Ipsos MORI
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Public dialogue on medical evidence

Report prepared for the Academy of Medical Sciences by Ipsos MORI

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In 2016, Ipsos MORI was commissioned by the Academy of Medical Sciences (the Academy)[1] to undertake a public dialogue project which sought the views of the public, patients, and healthcare professionals (HCPs) on how individuals can access, interpret and use medical evidence to judge the potential benefits and harms of medicines.

Over 100 participants – public, patients, and healthcare professionals – attended reconvened events in Glasgow, London and Leeds discussing the central objective for this dialogue: 'how can we all use evidence to judge the potential benefits and harms of medicines?'

This executive summary contains the study's key findings and suggestions for how the study's central objective could be achieved.

Spontaneous views of medicine

Few understood the principle of uncertainty, that as every patient is different, HCPs cannot know with 100% certitude how the patient will respond to medicine. Instead, medicines were typically seen as:

- cures that fix ailments;
- binary: they either work or do not;
- if they are on the market then they should be safe, with the exception of treatments for chronic conditions such as cancer.

Many expressed a strong desire to seek out non-medical alternatives, that was usually driven by a negative experience of taking a medicine due to the side effects. In this context, a decision would be whether to take a medicine or take no medicine and pursue 'alternatives', such as lifestyle changes or alternative medicines. Indeed, throughout this dialogue the issue of side effects was often the determinant of whether or not a medical solution was sought / continued, and it was consequently seen as more salient than medical evidence.

How does the public make decisions about medicines?

Information need	How this manifested itself
A central question was whether the medicine would work.	There was some interest in the effectiveness of drugs, but people did not connect this with the nature of evidence until it was highlighted later in the dialogue. Most saw the 'real test' as their own personal assessment of the effect of a medicine on themselves.

[1] The Academy is the independent body in the UK representing the diversity of medical science. The Academy's Fellows are central to its work: the excellence of their science, their contribution to medicine and society and the range of their achievements are reflected in the Academy's work.

Side effects of medicines and multiple medicines interacting with each other.	This was another salient issue and remained so at the end of the dialogue. The perceived / experienced side effect (mental or physical) could undermine confidence in a treatment plan and lead participants to search for non-medical alternatives.
Another key question was whether the medicine is needed.	Alternatives such as doing nothing, lifestyle choices, and natural remedies were also part of the decision although the severity of the condition itself usually determined the level of appetite for an alternative.
Had it been tested and it had been shown to work.	This was less common and was frequently expressed in a binary format, rather than questioning whether it is the best medicine available or whether there is consistent evidence about a drug's effectiveness. While there was a desire to know that evidence existed, there was less of a desire to hear about the technicalities of the research, such as who had done the testing and the details of the study.

Awareness and understanding of medical evidence

There was limited awareness of the role of medical evidence within medicine development, as well as taxpayer-funded medical research. The views that did exist of the testing of medicine featured the pharmaceutical industry heavily, which gave rise to concerns about the effect of the profit motive on the availability and cost of medicine, partly because so few appreciate the risks and the uncertainty associated with drug development. There was also limited awareness that medical evidence produced by the pharmaceutical industry (or indeed via public funds) can be subject to scrutiny through the regulatory regime, peer review etc.

Medical evidence rarely came into current individuals' decision-making. Personal experience was seen as a reliable way to judge the pros and cons of medicine, with most participants just as likely to seek information from friends and family or patient forums as from an HCP. Participants, including those with multiple health conditions, felt distant from medical evidence and many had this view to the end of the dialogue. It was generally believed that the expectation to use medical evidence had not been instilled in them. HCPs, typically GPs, were seen as the gate-keepers of this information, with most public participants adding that they did not think they were equipped to make sense of medical evidence and were unsure how it might be beneficial in the context of choosing to take a medicine.

Direct seeking of medical evidence was rare among the general public, largely because participants had no real understanding of what it is and thus how it might enable better decision-making in the context of medicine. The few who had searched for it, had been frustrated by a number of barriers such as pay-walls or access that required log-in details.

Reactions to learning more about medical evidence

Generally, information about the regulatory and testing system for medicine increased people's confidence in the evidence generation process, but in certain contexts information about a specific medicine and how it had been tested raised more concerns about that medicine.

Questions about the effectiveness of a drug often led participants to assume it was ineffective, rather than that it might be less effective, or only effective in some cases. Similarly, in cases where a medicine had been available for a long time, some questioned whether further tests were needed to establish if it had the same effect as first thought. There was concern about the historical lack of diversity of trial participants, leading some to doubt medicines that they had an implicit trust in. To some extent learning that the applicability of medical evidence is being addressed by the pharmaceutical industry alleviated the aforementioned concerns about the presence of profit-making motivations in the context of health and wellbeing. However, the issue of uncertainty was something that participants were less accepting of, as in most cases, their expectation of HCP advice is certainty.

Explaining the disconnect between the public and medical evidence

The dialogue revealed a disconnect between the public's decisions and medical evidence, despite the fact that many use some kind of information to inform their decision. The main reasons for this disconnect were:

- The context of the UK health system, where most do not expect to engage with weighing up the potential benefits or harms of a medicine, or to critique their doctor's decision. There was an expectation of paternalism that is, in many ways, appreciated.
- Linked with this, many felt that they were not equipped to question HCP advice relating to potential treatments and the underpinning evidence on which such treatments are prescribed.
- Participants generally did trust HCPs to make decisions in their best interests, reflective of Ipsos MORI's Veracity Index[2]. The level of trust in HCPs combined with the public's assumptions of how medicines work, and the (assumed) safeguards in place from basic research to the point at which medicines become available served as a proxy for trust in medical evidence.

But not all participants said they trusted HCPs or the NHS system. The reasons they gave for this mistrust were:

- Financial considerations: some questioned what kind of motivations might enter into the decisions of HCPs, such as incentives for prescribing certain medicines or treatments.
- Generalist vs specialist knowledge: in general, there was a belief that HCPs who work within a hospital environment as well as pharmacists were more likely to take a "right-first time approach" when it comes to recommendations about a medicine. They were seen to have more detailed knowledge of medicine and treatments, unlike GPs who tended to be perceived as "knowing a bit in a lot of different areas".
- Perceived uncertainty in HCP advice: linked with the point above, there was a belief that GPs did not always know how to best respond to a problem. Because effectiveness was assumed many did not appreciate that "testing" is sometimes the norm, effectively moving a patient from one treatment to another, in order to obtain the best possible health and quality of life outcomes.
- How medicines are conceptualised: as noted, the dialogue identified that some participants conceptualised medicines as cures. For participants whose expectations of a prescribed treatment have not been met, this could affect their propensity to act on HCP advice.

[2] https://www.ipsos-mori.com/researchpublications/researcharchive/3685/Politicians-are-still-trusted-less-than-estate-agents-journalists-and-bankers.aspx#gallery[m]/1/

How HCPs access and use medical evidence

HCPs have different levels of engagement with medical evidence. Specialists are more involved with primary sources and felt able to fit this in around their workload given its narrow focus. In contrast generalists reported accessing medical evidence through various filters and channels such as official guidelines, which they supplement with peer-to-peer discussion.

HCPs felt that there was a clear need to better inform patients, but there was concern that if HCPs are not given better tools to enable this then conversations around medical evidence could damage the doctor-patient relationship. It was also felt that that giving participants unfiltered medical evidence could be damaging to adherence.

HCPs considered an effective medical evidence system as ethical and transparent decision-making in medical research combined with a high quality and comprehensive peer review process. However, most felt this was a destination the medical and science community will find it difficult to arrive at.

Shared decision-making and the role of medical evidence

There are different conceptions of what shared decision-making is. Across the clinical and healthcare community shared decision making is generally accepted to mean putting patients into a full partnership in all clinical interactions. In practice this means patients and clinicians working together to decide on the course of action.

While there was broad support for the principle and its approach among participants, it was also clear that the HCP had a greater authority in the shared decision-making relationship, which many (both HCPs and the public) were, and would continue, to be satisfied with. A power dynamic that favours the HCP was seen as being in the interests of both the HCP, who aims for patient adherence to effective medicines, and the patient, who gains reassurance from devolving responsibility.

We heard of a number of challenges to incorporating medical evidence into patient decision frameworks due to the context in which HCPs and the general public have become accustomed to:

- medical evidence does not always provide answers to the questions patients are asking;
- medical evidence does not always resonate with patients, who struggle to see themselves as a statistic or in terms of a risk that is calculated at a population level; and
- there was a widespread belief that the role of the patient in society is currently one that receives care, rather than taking an active role in learning about the nature of that care.

Conclusions and opportunities

Below we present some ideas that could help address challenges raised in the public dialogue and make medical evidence become less distant from the general public's decision-making.

Opportunity	Target group	Action
Respecting differences in understanding and engagement when communicating to patients	Public and patients	The public have different levels of understanding and interest in hearing about evidence. Some medical evidence can prove useful for people, particularly information around effectiveness, but might be less useful for others. With any communication about medical evidence, communicators should consider how that information will slot into people's decision-making process. If communications do not adequately fit, they may go unnoticed or be potentially damaging to patients' confidence and understanding.
Providing information about evidence-based alternatives	Public and patients	The public has a desire to avoid medication when possible, and wish to do this by pursuing alternatives to medicines. 'Alternatives' can be taken to mean natural or lifestyle alternatives, and many people do not make a distinction between these alternatives (the key distinction for many is between medicating and not medicating). Evidence-based information about possible lifestyle alternatives may fill a gap for many people who might otherwise opt for alternative medicine such as homeopathy, by providing people with a safe and effective alternative to medication.
Informing people about medical evidence	Public and patients	While there was little appetite for having direct access to medical evidence, people do trust that their medicine is based on evidence. However, this trust is often a faith as they have little understanding of the reasons for uncertainty in medical evidence and clinical decisions. Providing people with a greater understanding of uncertainty might help increase the public's acceptance when they don't respond to a medicine. Information here should focus on some of the key reported misconceptions like treatments always being 'cures'.
Support in accessing medical evidence	HCPs	HCPs often talked about the barriers to accessing medical evidence directly, including time and understanding. They also talked about ways to facilitate keeping up-to-date: • collating publications by theme to make it easier to access an overview on a specific drug, or look into a relevant area; • social media/email alerts – some HCPs spoke about using quick summaries on social media and email to keep up-to-date, with the ability to dig further into interesting research; and • facilitating peer-to-peer knowledge sharing – HCPs mentioned that this was invaluable but recognised that they often did not make time to do it. Looking at ways in

		which knowledge sharing can operate and fit into HCPs' schedule might help HCPs keep up-to-date.
Support in understanding the implications of medical evidence	HCPs	Some HCPs found it difficult to assess the implications of some of the research they came across, particularly because results from one to two trials rarely provide a holistic picture of the potential benefits and harms of medicines. Others felt that meta-analyses were not necessarily very helpful in summarising and HCPs felt ill-prepared to evaluate these in-depth. There was a suggestion that using grading systems or kitemarks might be a way of making the assessment of medical evidence easier for HCPs, giving them a quick reference way of evaluating the quality of medical evidence.
Conflict in whether people feel they are influenced by the media	Journalists	Broadly, many people felt like they were not swayed by 'extreme' stories in the media. However, it was clear from the references that people made that they do generally take on board things that are covered by the media. Understanding that there can be a divide between what people say and how they act with regards to health and medical journalism need to be taken into consideration in understanding how research evidence is disseminated in the media.

