal Pap tests and HPV in women tested for HPV." Preventive medicine **43**: 165-170.

McMurray, R., F. M. Cheater, A. Weighall, C. Nelson, M. Schweiger and S. Mukherjee (2004). "Managing controversy through consultation: A qualitative study of communication and trust around MMR vaccination decisions." British Journal of General Practice **54**: 520-525.

Montemurro, P., A. Porcnik, P. Hedén and M. Otte (2015). "The influence of social media and easily accessible online information on the aesthetic plastic surgery practice: literature review and our own experience." Aesthetic plastic surgery **39**: 270-277.

Passalacqua, R., C. Caminiti, S. Salvagni, S. Barni, G. D. Beretta, P. Carlini, A. Contu, F. Di Costanzo, L. Toscano and F. Campione (2004). "Effects of media information on cancer patients' opinions, feelings, decision-making process and physician-patient communication." Cancer **100**: 1077-1084.

Rains, S. A. (2007). "Perceptions of traditional information sources and use of the world wide web to seek health information: findings from the health information national trends survey." J Health Commun **12**(7): 667-680.

Ramanadhan, S. and K. Viswanath (2006). "Health and the Information Nonseeker: A Profile." Health Communication **20**: 131-139.

Robinson, E. J., C. Kerr, A. Stevens, R. Lilford, D. Braunholtz and S. Edwards (2004). "Lay conceptions of the ethical and scientific justifications for random allocation in clinical trials." Social Science & Medicine **58**: 811-824.

Rokade, A., P. K. D. Kapoor, S. Rao, V. Rokade, K. T. V. Reddy and B. N. Kumar (2002). "Has the internet overtaken other traditional sources of health information? Questionnaire survey of patients attending ENT outpatient clinics." Clinical Otolaryngology and Allied Sciences **27**: 526-528.

Schapira, M. M., D. Imbert, E. Oh, E. Byhoff and J. A. Shea (2014). "Public engagement with scientific evidence in health: A qualitative study among primary-care patients in an urban population." Public Understanding of Science

Sciberras, E., S. Iyer, D. Efron and J. Green (2010). "Information needs of parents of children with attention-deficit/hyperactivity disorder." Clinical pediatrics **49**: 150-157.

Shea-Budgell, M. A., X. Kostaras, K. P. Myhill and N. A. Hagen (2014). "Information needs and sources of information for patients during cancer follow-up." Current oncology (Toronto, Ont.) **21**: 165-173.

Smallman, M. (2014). "Public Understanding of Science in turbulent times III: Deficit to dialogue, champions to critics." Public Underst Sci.

Tio, J., A. LaCaze and W. N. Cottrell (2007). "Ascertaining consumer perspectives of medication information sources using a modified repertory grid technique." Pharmacy World & Science **29**(2): 73-80.

Virdee, S. K., S. M. Greenfield, K. Fletcher, R. J. McManus and J. Mant (2015). "Patients' views about taking a polypill to manage cardiovascular risk: a qualitative study in primary care." Br J Gen Pract **65**(636): e447-453.

Williams, B., A. Shaw, R. Durrant, I. Crinson, C. Pagliari and S. de Lusignan (2005). "Patient perspectives on multiple medications versus combined pills: a qualitative study." QJM **98**(12): 885-893.

Zorn, T. E., J. Roper, C. K. Weaver and C. Rigby (2012). "Influence in science dialogue: Individual attitude changes as a result of dialogue between laypersons and scientists." Public Understanding of Science **21** 848-864.