Introduction

1 Introduction

In 2016, Ipsos MORI was commissioned by the Academy of Medical Sciences (the Academy)[3] to undertake a public dialogue project which sought the views of the public, patients, and healthcare professionals (HCPs) on how individuals can access, interpret and use medical evidence to judge the potential benefits and harms of medicines.

1.1. Background to this public dialogue

In recent years, questions have been raised in the general and scientific media about the evidence underlying decisions about treatment options (for example the use of statins[4] and Tamiflu[5]). The ways in which evidence has been collected and analysed has been a big part of this debate. But a wider discussion of issues such as over-medication and conflicts of interest in the way that evidence collection is funded and/or analysed has also emerged. This has led to questions surrounding the trustworthiness of, and trust in academic researchers, clinicians, the media and the pharmaceutical industry.

These high profile debates caused concern among the Academy's Fellowship and were also the subject of a letter from the Chief Medical Officer to the Academy's President. To explore these issues further, the Academy launched a major work stream called 'Improving the use of scientific evidence to judge the potential benefits and harms of medicines' in summer 2015. This work stream was overseen by an Oversight Group chaired by, Professor Sir John Tooke FMedSci[6].

This workstream has examined the evaluation of scientific evidence for medicinal products and how this evidence is interpreted and assimilated by different groups (including, but not limited to, patients, the public, healthcare professionals, researchers and communicators). It will aim to better align evidence generation with user expectations, and facilitate decision-making about therapeutic options.

1.1.1. Work stream components

The work stream included 4 key sub-projects:

- 'Sources of evidence for assessing the safety, efficacy an effectiveness of medicines' working group - An exploration of the strengths and limitations of the different sources of evidence used to evaluate the benefits and harms of medicines.
- 'Conflicts of interest' workshop - An exploration of the ways in which conflicts of interest impact on the validity (or perception of validity) of evidence.[7]

[3] The Academy is the independent body in the UK representing the diversity of medical science. The Academy's Fellows are central to its work: the excellence of their science, their contribution to medicine and society and the range of their achievements are reflected in the Academy's work.

[4] http://www.bbc.co.uk/news/health-27423152

[5] http://www.bbc.co.uk/news/health-26969811

[6] For further information see http://www.acmedsci.ac.uk/policy/policy-projects/how-can-we-all-best-use-evidence/

[7] Further information and the workshop report can be found here: http://www.acmedsci.ac.uk/policy/policy-projects/conflicts-of-interest-workshop/

- 'Communicating evidence' workshops - An exploration of the ways the communication of evidence informs decision-making.[8]
- Programme of dialogue - An exploration of the perceptions and perspectives of society on scientific evidence (including in the context of shared decision making between the public, patients and their clinicians), culminating in this report.

The overarching report will embrace and inform decision-making about medicines, and develop a list of practical and impactful recommendations relating to the interpretation, weighting, and communication of evidence. These will aim to enable a wide range of groups (as described above) to better consider the benefits and harms of medicinal products. The report will draw on examples of dilemmas in current therapeutic practice, but will not seek to address all such areas of contention, nor to replicate the work performed by the Medicines and Healthcare Products Regulatory Agency and the National Institute of Health and Care Excellence. The remit of this project requires expertise from outside of the Academy, and we have therefore engage widely via a call for evidence, workshops, and further dialogue with a broad range of stakeholders.

1.2. Project design

1.2.1. The dialogue design

The main part of the study consisted of two face-to-face dialogue workshops in London (32 public participants) and Leeds (30 participants) in June 2016. Workshops in the two locations were reconvened so that participants came to a day-long session on Saturday then returned on a week night for a reconvened evening session. The same participants were invited to attend both sessions, and all except two participants returned for the reconvened discussion.

The dialogue workshops were attended by members of the public and patients[9], and they were then joined by GPs and other HCPs at the evening events. This was to enable all participants to join the debate, and for HCPs and the public to have discussions separately and then together. Allowing participants to speak directly with HCPs was key in answering the central dialogue question: how can we all use medical evidence to judge the potential benefits and harms of medicines?

Participants were recruited using a 'purposive sample'; recruited by quota to reflect the spread of ages, gender, life stages and sociodemographic segments of Leeds and London respectively. Participants voluntarily joined the process; and they were incentivised with a thank-you gift of money for giving up their time and to cover their expenses.

As noted, the findings in this report are also derived from a number of sessions with HCPs in different locations. We ran a workshop in Glasgow with GPs, pharmacists and research nurses. This took place in May 2016 before the dialogue events and served two purposes: a) to seek views on the question which the dialogue sought to answer 'how can we all use evidence to judge the potential benefits and harms of medical

[8] Workshop reports can be found here: http://www.acmedsci.ac.uk/policy/policy-projects/communicating-evidence-workshop/

[9] For the purpose of recruitment patients were defined as someone taking more than one medicine.

evidence?'; and b) to help the Ipsos MORI team devise the most effective way of bringing together the public and HCPs in the mainstage dialogue events. Then, before the start of the reconvened dialogue events in London and Leeds, different groups of HCPs took part in extended, three-hour long sessions. Again, their views were sought on how can we all best use evidence to judge the potential risks and harms of medicine. After the session ended HCPs sat at tables with public participants.

Healthcare professionals were mostly recruited using Ipsos MORI's panel of GPs and consultants. The panel members were recruited via an online screener, ensuring a mix of gender and number of years of professional experience. Other HCPs, such as pharmacists, community nurses, hospital consultants and additional GPs were recruited using leads provided by the Academy of Medical Sciences.

1.2.2. Techniques used to enhance the dialogue process

A variety of techniques were used to help people engage with the topic of medical evidence and convey the important yet unfamiliar associated issues. This included exploring topics like competing or conflicts of interests, uncertainty, applicability, conflicting evidence, and so on. The techniques outlined below allowed us to better understand the values and priorities that both the public and HCPs brought to the debate:

- mocked-up pen portraits that pushed research participants into making difficult choices relating to medicines[10];
- an immersive pop-up pharmacy, allowing people to interact with fictional medicinal products, thus bringing "the issues to life[11]";
- educative plenary sessions in which videos illustrated how evidence is generated and dialogue practitioners explained the stages from the lab to medicines becoming available on the market and the checks and safeguards in this process[12];
- a video of HCPs talking about how medical evidence fits with other considerations they have when making clinical decisions and offering clinical advice;
- "drug fact boxes" where participants (public and HCPs) interacted with information on different aspects of medical evidence and discussed the potential implications, including benefits and shortcomings of using this kind of information in practice"[13];
- participants designing a medicine to explore some of the principles of medical evidence generation; and
- allowing participants to ask questions directly to members of the oversight group, and using the groups' expertise as an information drip-feed.

[10] See appendix document.

[11] The pharmacy used in this dialogue is on display at the Academy's office at 41 Portland Place, Marylebone, London W1B 1QH until

[12] See appendix for plenary presentation. Generating evidence video: http://www.testingtreatments.org/ecran-video-introduction-to-clinical-trials/?nabe=4876413604724736:2#jump

[13] See appendix document.

1.2.3. Stakeholder involvement

In developing the dialogue approach and stimulus Ipsos MORI consulted with stakeholders within and beyond the immediate commissioning client sector by interview and in a materials development workshop where they contributed their thoughts as to the issues they thought should be raised with the public.

At the outset Ipsos MORI also met with the Academy's Oversight Group for the medical evidence workstream who were able to contribute to discussion of materials and approaches used within the dialogue, and to provide a sounding board for the final report.

1.2.4. How were healthcare professionals involved at the events?

Attending HCPs were briefed by the facilitation team to join in, in an informal fashion, with discussions, while also giving participants time and space to develop their own ideas. Several HCPs sat with a particular group of participants, such that across the dialogue different groups had exposure to HCPs working in different specialisms, including GPs, consultants, nurses, pharmacists, clinical nurses, hospital consultants and others. HCPs also had one-to-one conversations with individuals in breaks and lunchtimes. This naturally gave participant groups different perspectives on the issues discussed.

Conversations with the HCPs typically started with a more formal introduction to the group where the HCP described their work. Then the HCPs became part of the general conversation. Responding to participants' questions, the HCPs were able to offer tailored explanations of if and how they access and communicate medical evidence, as well covering the range of considerations they have when prescribing a medicine. This helped participants understand how very complex issues can underpin the nature of conversations between patients and HCPs.

Feedback from independent evaluation suggests that both the public and HCPs found it rewarding to have the opportunity to speak to one another candidly about the issues. From an enquiry perspective, these conversations helped us to better understand how the public conceptualise medicine, the trust they place in HCPs to make decisions in the best interests of their patients, and the level of appetite amongst both the public and HCPs for shared-decision making on medicine and the role of medical evidence in that context.

1.3. How to read this report

1.3.1. Interpretation of findings

For reporting on dialogue we use the conventions of qualitative social science reporting, described in the following table.

Qualitative reporting	Value to decision making
Deals with a small sample: in this case we are describing the views of 62 members of the public, including patients.	Reflects, rather than represents, the public as a whole.

Gives insights into typical perceptions, thoughts and feelings of people, rather than statistically reliable evidence.	Allows hypotheses about the drivers of beliefs and perceptions, grounded in evidence. Identifies areas which could be investigated further, perhaps quantified, or discussed with wider groups.
Where views apply only to a subset of participants, e.g. participants in London, we have highlighted this in the text.	Allows identification of differences by region.
We indicate via "a few" or "a limited number" to reflect views which were mentioned infrequently and "many" or "most" when views are more frequently expressed. Any proportions used in our reporting should be considered indicative, rather than exact.	Provides an understanding of the strength of feeling about a point and also a sense of which ideas enjoyed most 'air time'. Does not give 'false quantitative' answers as it avoids counting the (statistically not significant) numbers of people who held particular views.

1.3.2. Structure of chapters

An initial introduction sets out what each chapter contains.

A text box gives you key messages and together these text boxes form the executive summary of the document.

We then describe the findings and implications in detail illustrated by verbatim quotations from participants. In brackets there is a reference to where the quote is taken from: 'London' and 'Leeds' for Event 1; 'Reconvened' for Event 2; 'HCP, Reconvened / Leeds / London', if the quote comes from a healthcare professional.

The remainder of this report is structured as follows:

Chapter 2: sets out a range of starting points for participants; it covers how medicine is conceptualised, views and understanding of medical evidence, and the variety of information sources used to make health related decisions. It ends with commentary on the apparent disconnect between the public and medical evidence.

Chapter 3: looks at participants' reactions to learning more about medical evidence and their thoughts on the content and the adoption of communication tools (drug fact boxes) containing medical evidence.

Chapter 4: looks at HCP views of medical evidence and its role in their clinical decisions.

Chapter 5: looks at how HCPs think the public conceptualise medicine and medical evidence, how HCPs perceive their own role when it comes to clinical decisions, and the role of medical evidence within that.

Chapter 6: looks at the potential for shared decision-making and the role of medical evidence within this.

Chapter 7: sets out the study's conclusions and considers a series of measures to support the public and HCP's use of medical evidence to judge the potential harms and benefits of medicine.

1.3.3. Glossary of terms

This report deals with issues that are technical in nature. Below we provide some explanations for some of the terms that are used in the report. Please be aware that these are general definitions and **do not necessarily reflect the meaning that participants attributed to them** throughout the report. In cases where participants are quoted as using these terms in a different way, these differences are usually commented upon in the text. In order to distinguish some concepts from similar ones in the list, there is also a brief explanation of where a distinction might lie between similar ideas.

Term	Explanation	Related concepts
Adherence	Adherence refers to the degree to which a patient follows an agreed course of medical action correctly.	Adherence differs from **compliance** insofar as adherence implies the presence of the patient's involvement in deciding the course of treatment to be adhered to. Adherence and compliance also differ from **concordance** in that this is a wider concept that describes the involvement of the patient in the making of decisions and the communication of medical information from the healthcare professional[14].
Comorbidities	A comorbidity is the presence of additional conditions and diseases that occur concurrently with a primary disease or disorder. A patient with co-morbidities has multiple conditions or diseases at the same time.	
Compliance	Compliance is the degree to which a patient follows the instructions of the healthcare professional.	See **adherence.**
Concordance	Concordance refers to the concept of patient involvement in the decision-making process, including the communication of medical information from healthcare professional to patient.	See **adherence.**

[14] There is significant discussion of the differences between compliance, adherence and concordance in the literature. The distinction used here has been derived from Horne at al. (2005) 'Concordance, adherence and compliance in medicine taking', http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0007/81394/ES-08-1412-076.pdf (accessed: 24/08/16)

Drug safety	The safety of a drug refers to measures that are taken to identify and mitigate against adverse effects.	
Effectiveness	Effectiveness in relation to medicines refers to the ability to achieve a required result in a patient. Effectiveness includes different criteria of a successful medicine, including whether it is efficacious and whether a specific patient responds to it.	
Guidance / guidelines	These terms refer to information that has been derived from medical evidence to provide summarised and consolidated access to medical evidence. Examples include NICE pathways (for HCPs) and www.patient.co.uk (for the public).	**Guidance and guidelines** are, again, subsets of medical information that take medical evidence as their starting point, but aim to be more accessible and practical than **medical evidence.**
Medical evidence	Medical evidence is information that supports a specific claim about the characteristics of medicines and treatments. In this report, it frequently refers to outputs of clinical trials and other tests that follow principles of scientific research, for example, research papers.	Medical evidence differs from **information** in that it is a sub-set of information. Evidence is a specific type of information about a medicine that systematically tests a claim using scientific methods and describes the results of this claim in an unbiased way.
Medical information	Medical information is used in this report to describe any kind of information about the effectiveness, side effects or other characteristics about a medicine or treatment.	Medical **evidence** is one type of information that people may receive about treatments. Medical information can be derived from medical evidence (in the form of **guidance or guidelines**) or it may be entirely unrelated to medical evidence, like anecdotal evidence.
Placebo	A placebo is an inert substance used as a comparison to a drug or treatment in blinded trials. Placebos are given in certain studies to provide a control group to compare the effects of the real drug against.	

The range of public starting points

2. The range of public starting points

This chapter explores the range of public starting points, looking at how participants conceptualise medicine and medical evidence, where people obtain medical information from and the extent to which this is used in people's clinical decisions.

Key findings

- **Some common misconceptions about medicines included:**
  - **they are cures that fix ailments;**
  - **they are binary: they either work or do not;**
  - **if they are on the market then they should be safe, with the exception of chronic treatments.**
- **Many expressed a desire to seek out non-medical alternatives. This meant taking no medicine or pursuing 'alternatives' like lifestyle changes or alternative medicines.**
- **Participants had very limited understanding of how medical evidence is generated and which actors are involved in this yet most associate drug development with pharmaceutical companies.**
- **Despite the concern around the existence of the profit motive in the practice of medicine drug development, there was an assumed system of checks and balances on the pharmaceutical industry.**
- **Medical evidence rarely came into patient decision-making and many saw personal experiences as reliable and trustworthy.**
- **While direct seeking of medical evidence was rare, there are barriers (e.g. pay-walls) that make this even more challenging.**
- **Many people felt that it was not their place to be looking up medical evidence and that this expectation had not been instilled in them. The doctor was seen as the gate-keeper of this information.**

2.1. Views on medicines

Participants' different attitudes towards medicine can be seen through the lenses of 'medicines cure' or 'medicines harm'. Which of these perspectives participants start from is one of the key determinants of their being more or less receptive to taking a medicine. There was focus on whether a medicine would fix a problem, rather than considering that medicines could have different levels of effectiveness and side effects, reflecting the low awareness of uncertainty and applicability.

There was very low awareness that the same medicine can have different outcomes (i.e. better / worse / no effect) for people with the same condition. For most participants, if a medicine is made available on the market and it is prescribed then it should be effective. Participants described getting the right medicine for their problem / symptoms, rather than getting the right medicine for them as a patient (which is how HCPs[15] talked about it).

Medicine was often seen as one of a suite of solutions to people's health problems. There was strong support for non-medical alternatives such as natural remedies, and lifestyle changes were seen as a panacea for not having to take preventative and long-term treatments. Support for such alternatives was often based on hearsay, a desire to believe that non-medical options work, but also personal experiences of alternative medicine or bad experiences of taking medicines.

"I go homeopathic first, always. If the holistic remedy didn't help my case, then I'd go see a doctor".

London, event 1

Many of those who rejected the idea of preventative and / or long-term treatments said they would rather "do nothing"; the potential condition not being immediate enough for people to take these long-term risks seriously.

2.1.1 Explaining attitudes towards medicines

We identified several key factors which influence how receptive participants are to a medical solution.

- side effects – the nature of side effects was the key factor in whether or not people choose to take a medicine and was the key point of interest for participants throughout the dialogue. If side effects are considered too onerous, the medicine itself does not have the expected outcome (e.g. cure), and the symptoms can be tolerated without a medicinal intervention, then there was usually support for non-medical solutions. For people with multiple conditions, although some of their concerns differed (e.g. what is the effect of multiple treatments interacting with one another?), they were more likely to see side effects as a 'necessary evil'.

"I've had to take tablets to counteract other tablets. I didn't need them at first, but I need them because I'm taking the other ones, and that puts me off taking it but I still do".

Leeds, event 1

[15] See chapter 5 for discussion on views of HCPs relating to medical evidence.

- severity of condition[16] – for minor ailments with a low pain threshold and conditions for which individuals believe there is a low chance of harm, there was support for a variety of non-medical interventions. However, when the context was a life threatening condition, participants unanimously supported an evidence based medicinal solution. A change in the healthcare context, from GP surgery to hospital triggered a similar response.

"I'm not really a medicine person. I'll take it but I have to be really poorly to take it. I'd try to fight it as best as possible unless I'm really in bad pain. I try to stay away from medicine and use natural stuff".

Leeds, event 1

- individual affected by condition – throughout the dialogue participants were asked to consider their attitudes to medicines if a child and / or family member had a condition, rather than themselves. Again, this change of context shifted support towards a medicinal intervention.

2.2. How is medical evidence conceptualised?

There was very low awareness of what medial evidence is and it is something which does not currently feature when it comes to choosing whether or not to take medicine. Medical evidence was usually conceptualised as something which is factual and proven. There was very low awareness of the idea that medical evidence is effectively the best that 'science' currently knows, linking to another misconception that if a medicine is prescribed then its effectiveness is assumed. It was difficult for participants to weigh up considerations of how effective a drug could be – questions were about whether or not the drug would work, rather than to what extent it would work. There were some spontaneous mentions of 'statistics' and 'probability' but these were very uncommon, reflecting a limited appreciation of uncertainty and applicability.

Medical evidence was usually associated with clinical trials and testing on animals or people but few understood the different types of study design, or that placebos are used to understand effect. Participants generally did not know that testing for safety and effectiveness can be an-ongoing process (even after a drug is available on the market), through pharmacovigilance observational studies for example. There was much better awareness of scenarios where treatments administered in trials have had unintended, negative consequences, with many participants having heard about people who have been harmed due to an adverse reaction to a trialled or prescribed treatment.

"But, my concern isn't the feedback from the users, I am concerned about the testing that was done before the drug was marketed. No one my age forgets thalidomide".

London, event 1.

[16] It is important to note that most participants in the dialogue had not experienced any serious illness and / or condition, thus attitudes towards medicinal interventions were typically grounded on experience of problems with relatively low levels of discomfort, rather than life threatening or long-term conditions.

2.2.1 Upstream is seldom top-of-mind

Most participants associated medical research exclusively with the pharmaceutical industry. This itself raised a number of number of assumptions, namely:

- That the pharmaceutical industry makes excessive profits from people's discomfort. There seemed to be a genuine unease about the profit motive associated with health, which itself is tied up with concern about the perceived privatisation of the NHS.

- Although there was some recognition of the time and resource needed to bring a medicine to market, and the number of products which fail to make it there, there was a belief that drug prices are inflated and, consequently, constrain HCPs from prescribing effectively.

- A few speculated that testing carried out in the absence of the profit motive (e.g. publicly funded research institutes) is more rigorous and independent, so concluded that these test results are likely to be more trustworthy.

"Business, the medical industry is a business more than to help people".

London, event 1

Participants with multiple conditions had a better awareness that medical evidence is generated by both the public and private sector having received information about the development of treatments via patient groups and / or medical research charity websites. However, even here there was frustration that it can be difficult to find out the outcomes of trials.

In terms of the place of regulation and licencing, again there was very low awareness. Although it was assumed that a system of checks and safeguards are in place, few could provide any details. Overall, it was assumed that the historical system of checks and balances was less rigorous than the current one.

2.3. How decisions about medicine are made

While participants spoke of a wide range of information needs when choosing whether or not take medicine, it was almost always medical information[17] rather than medical evidence which informed it.[18] Decisions about the course of action would be based on questions about the treatment that patients said they would ask, either of themselves or of HCPs.

[17] Medical information is used in this report to describe any kind of information about the effectiveness, side effects or other characteristics about a medicine or treatment.

[18] Medical **evidence** is one type of information that people may receive about treatments. Medical information can be derived from medical evidence (in the form of **guidance or guidelines**) or it may be entirely unrelated to medical evidence, like anecdotal evidence.

Table 1: the reported information needs of public participants

Information need	How this manifested itself
A central question was whether the medicine would work.	There was some interest in the effectiveness of drugs, but people did not connect this with the nature of evidence until it was highlighted later in the dialogue. Most saw the 'real test' as their own personal assessment of the effect of a medicine on themselves.
Side effects of medicines and multiple medicines interacting with each other.	This was another hugely salient issue and remained so at the end of the dialogue. The perceived / experienced side effect (mental or physical) could undermine confidence in a treatment plan and lead participants to search for non-medical alternatives.
Another key question was whether the medicine is needed.	Alternatives such as doing nothing, lifestyle choices, and natural remedies were also part of the decision although the severity of the condition itself usually determined the level of appetite for one.
Had it been tested and it had been shown to work.	This was less common and was frequently expressed in a binary format, rather than questioning whether it is the best medicine available or whether there is consistent evidence about a drug's effectiveness. While there was a desire to know that evidence existed, there was less of a desire to hear about the technicalities of the research, such as who had done the testing and the details of the study.

HCP advice was seen as a vital resource for patients when faced with such questions. However, there was a marked difference between individual doctors, who were trusted, and doctors in general, who were criticised for a whole variety of reasons, including the perception of inconsistent advice, and lack of specialist knowledge. As such, some considered HCPs the starting point, with many undertaking their own research or checking with other HCPs, in particular pharmacists for their own reassurance.

2.3.1 Medical evidence in decisions?

Although many participants do engage with information to inform their decisions, either before and /or after their interaction with an HCP, evaluation of medical evidence rarely came into participants' decisions. Instead they were influenced by a range of sources, namely:

- anecdotal evidence and personal experience;
- 'official' sources such as the information leaflet which comes with a medicine;
- sources which reflect their own attitudes (e.g. website for alternative medicine); and
- testimonials from people with similar conditions (e.g. charity websites, patient forums).

Some use these sources in isolation, while others cross check information from one source to another, so even those who are more receptive to a non-medicinal solution may also check what medicinal options are available.

For those who access multiple sources, usually participants with multiple conditions or those who have had a negative experience with a medicine and / or HCP, such cross-checking increased their confidence in the

information they choose to believe. Others felt more equipped to challenge HCP advice or to have a more informed conversation with an HCP if they had checked multiple resources.

"I try to get information from all sources. I follow my feeling about it. I won't listen to just friends. I try to get all the information and question it. Mainly from internet, books, GP".

London, event 1

Many however remained satisfied to act in accordance with HCP advice, either because they were confident that an HCP would make a decision in their best interests or they assumed they would not be able to make sense of medical evidence even if they could find it. Overall, if a problem 'felt' serious then more often than not participants would seek out HCP advice, rather than rely on other information sources.

2.3.2 Critical pieces of information on the information leaflet

For many, the decision whether to take a medicine would be informed by the nature of the information provided in the leaflet, although again this was often in the context of a relatively minor condition. Few appreciated that the information is derived from medical evidence, and there was little understanding that leaflets are intended to convey the uncertainty of drug outcomes on different people. Here, salient information was possible side effects and practical information like frequency and administering.

"I've been prescribed tablets, read the side effects and then decided not to take them".

London, event 1

2.3.3 Individual experience often on a par with evidence based research

Despite fairly high awareness that clinical trials are one of the principal ways in which medical evidence is generated, individual experiences was often seen as another form of medical evidence.

"Through medicines I get less seizures, less back pain, less sweats, this is my evidence for them working".

Leeds, event 1

Indeed, there was a sense that a person is the 'test case' for the medicine and the decision on whether or not to take it was informed by their own assessment of whether their condition had improved and any side effects not being too onerous. Similarly, medical evidence was also seen as the experiences of people who have the same health problem and participants said they take seriously anecdotal evidence (e.g. online testimonials or word-of-mouth) on what medicines have been taken and the effect it had.

"The only good medical evidence that I would trust is friends that have taken medicines that have told me about what they've taken. They have one ailment, they take something for that, they take another tablet to reduce the water retention, another to thin the blood, they have a whole medical cabinet at home. I asked what effect it had on them".

Leeds, event 1

2.3.4 Internet and social media

Participants' internet-searching habits were multifarious and it was no different when they looked for information about medicines, with people doing internet searches, accessing online patient forums, charity websites and social media. Participants saw the internet as a place where their questions are answered /or where they gather pieces of information which support their views (i.e. confirmation bias). This played out in two ways when it comes to medicines: discussing what they found online with HCPs (usually GPs), or combining it with advice from GPs and / or others who have the same condition, to decide whether to take a medicine.

"I heard about not giving anti-inflammatory drugs like ibuprofen to children with chicken pox; and brought this up discussion with GP".

London, event 1

Those who accessed medical information online were more likely to search for symptoms and engage in the question of what their diagnosis might be / what treatments have worked for others with the same condition, than they were to investigate underlying medical evidence (e.g. about effectiveness).

While different types of information were frequently considered as 'evidence', only a few participants had used the internet to engage directly with medical evidence such as academic papers of clinical trials. Typically, this was participants who had been prompted by a family member's condition and / or their own condition. One participant described how, having searched for information about their child's condition and being confused by the number of search results, they chose to look for relevant research published by a reputable university, seen as a proxy for reliable and trustworthy information. However, they were left feeling frustrated as detailed information on the nature of the evidence could not be accessed without the necessary log in details. Participants also rightly identified that access to evidence often required a paid-up account.

"You have to be a doctor [to gain access to the journal]. Why is it so limited, not honest and open?"

London, event 1

Many said they struggled to know what is reliable and trustworthy online. There was appetite for further information on medicines, suggesting a role for evidence based information that can enhance decision making, provided it is communicated in an appropriate manner.

2.3.5 Media coverage a key influence on behaviour

There was frustration with the nature of media reporting about medicines[19]. Participants bemoaned sensationalised reporting of new 'cures' or 'breakthroughs', conflicting reports on medicines like statins and hydrocortisone and a lack of sufficient contextual information.

"The media work to extremes. If it's really bad, it's really bad. If it's really good, it's really good. You don't get that middle ground: 'this works over a certain period of time".

London, event 1

Media coverage of specific studies (e.g. statins) was reported to affect people's behaviour and decision-making, an effect which is exacerbated by the lack of engagement with the details of medical evidence[20].

[19] See http://www.acmedsci.ac.uk/policy/policy-projects/communicating-evidence-workshop/ for information on the Academy's 'Communicating evidence about medicines' events.'

[20] It has been suggested that the widely reported controversy surrounding the effectiveness of statins resulted in c100,000 people having stopped taking the pill, which is estimated could lead to 2,000 extra heart attacks or strokes in the next decade. Bhaskharan, Smeeth, Goldacre et al. (2016), 'Impact of statin related media coverage on use of statins: interrupted time series analysis with UK primary care data', *BMJ 2016;353;i3283* http://www.bmj.com/content/353/bmj.i3283

Reactions to learning more about medical evidence

3 Reactions to learning more about medical evidence

A range of research techniques were used as starting points for discussions about medical evidence and the issues associated with it such as applicability, vested interests, and when and if testing had taken place:

- A pop-up pharmacy allowed participants to pick up fictional medicinal products and read about the evidence behind the medicines.
- A series of pen portraits were presented to participants, each addressing different issues associated with medical evidence.
- Participants watched videos learning about how medical evidence is produced and the checks and balances from lab to market.
- Drug facts boxes were shared with participants to give examples of how evidence of benefits and risks of a treatment could be communicated in a digestible form.

This chapter looks at how people reacted to the information and the resulting discussions it triggered.

Key findings

- **Generally, information about the regulatory and testing safeguards for medicines increased participants' confidence in the evidence generation process, but information about testing (e.g. representativeness of trial participants) led some to question the system.**
- **Questions about the effectiveness of a drug often led participants to assume it was ineffective, rather than that it might be less effective, or only effective in some cases.**
- **Participants had concerns about the involvement of the pharmaceutical industry in the medical evidence process, and, particularly, the presence of profit-making motivations and its effect on the cost and availability of treatments.**
- **Misunderstandings around statistics were common – statistics describe effects of medicines that most participants do not engage with and find difficult to evaluate.**

3.1. Pop-up pharmacy

The pop-up pharmacy was commissioned by Ipsos MORI especially for this dialogue. The installation was designed to imitate a pharmacy, with its rows of medicine. Each box of drugs had its own short description of an issue in medical evidence. The example of fictional penicillin is provided overleaf.

FICTIONALYCILLIN

Antibiotics are used to treat, or in some cases prevent infections caused by bacteria in different parts of the body.

Penicillin, the first antibiotic drug to go into mass production, was tested and developed by pharmaceutical companies in the early 1940s. It has not been put through any testing since it first went into production.

3.1.1 Pop-up pharmacy: effectiveness

The information participants were presented with seemed to undermine some of the confidence that they had in medicines and the medical system. When introduced to the probability that a drug would be effective, some said they would not want to bother taking a drug that they assumed would be ineffective.

Effectiveness of medicines were dealt with in a few forms in the pop-up pharmacy. One example that led to particular concern was the declining effectiveness of antibiotics even though they were aware of the over-prescription of antibiotics. However, others interpreted this as redundant, rather than just less effective, and as result advocated alternative medicines as optimal.

"What I've got here, 'losing effectiveness at an increasing rate', I won't take that medicine then, it's a waste of time".

London, event one

3.1.2 Pop-up pharmacy: applicability

Linked to effectiveness of drugs, participants were also introduced to the idea that medicines are not always tested on a large and diverse number of people, and can frequently be tested on smaller populations with specific characteristics, such as ethnic groups. There was concern that the outcomes of such drugs could not be predicted and wanted confirmation that trial participants are representative. Others questioned research that had been conducted in other countries, even where these countries were comparatively similar to ours as those populations could have different characteristics to the UK.

"Also I want to know the country it was done in. I think it has an effect if it's in America. Health conditions in minorities, mental health could be different than over here".

Leeds, event one

Pop-up pharmacy: risks

The 'fakeastatin' product helped illustrate the issue of the potential harms and benefits of preventative medicine. Some incorrectly interpreted the information on the box that this drug could raise the chances of diabetes by "10-22%" as 10 to 22% of people on the drug would become diabetic. However, once explained people did see benefit in having information about risks included on packaging although there was preference for a different format.

"You can look at that and make an informed decision, taking a low dose, 1 in 1000, that's fairly good odds, that's better than 40 out of 100".

Leeds, event one

Pop-up pharmacy: testing and research

Introducing information about some of the deficiencies behind the testing of a drug – such as the sample size, the extent to which the study was blinded, the fact it had not been tested for many, or it had never undergone testing - also raised concerns about the safety of medicine, with some suggesting that any issue in the reliability or the perceived validity of the evidence is a reason for not taking the drug.

"I'm happy I'm allergic to it [penicillin] so that I don't have to take it. It makes you question what other things haven't been tested".

London, event one

3.2. Pen portraits

Following the pop-up pharmacy, participants were shown three fictional pen portraits for Phil, Pauline and Maria, each illustrating key issues in medical evidence.

- Phil – Phil is presented with two drugs, one of which is independently tested and widely used and the other drug is newer, and claims to be more effective, but has only been tested by pharmaceutical companies.
- Pauline – Pauline has been offered a medicine that if she takes it every day can reduce the risk of a heart attack, but Pauline struggles to work out exactly how much the drug might reduce her chances of a heart attack.
- Maria – Maria is a seven year-old with a rare condition that affects her concentration levels. No studies on the standard treatment have been done in children. Given the lack of evidence, Maria's mother is told by the doctor that doing nothing would be a reasonable option.

This section discusses the reactions to each pen portrait[21].

3.2.1 Pen portrait: Phil

Suspicion of vested interests

Participants often felt that Phil would be rightly confused in this situation and potentially stressed by the decision. The consensus across the groups was that opting for drug 1 was the safer option because it had undergone more testing. Although drug 2 was shown as having fewer side effects, it was generally assumed that the pharmaceutical company would have a strong motive to manipulate the results.

Others suggested that if it was on the market then it had been tested and so it should be safe. Regulation was seen as being able to constrain the bad practices of pharmaceutical companies, although for many they wanted to see more punitive action in relation to price control.

Distrust of profit

Although distrust was usually seen in the context of the pharmaceutical industry, concern was generally about the existence of the profit motive in the entire healthcare and clinical ecosystem. There was also concern where pharmaceutical companies worked with academic researchers. Rather than raising pharmaceuticals up in the eyes of participants, these partnerships dragged academic researchers down, suggesting they could be influenced by commercial interests.

Transparency was viewed with suspicion as well. Participants were sceptical as to whether the pharmaceutical industry would open up all of their research, or only release that which would assist their cause. Some asked whether the public needed to see this information, so long as regulators do.

[21] See appendices for the full case studies as presented to participants.

"The public perception of pharmaceutical companies is based on information we have read about them supressing information".

London, event one

Looking for another option

Participants often felt that they needed to find a 'third option', because they did not like either of the options available in the pen portrait. These third options could involve different alternatives, including getting a second opinion or speaking to friends and family. Others felt that Phil was best trying drug 1 to see if he was going to get the side effects and then, if he did, moving to the other drug instead. Frequently, participants would opt for the most risk-averse option, even if this was not given to them as a choice.

"In this case though, if [drug 1] was giving you side effects, you could just stop. It won't kill you".

Leeds, event one

3.2.2 Pen portrait: Pauline

Preventative medicine?

Many people felt that Pauline should not be taking any medication if she was not ill. Some spontaneously mentioned their own experience of turning down statins due to concern of the side effects and their stated low risk profile in terms of developing heart complications. As such there was a reaction to advocate better lifestyle, even though they described not leading particularly active lives.

Other spoke of a desire to do what it takes to prevent heart disease, particularly, when people can understand the benefits in terms of increased lifespan and health. This led participants to become more focussed on the chances of it benefiting them, but felt that to make an informed decision they would need to be certain about its benefits.

"How many people are taking it and how many people went on to have a heart attack?"

Leeds, event one

3.2.3 Pen portrait: Maria

Applicability of research

Many people saw the lack of applicable research as a real issue, as in the absence of proof they would not accept medicine for them or their children. Others felt that such medicine should be tried because doing nothing was always worse and suggested mitigating the risk by starting Maria to start on a smaller dose. Others felt that the treatment was too dangerous to be tried, especially as the condition was not life-threatening.

"You know what the condition causes, but if she takes that medication, it's unknown. She could take it once and she could die".

London, event one

Alternative ways forward

Participants felt that Maria's mother was in an unenviable position. They recommended various ways of overcoming the situation, including obtaining a second opinion, educating herself about her daughter's condition, and learning more about the options available (including medical alternatives).

"She can research into a holistic alternative healthy way to introduce things into the lifestyle to support her child's issues".

London, event one

Responsibility of children

Participants also expressed concern about Maria and her capacity to make decisions. While they felt she should have a say in the process, they believed that the end decision-maker should be Maria's mother.

"You could tell her there was a way she could get better. I wouldn't communicate risk to her because that's not something she needs to know. That's something you, as a parent, make a value judgement on. If she said she wanted to try it, I'd take that into consideration".

London, event one

Because this pen portrait involved a child, most felt that a medical solution was necessary but that it should be quickly halted if the medicine appeared to make her worse.

3.3. Stimulus videos

Participants were shown two different videos that provided them with different perspectives on medical evidence.

- Before the afternoon of day one, participants were shown a video of healthcare professionals (recorded at the Glasgow HCP event) speaking about how they use medical evidence in their practice.
- At the end of day one, participants were also shown a video about the process of generating medical evidence, designed to give them more technical understanding of what clinical trials are[22].

[22] The video can be found here: http://www.testingtreatments.org/ecran-video-introduction-to-clinical-trials/?nabe=4876413604724736:2#jump

They were then given the opportunity to discuss the issues raised in these videos in greater depth.

3.2.4 Healthcare professional video

This video allowed participants to hear directly from healthcare professionals about how they use medical evidence and include patients in this process.

Participants wanted to know how prescription of drugs becomes individualised, given the differences in the population. Many people were curious about how HCPs actually make decisions about patients and how they take their views on board to ensure that they deliver a personalised form of care.

"I want to know, how do they individualise it, rather than it being generic? Applying drugs generically to people, or do they sit down with a patient and say, 'This is your medical history, and based on this this is the drug that you should take.' You don't see the GP on a regular basis, they don't know you, they don't know your history, they can't read everything before your appointment".

Leeds, event one

Other questions were more specifically about how medical evidence is used in their practice. Participants were curious about how HCPs judged evidence, and how they could overcome perceived biases in the evidence like the role of vested interests in the generation of the medical evidence. Others wanted to know if HCPs actually kept up-to-date with evidence, or whether or not they questioned their own decisions.

"How many actually do that? I have never been in a consultation with a doctor where they have gone for a second opinion. I have even seen some doctors type into google what my symptoms are. You don't want to challenge your doctor on their profession, so you will just go home and research it yourself".

London, event one

This video encouraged participants to think about their interactions with healthcare professionals. Here, there was a general tone of scepticism that healthcare professionals had weighed up these issues when discussing a possible of course action.

3.2.5 Video about clinical trials

The video shown at the end of the first day was a digested explanation of how clinical trials are conducted, with concepts like randomised control trials and representative samples explained.

Participants were surprised by some of what they saw in the video. Some did not expect that drugs that are approved would have to be measurably better than those that are already offered and there was surprise that double-blinding existed to eliminate the bias of scientists, although for others this just supported their scepticism in the claims of scientists.

"In natural sciences when you do research you think everything is empirical and objective. Scientists are still biased in certain areas depending on the scientists, so this is good to have".

London, event one

Others were concerned about the possibility of there being higher and lower qualities of evidence, interpreted to mean that some drugs would not be as rigorously tested as others. Broadly speaking, however, the information conveyed on clinical trials did seem to surprise people and fill in some of the gaps that people had expressed around how medical evidence is generated. In some ways, the video confirmed their concerns, but at the same time gave some reassurance that their faith in some kind of system of checks was warranted.

3.4. Drug facts boxes

After the healthcare professionals had joined participants at the reconvened event, drug facts boxes were introduced, which the public and HCPs discussed the content and implications of.

3.3.1 Using the facts boxes

Attitudes towards using the facts boxes were mixed. Those who were positive generally felt that the fact boxes could fit into their current decision routines, such as discussions with the doctor or using them as an additional information sheet to take home after consultations.

"I like the idea of this being used to facilitate an open dialogue with my doctor. At a glance you can get an idea from this, and you could take it away and then come back. It gives you confidence".

London, reconvened

Others found the information challenging to understand, especially where risks and effectiveness were communicated using statistics. It was felt by some that it would require an HCP to help them interpret it. Some felt that they might find the information useful if it was long-term medication, but they might put less effort into understanding it in the short term.

"I didn't think it was helpful. It's ambiguous as it stands. How many times are we going to have a [doctor] sat next us whilst we're reading the pamphlet?"

Leeds, reconvened

3.3.2 Information about side effects

One of the key pieces of information that the facts boxes provide is straightforward information about the most common side effects. This was seen as the most important thing that the facts boxes could offer participants as it allows people to safeguard themselves, where the side effects could have a detrimental effect on behaviour for instance driving a vehicle.

"You can't dish out lots of figures. The important bit for me is about the side-effects. If these are potential side-effects, if this person is so much at risk, they need to be retained somewhere because they could be a danger to themselves and others".

Leeds, reconvened

Prevalence of the most common side effects resonated with participants. This answered a particular question that participants had with the side effects detailed on medicine leaflets: they knew such side effects *could* happen, but were they really likely to occur or were the side effects mentioned to protect drugs manufacturers.

"The side effects are good. Having the numbers in-line with the common side effects is good, but with the rare ones the name is enough."

London, reconvened

There was concern that more nuanced information about side effects could not be used by those with low literacy levels or those with a mental health condition. Some conclude that the information should be shared with some patients but not others, although there was no consensus over who should be the arbiter of this decision. While doctors were the most common suggestion, others thought that this might make people feel discriminated against if their doctor was withholding information from them.

"The level of anxiety that I would feel when looking at this would cause more problems, but it is also detailed. You need to work out how to deliver this information to someone suffering".

London, reconvened

3.3.3 Evaluating effectiveness

The fact boxes also displayed information on how effective drugs had been in clinical trials. On the whole, people did not understand this information well, partly due to it being conveyed statistically. Some believed that the information provided on effectiveness showed that the medicine was ineffective.

"Why give out something when the placebo gets better results?"

London, reconvened

Some participants suggested that this extra information met a need, and felt that they had a responsibility to use it if it was given to them. Though the information was difficult to understand, it was at least giving them the facts about the medicine they were taking, including information that they would not usually have access to. For others, though, these were just more 'facts' that did not have any real meaning.

3.3.4 Lifestyle alternatives

One of the most appreciated types of information on the facts boxes was the detail about other alternatives that people could pursue instead of medication.

However, it was clear that many participants were interested in the possibility of alternatives being presented because they felt it could open the door to being recommended natural remedies. This was another instance of how natural alternatives and lifestyle alternatives were seen as two sides of the same coin, and that many participants did not draw a distinction between them.

"Yes. Things like changes, alternatives, herbal treatments and therapy. If it's a direct consequence of your lifestyle".

Leeds, reconvened

How HCPs access and use medical evidence

4 How HCPs access and use medical evidence

This chapter briefly looks at how HCPs view medical evidence and its role in their clinical decisions.

Key findings

- **Specialist HCPs are more likely to engage with primary medical evidence (e.g. individual clinical trials) than GPs, who often resort to syntheses of evidence (e.g. clinical guidelines).**
- **Most HCPs have concerns about the integrity of the way medical evidence is generated and communicated.**
- **Evidence (either primary or synthesised in the form of guidelines) is a key input into HCP clinical decisions; others include:**
  - **patient factors, such as their symptoms and behaviours;**
  - **HCP knowledge of patient outcomes; and**
  - **financial considerations.**
- **HCPs called for support to help them make the best use of evidence, including support for:**
  - **accessing and keeping up to date with evidence; and**
  - **understanding the relevance and implications of medical evidence to their practice.**

4.1. Top-of-mind reactions to the term 'medical evidence'

What HCPs think constitutes medical evidence focussed on the mechanics of medical evidence, then led to concern about the system underpinning the production of medical evidence, and finally to thinking about its potential to support decision-making and how it might be communicated to patients.

- Mechanics of medical evidence – HCPs showed a remarkable readiness to describe the technical features of medical evidence, where the public often struggled to do so. They usually talked about 'clinical trials' or the detail of actually undertaking a trial, such as who takes part, and the applicability of research findings to other patients.
- Concerns about medical evidence – although medical evidence and associated guidelines The National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidance Network (SIGN)

guidelines etc.) were seen as an important input to their decision-making, many had concerns relating to the quality and reliability of medical evidence, namely:

- the extent to which the evidence is applicable to all patients;
- a widespread belief that some evidence may be supressed and / or manipulated;
- the potential for bias due to vested interests in the drug development process;
- the use of studies to publicise and market a drug, rather than contribute to the evidence base; and
- a perception of insufficient data on the effectiveness of some drugs.

"Fraud. There's been, certainly in the journals, some of the clinical trials have been... Well, there's been some underhandedness or people have got vested interests and so forth".

GP, Glasgow

- Accessing and using medical evidence – for some HCPs, *medical evidence* and *guidance* [23] were inter-changeable and the two ideas were often run together. GPs spoke positively of the guidelines available, such as SIGN guidelines in Scotland, as a way of summarising evidence for them. GPs also spoke about a need for the evidence to be accessible to them quickly and simply. Journal articles were not necessarily the easiest way to do this, and so the guidance and syntheses of relevant evidence were valued.
- Communicating medical evidence – while generally the principle of communicating evidence was supported by HCPs, in practice they said that it was difficult to identify an appropriate time and way to do this. It was felt that if both HCPs and patients were better supported to engage with medical evidence and the medical evidence itself was more accessible then this could have better outcomes for patients.

  The media portrayal of medical evidence was a concern in the context of communicating medical evidence, with many suggesting that the public is exposed to potentially misleading information that lead to ill-informed choices.

"It [the media] can influence the public's understanding and therefore a patient's willingness to take a medication".

GP, Glasgow

4.2. How healthcare professionals engage with medical evidence

For many then there was a tension between feeling like they had to engage with medical evidence to keep abreast of the latest medical developments while at the same time feeling like there are barriers to doing this,

[23] See glossary in 1.3.3 for definitions of medical evidence and guidance.

mainly due to the volume of evidence, the associated challenge of identifying relevance, and seeing their patients.

4.2.1 Sources of medical information for HCPs

Evidence published in journal articles (e.g. the Lancet, the BMJ) was seen as the go-to place for detailed information on the outcome of medical studies. However, few had the time to do so. Instead they engaged with medical evidence in other ways:

- Official guidelines, such as (SIGN), in Scotland, or NICE Pathways in England;
- Summaries of medical evidence, through official sources e.g. NHS email correspondence;
- Informal sources, such as other trusted websites and peer networks.

Journal articles

Journal articles occupied a position of purity for HCPs despite concerns described above (e.g. possible suppression of trial findings). Most said that ideally they would have the opportunity to critically assess the studies themselves, rather than rely on a more digestible version such as abstracts and summarises, but felt that practical constraints, mainly time, meant this was seldom possible. Those who do access journals, described using a checklist – such as the authors, the size of the study and the country the study was conducted in – to judge the quality of the source, and whether reading it is worthwhile or not.

"If it's published in an approved journal, it's peer reviewed, the abstract makes sense, you know the authors then it's probably reliable".

GP, Glasgow

Specialists said they have to access medical evidence in an unabridged form. They spoke of a need to keep up to date with journals on their specialism, and to delve deeper into the research, but even they suggested that the volume of information could be bewildering.

"I think [participant] is right in what he says about there being a lot of knowledge and evidence out there and for general practitioners it's quite overwhelming. Even as a specialist it is".

Specialist, Leeds

Official guidelines

Such barriers meant that most rely instead on guidelines when making prescribing decisions. Guidelines were generally appreciated, although some were seen as more useful than others. In the Glasgow workshop the SIGN guidelines were regarded as being internationally renowned and respected, with a perceived high standard of peer review.

While guidelines had a respected role of summarising medical evidence, they were also seen as a much more accessible source of information, even though they did not always reflect the latest scientific developments. There was the suggestion that the guidelines are also framed by political and financial considerations and while accepted, some wondered if such issues should be communicated to patients.

"I think it depends on the guidelines. Some are very politicised. NICE depression ones are very politicised and they said Citalopram should be taken as a blanket drug for depression".

Pharmacist, Glasgow

A number of HCPs suggested the guidelines are too prescriptive, citing a number of examples where they felt that the recommended approach may be disproportionate to risk, reflecting the stated importance of professional judgement.

Additional ways to access medical evidence

A number of other strategies that HCPs use to keep up-to-date about medical evidence are summarised below:

- many received notifications (via email) when there had been a change in the evidence-base, changes to the risk profile or effectiveness of a licensed medicine.
- specialist GP magazines, sometimes referred to as 'GP comics'[24], offering summaries of new research, as well as more 'human interest' stories;
- Twitter accounts that have been set-up to receive alerts when new articles relevant to their specialism are published;
- some pharmacists and research nurses talked about using Cochrane systematic reviews of research[25] as a resource; and
- general internet searches if a specific question about medical evidence was asked by a patient and could not be answered by any of the aforementioned sources.

HCPs also tapped into various networks to remain updated on medical evidence. These networks played an important role in validating new practices and giving HCPs the confidence to deviate from their standard practice if they encountered a patient who was not responding well to treatment.

[24] 'GP comics' refer to GP news publications such as http://www.pulsetoday.co.uk/ and http://www.gponline.com/.

[25] http://uk.cochrane.org/

Although 'drug reps' were said to be increasingly less influential, for some they retain an important role in providing GPs with information about possible alternative treatments. The extent to which the opinion of drug reps was listened to and acted on was based on a trusted relationship.

"If you know the rep that comes to see you and they tell you about a new product and it's obviously approved for us, and you've got a patient couldn't tolerate different products, it might be an option for them".

GP, Glasgow

4.3. Inputs to HCP advice

The dialogue identified that medical evidence is just one of a number of factors when it came to giving advice and / or recommendations to patients.

Medical evidence and patient factors were often seen on a par when it came the decision-making processes. Medical guidance was used as a reference point for HCPs and was then placed in the context of patient factors, such as the nature of their symptoms, their history and their background. The mediator between medical evidence and patient factors was typically the HCP's personal experience. Financial considerations also overtly played a role in decisions, but also permeated the other decision-making inputs, such as the guidance itself. While each of these factors was said to have a bearing on decisions, it was recognised that guidelines are in fact guidelines, thus professional judgement was seen as critical in making an effective one.

- Guidelines – they were frequently mentioned as a go-to resource, seen as the next best thing for a detailed look at the actual evidence. They were regarded as clinical support for HCPs, especially in uncertain situations, where an HCP has less experience or where they are dealing with a rare condition.

- Patient factors – HCP decisions were based on more than diagnosis and treatment. They also included understanding patients' psychological state and social background, on the basis this would produce a more personalised treatment plan.

- Personal experience – experience, for many HCPs, was the knowledge gathered after trying different clinical options. There was, however, appreciation that recognition that this approach could lead to mistakes being made or systematic biases affecting decision-making. Overall, experience was seen as an effective complement for other kinds of decision-input. Experience moderates the blunt-instrument of guidelines on the one hand, and the demands of patients on the other.

- Financial considerations – HCPs saw financial consideration as an unfortunate, but necessary part of their day-to-day work, particularly if a patient requested a certain brand-drug when only the cheaper generic alternative was available. There was frustration that guidelines on the effectiveness of a particular medicine could change as soon as the patent expired and a generic alternative became

available as this can give the impression that HCP advice is inconsistent. Most said they would not bring price up with patients, instead they would hope to convince the patient of the benefits of an alternative.

4.3.1 Making decisions with the patient

There was a general consensus that decision-making now took into account the patient to a great extent, and that this was something that had changed more recently. This reflected a shift in medicine from paternalism to patient-centred care, though it was clear throughout the dialogue that patients and HCPs still value to a certain level of paternalism.

HCP views of medical evidence, and the role of medical evidence in clinical decisions-making

5 HCP views of medical evidence, and the role of medical evidence in clinical decision-making

This chapter looks at how HCPs think the public conceptualise medicine and medical evidence, how HCPs perceive their own role when it comes to clinical decisions, and the role of medical evidence within that.

Key findings

- **Patients felt that patients can have unrealistic expectations of medicine, and that some are satisfied with being 'medicated'.**
- **Medical evidence was often seen by HCPs in terms of how it might impact patient outcomes. However, they doubted that patients could understand it.**
- **Some felt that giving participants unfiltered medical evidence could lead to worse patient outcomes such as declining adherence; others could only see a role for it with more engaged patients.**
- **There was disagreement between HCPs over what kind of information qualifies as suitable for patients.**

5.1. How HCPs think the public conceptualise medicine

The public was perceived by HCPs to conceptualise medicines as 'cures' or 'pills' for 'fixing' things, rather than complex treatments with different levels of effectiveness, characteristics and risks. In practice, this meant that patients could have unrealistic expectations of medicine, and that some were satisfied with being 'medicated'.

Overall HCPs speculated that some patients would not be able to understand relatively basic medicinal information such as the fact that medicines have both benefits and harms. Despite this, patients were said to be an important source of feedback on the treatments they are prescribed in the context of future clinical decisions.

"The good thing about long-term medication is that there is the chance to try it out. If they get side effects they can tell you. It's keeping the dialogue open".

Specialist, Leeds

5.2. How HCPs think the public conceptualise medical evidence

HCPs understood that patients obtain information from a variety of sources e.g. media, word of mouth. These were generally considered as 'unreliable'; based on 'hearsay' and 'conjecture' and seen as an annoyance where the patient presents them as a competing opinion.

"They'll come in with scare stories. The health page from the Daily Mail".

GP, Glasgow

Increasingly the internet has become a key information source, which patients use to bring in what they *thought* was medical evidence. Instances of patients having medical evidence prepared in order to discuss with HCPs were said to be very uncommon. However, where patients were better informed, this could give rise to potentially unrealistic expectations which the system could not always meet.

"Some patients will come in with the study. There was something on the introduction of peanut into the diet of children at high risk of peanut allergy. It's difficult because we're not funded to check individuals. Ideally we would skin prick them to check their allergic risk and make a judgement on whether they're adequately supported to give them peanuts three times a week. There's difficulty in allowing the trials to be generalised into general practice".

GP, London

HCPs said that few, if any, patients expected to receive medical evidence although there was a clear need for information such as what the condition is, and what the symptoms and treatments are, as well as practical issues such as frequency and administering the medicine. This demand tends to be greatest among those who are better educated and from a higher social economic background.

"It depends on the area of your practice and demographics. In a more prosperous area, [patients] they're more likely to read a natural health magazine, they also have different expectations. Whereas in a lower socio-economic area, they don't really want discussion".

GP, Glasgow

HCPs thought that patients generally could have trouble understanding and interpreting medical evidence and as a result they were, at best, hesitant to discuss the details of medical evidence.

The concern was that patients would not be familiar with the language and concepts of probability and statistics and even if this was conveyed then it would likely be misinterpreted. Overall HCPs felt there was a disconnect between the public and medical evidence. They felt they currently lacked the tools to change this.

5.3. How HCPs perceive their own role when it comes to the course of action

HCPs felt that patients trusted them to make a decision that would improve their health. Some saw themselves like guides helping patients to navigate different treatment options. Crudely, it's also possible to see HCPs on a spectrum of how much autonomy they feel comfortable offering their patients, but in reality such relationships are much more nuanced and take into account various factors about the patient and their situation.

5.3.1 HCP perception of the nature of their relationships with patients

Most HCPs thought that the relationship with the patient ought to be one that encourages adherence[26] to a course of treatment. While this focus on adherence may appear to be paternalism, or even be seen as creating the potential for over-medicalisation, for most it was seen in the context of achieving the best possible patient outcomes.

Many were sceptical that true concordance – the full inclusion of patients in the decision-making process – had been achieved in medicine. While they acknowledged this is the direction of travel, and indeed most supported the idea, some felt the destination of shared-decision making is still a long way off.

"We never got from compliance to concordance. Anyone can adhere to a treatment regimen no matter what. Do they actually buy into that treatment regimen? Do they have the cognition and intellect to understand what the treatment is trying to do?"

Pharmacist, Glasgow

5.3.2 The needs of a patient

HCPs said that discussions about the course of action are influenced by their assessment of the emotional, physical and informational needs of a patient. Indeed, some spoke of withholding information from patients in order to prevent unnecessary alarm, and avoidance of an unwillingness to take a medicine. This included occasions where guidelines recommended something that an HCP regarded as disproportionate to risk, but was also about not wanting to scare patients with known, but very unlikely, side effects.

"If you decide to look at cancer guidelines, but you don't think it's relevant you're not going to say, 'here's the cancer guideline'. You'll be selective of what you can say".

GP, Glasgow

5.3.3 The patient's experience of medicine

A patient's own experience with medicine also affected the nature of relationships. Adherence was said to cease if patients do not quickly see a positive outcome. Similarly, a past negative experience could hinder

[26] For definitions of 'adherence' and 'concordance' please see the glossary in 1.3.3.

adherence, even in cases where an HCP felt they had explained the implications of not taking it. HCPs emphasised that it was important for treatments to remain stable and familiar for patients and to keep this in-line with what has worked for the patient.

5.4. Communicating medical evidence to patients

As discussed, HCPs said they seldom communicated medical evidence to patients, and they tend not to signpost patients to medical evidence either. Uncertainty within the evidence itself was something that HCPs chose not to bring up with patients as it was assumed this could be interpreted as HCPs lacking the knowledge to be able to advise effectively.

However, there were occasions when it was considered appropriate to communicate uncertainty such as when the evidence base had changed or where there was no evidence. In these cases, 'best practice' was the term used to cover the knowledge gap, which they felt instilled confidence.

Most supported the principle of providing medical evidence patients, but overall were uncertain how this could be best achieved given its complexity and the potential for unwanted consequences (e.g. leading to non-adherence with a medicine).

Instead of medical evidence itself, HCPs described several methods of providing medicinal information to patients. Websites and hand-outs were the most popular ways of communicating this information to patients. Information sources that could be consumed in the patient's own time were a priority on the basis this would save time, as well as give the patient more time to digest the information. Overall HCPs were confident that the sources they signposted were derived from evidence but crucially were more digestible for patients.

"I use Patient.co.uk. I recommend patients go there, it's nice and easy. It's all evidence-based and up-to-date, and quite easy to understand".

GP, Leeds

Shared decision-making and medical evidence

6 Shared decision-making and medical evidence

This chapter looks at the potential for shared decision-making and the role of medical evidence within this.

Key findings

- **Patients and HCPs saw medical evidence as central to the idea of shared decision making on the course of clinical action.**
- **The principle of shared decision-making is agreed by most, but it is clear that the nature of shared decision-making leans towards the HCP.**
- **This is seen (by the public and HCPs) as being in the interests of both the HCP, who seek the best outcomes for their patients, and the patient who gains reassurance from devolving responsibility.**
- **There are challenges to the use of medical evidence into patient decision frameworks; namely:**
  - **medical evidence does not necessarily fulfil current information needs;**
  - **medical evidence doesn't resonate with most people, as they struggle to see themselves as a statistic; and**
  - **a recognition that the role of the patient in society is currently one that receives care, rather than taking an active role in learning about the nature of that care.**

6.1. Shared decision-making

Over the course of this dialogue, it became clear to participants that shared decision-making is central to the question of how to engage the public in medical evidence. Shared decision-making can be distilled to several broad themes[27]:

- Shared decision-making requires input from an HCP and a patient;
- Both of these parties positively engage in decisions about treatments;
- Information sharing facilitates shared decision-making; and

[27] These headings draw on Charles et al (1997). 'Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango).' In *Soc. Sci. Med Vol. 44, No. 5, pp 681-692*

- Treatments are decided and agreed by both parties.

While overall the principle, and its approach were supported, in reality the extent to which decisions are collaborative is based on the amount of information which the HCP thinks the patient can tolerate. Information sharing can be seen as a valve that could be switched on or switched off depending on the perceived impact it would have on patient behaviour. Moreover, there are many challenges in incorporating medical evidence into shared decision-making, not least its complexity and the unfamiliarity for the general public.

"There needs to be an emphasis on a shared decision. The doctor is trying to explore further what your understanding is and whether you have anything else you want them to take into consideration. It was found that if you've not involved the patient in a discussion, the likelihood of them taking the medication is less compared to when you have contributed to that decision on what the right way forward is".

GP, Leeds

6.1.2 Bringing the public and HCPs together in dialogue

In the first session, the public suggested that HCPs are distant from some forms of medical evidence and medical information. They felt that if HCPs have to rely on technology (databases, information repositories, online searches) to aid decision-making then the public will struggle even more. In the reconvened session, this concern turned to a sympathetic acceptance that HCPs, in particular GPs, could not know everything.

"You [HCP] can't know everything. Sometimes it's okay for the GP to say they don't know what it is".

Leeds, reconvened (after HCPs and public brought together)

Shared decision-making in dialogue

While HCPs could understand the principle of increasing access to medical evidence, it was initially cautioned against on the basis there could be unintended consequences. By the second session, there was some appetite for medical evidence however this was generally limited to effectiveness and there was consensus that HCPs continue as the ultimate arbiter.

"I think it's the doctor's [responsibility]. Some people are totally clueless so you do put all your trust into your GP. I would definitely go and research now but I wouldn't have before these sessions, so I think the GP has a lot of responsibility".

Leeds, reconvened

This reliance on HCPs, in part, emerged as a result of participants discussing the drug fact boxes. In the dialogue, HCPs took on a role of explaining the content to participants, which meant that participants could envisage HCPs as the conveyor of more complex information about medicine.

"It's worth pointing out that most of us didn't understand how the information was presented on the second drug fact box. We'd need our GP to talk through it with us".

London, reconvened

Given the perceived challenges associated with increasing public access to medical evidence (see section 6.2), many thought that HCPs ought to decide if the detail of medical evidence should be discussed with patients. It was felt that this would involve consideration of many factors, but mainly whether a patient having such information would result in better clinical outcomes.

It was envisaged that medical evidence could be used to set the parameters of a decision; and on the basis of their own priorities and values, patients choose on the course of action while being supported by the expert knowledge of the HCP. Others while supportive of this idea, felt that the HCP would need to prepare for a decision on the course of action being too difficult for patients.

6.2. Barriers to the use of medical evidence in decision-making

The barriers to incorporating medical evidence into people's decision-making were seen to be:

- understanding and interpretation of medical evidence
- the nature of the current HCP-patient relationship.
- people's current shared decision-making framework

Together, these issues were significant barriers to medical evidence being used by patients to evaluate the harms and benefits of medicines.

6.2.1 Understanding and interpretation of medical evidence

Even barring the obvious technical knowledge required to properly interrogate medical evidence, there are blurred lines between the different kinds of information for what constitutes as evidence. We have noted previously that various information sources are called upon before a decision is made, and 'evidence based' medical evidence is seldom among these. Often what is understood to constitute as evidence differs entirely from an established definition of medical evidence.

"I know people that have been on medication. That in itself is a trial".

London, event one

There was also the issue of evidence being made available to patients and the difficulty in making sense of it. It was felt that misinterpretation is a likely outcome, and both HCPs and public were concerned that this may have a negative effect on patient's adherence to a course of treatment.

"We'd want to know any major side effects that may occur. You wouldn't want to be told what could happen to 1 in 1,000. It's a scare factor".

Leeds, reconvened

6.2.2 The nature of the existing HCP-patient relationship

The current HCP-patient relationship entails the HCP taking on the role as a guide through medical information in the context of the patient's health and wellbeing situation. This suits most patients, who do not have confidence in their own ability to interpret complex information, but it also suits HCPs as they feel better able to have a degree of control in what patients do, thus what their outcomes are. Indeed, as participants learned more about the issues associated with medical evidence, most concluded that patients would accept deferring the responsibility for understanding the harms of medicines to HCPs.

Although there was a tension between this kind of relationship and one that is more equitable, the dialogue identified there was in theory appetite for discussions about medical evidence. However, practical barriers such as being time limited means that HCPs are struggling to find the time to access the information and to be able to fully discuss it with the patient.

"Has the doctor got time to do all this? That's the thing. Would he have time to explain all this?"

London, reconvened

6.2.3 The current shared decision-making framework

Another challenge is how medical evidence can fit within the current decision-making framework.

Current information needs – these tend to be binary in nature, e.g. whether the drug would work, as opposed to how well it might work. That said, information provided in the drug box about the drug's effect vs placebo had appeal. Needs are also context-dependent. If their condition was serious, then most said they would be receptive to medical evidence that allowed them to weigh up the benefits and harms of different treatment options. In contrast, others felt that if the condition was serious e.g. life threatening, then most were sceptical that meaningful engagement with medical evidence would be possible.

Ensuring patients act in their own best interests – there remains a deeply rooted expectation that HCPs pass on medical information in a way which ensures that patients act in their own best interests, that HCPs choose which side effects are communicated, based on their likelihood.

Relevance of medical evidence - medical evidence and its associated issues do not map onto the types of information that people said they need to make a decision. In general, there was a feeling that information about trials was quite abstract and, while some were interested, very few were able to articulate how this information could provide answers to their questions. The significance of the effect of a medicine on an individual is, in part, why many find it difficult to see medical evidence as relevant.

"I think because individualised cure is the most important thing. Every individual is different. You cannot use the same medication for all patients".

Leeds, reconvened

The patient in society - the final barrier to medical evidence in shared decision-making is that patients in general act in a submissive way in society. Even though some suggested that as a destination shared decision-making may be on the horizon, it was felt that the public expectation of HCPs providing a solution to the problem would continue.

Conclusions and opportunities

7 Conclusions and opportunities

Participants were increasingly interested in medical evidence as they learned more about the associated issues. However, when participants were returned to the central objective of the dialogue: how can we all use evidence to judge the potential benefits and harms of medicine, almost all had come full circle and reiterated the information needs outlined at the outset, namely:

- Understanding the diagnosis, treatments and health outcomes of people with the same conditions;
- Understanding the side effects of the treatment and how they applied to them as individual patients; and
- Identify non-medical solutions (alternative medicines or lifestyle alternatives) to problems and what effect they have.

Despite certain aspects of medical evidence not seen as particularly relevant to people's decision-making processes, we identified certain opportunities which could be used to leverage medical evidence into the decision-making process.

Some of these were directly linked to communication with patients, while others are related to making evidence more easily accessible to HCPs – who frequently act as the gate-keepers for patient interaction with medical evidence.

7.1. Opportunities for patients and the public

Communicating medical evidence so that the public use needs to cut through quite natural behavioural biases and ways of learning that have developed in a healthcare system that takes so much of the responsibility away from the patient.

7.1.1 Using medical evidence to respond to current information needs

The public and patients voiced different levels of interest in medical evidence, with some more disposed to hearing about evidence than others. There are differences between those who are broadly interested in medical research – an abstract interest – and those who want to use it in their own decision-making.

Information about the side effects and administering the medicine was considered essential in the context of a decision. There was appetite for more detailed information on the most common, as this was something that the public could see using. For example, the proportion of recipients who could be expected to suffer from a given side effect, as shown on the drug-fact boxes. Information therefore should focus on the key requirements that patients have, but with signposting to more detailed medical evidence as needed.

7.1.2 The importance of experience

There are potential downsides when patients make decisions based on the experiences of others, yet this approach does pose an opportunity. Providing the experiences of patients in a way that reflects medical evidence might communicate better engage patients in the notion of benefits and harms of particular treatments. Such patient illustrations could harness the association and empathy that patients can feel with someone in a similar situation to them, while at the same time communicating important information about effectiveness.

Given the significance many assigned to online forums, there might also be a way of incorporating certain elements of review sites with properly researched information on medicines in order to promote desirable behaviours. There is evidence, for instance, that positive ratings online for a particular consumer option lead to a social effect with people using these reviews as reputation and trust proxies[28]. If a way could be found of using the social element of reviews and ratings to communicate the implications of medical evidence, this could potentially fill a gap in patients' information gathering that is currently filled by friends, family and forums.

7.1.3 What is medical evidence?

The medical evidence system plays a conceptual role in manufacturing trust in it, even if few participants really understood how the system works in practice. If the direction of travel is to enhance public trust in the medicine then there could be an opportunity for a better understanding of how the system works, and the role that medical evidence plays within that system.

Importantly, communication around this would disentangle medical evidence from other concepts that the public ran together with medical evidence, such as medical information. This could also be useful in terms of distinguishing medical evidence from patient experience, which many regard as tantamount to evidence.

Attempts at educating people about medical evidence could be successful in targeting some of the basic misconceptions outlined in this report.

7.2. Supporting HCPs to access and use medical evidence

Overall HCPs spoke of their interest in medical evidence, and keeping up with best practice, but as has been shown, this poses a number of challenges for HCPs, not least the issue of time. There was a tension between specialists and general practitioners about the extent to which HCPs had a responsibility to stay up-to-date with current evidence, even though both acknowledged the challenges this has. In addition, the evidence gathered in this dialogue suggests that medical evidence is likely to remain outside of people's decision-making unless HCPs are encouraged, supported and given the necessary tools to tailor medical evidence to the different contexts which they encounter. However, even if this was realised then it is likely that only certain

[28] Luca, M. (2011). 'Reviews, Reputation, and Revenue: The Case of Yelp.com'. Working Paper 12-016, http://www.hbs.edu/faculty/Pages/item.aspx?num=41233 (accessed 26/08/16)

aspects of the medical evidence (e.g. effectiveness) will resonate. This brief section examines the suggested approaches that it was felt would support HCPs, to keep up-to-date on current best practice.

7.2.1 Support in accessing medical evidence

The main barrier to accessing medical evidence was the time consuming nature of keeping up-to-date, partly due to length of published papers, but more crucially, the volume of research that is produced. Suggestions were made about how this could be made more accessible, and HCPs shared their own ways of accessing medical evidence.

Collating publications by theme

Some HCPs mentioned systems for collating publications on specific topics. These were seen as useful, but were said to be limited to certain fields and for certain kinds of research. Using this approach was felt to be an effective way to navigate the amount of medical evidence there is and quickly see what is relevant and / or interesting new treatments.

Social media and email alerts

Social media is widely used to keep up-to-date with the latest evidence. This had the added benefit of fitting in with routines and did not require extra effort to find it – the interaction with the summary was a passive one and reduced some of the effort required in keeping updated. Twitter was an easy entry point for specialists who felt the responsibility to research new medical evidence, but could be a relatively unobtrusive way of other HCPs being able to quickly access new studies that they find of interest. Registering with mailing lists that provide summaries, the NICE mailing list for example also proved popular. It was felt that summaries ought to be written in plain English so they could be digested more easily.

Facilitating more peer-to-peer knowledge sharing

Peer-to-peer networking is an important area for cascading medical evidence and helping HCPs to triangulate their own practice with others. Facilitating this kind of networking was felt to be an effective way of spreading experiences about new treatments and medical evidence. Although because of time and resource constraints it was felt that increasingly such events would need to run online. There was a note of caution in case anecdotal evidence was seen on a par with medical evidence.

7.2.2 Support in understanding the implications of medical evidence

A number of HCPs had issues with understanding what medical evidence meant in practice. As a result of conflicting evidence, and in the absence of summaries e.g. NICE, it was difficult to know what to take account of and have trust in. Assessing the quality of evidence made it difficult to put this in the context of HCP practice. Similarly, relevance was frequently a term used by HCPs, which meant relevance to their own practice and role, especially if they were not a specialist.

Meta-analysis was appreciated as synthesis of multiple studies, but they were often viewed as a complex and nuanced, that many did not have the time to engage with.

These issues may be leading to a malaise towards evidence in general. One way of combatting this malaise might be systems like 'kitemarks' or grading systems that independently evaluate the strength of evidence about a particular drug. Though these exist for some evidence[29], one HCP felt that the grading system should encompass the entire evidence base.

7.3. Opportunities for science in the media

Although the role of the media was not a focus of the dialogue, there was consensus that it has a 'big responsibility' in communicating evidence. Most saw themselves as able to critically evaluate information in the media and called for the media to provide sufficient information, as well as signposting, that allows any reader to be able to critically analyse the editorial narrative.

People do take on-board some of the stories that are distributed by the media and for some people this can impact their behaviour. Healthcare professionals corroborated this. Part of any effective communication to the public around medical evidence will need to understand the cognitive dissonance that lies with people who do not think they are swayed by the media, and yet can recite medical scandals they have seen or read with pinpoint accuracy.

7.4. Opportunities for further research

There are opportunities for integrating medical evidence into patient decision-making. However, importantly, this report has also demonstrated that there are significant difficulties with this. The conclusions here have suggested some lighter touch ways of providing evidence-based medical information in a way that the public may take account of. There was much more that can be done to identify specific interventions and communications that may facilitate this kind of light-touch information provision:

- Further research might look in more depth at different patient journeys and where the touch-points for medical evidence are. Research in this vein could look at everything from placement of information in a GP surgery to the language used by healthcare professionals.

- Further testing of communications that are used to convey medial evidence. Drug fact boxes were a good start and hold some worth for some patients, but most failed to see how the versions looked at could form part of their decision, and regarded some of the information as damaging. There is work here to be done to see how information might be provided in this kind of form to aid decision-making, as opposed to just aiding understanding.

[29] See 'Levels of evidence' https://www.essentialevidenceplus.com/product/ebm_loe.cfm?show=grade (accessed 26/08/16) for one example of what this might look like.

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