The Right Click?

Exploring levels of trust in online healthcare information

Part of the *My Healthcare, My Future* Series

An Ipsos MRBI report, in partnership with MSD Ireland

Foreword

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Not a day goes by when we don't hear about fake news and misinformation, particularly online, and its impact on people's lives and everyday decision-making.

In the healthcare arena, recent years have seen the advent of virtual doctor and consultation services that can be accessed via our smartphones and there now appears to be a website or blog for every medical condition or query. But how can we, and the population at large, be certain that the healthcare information we're accessing is accurate? How can we trust services that we can't see?

Trust in general online information and sources is an ongoing hot topic these days, but when it comes to our health, making the wrong choice can have a direct and indeed an immediate short and long-term effect on our wellbeing and the healthcare choices we make.

Part of MSD's *"My Healthcare, My Future"* research series, which first began in 2016, *"The Right Click? Measuring trust in online healthcare information"* delves deeper into the area of online healthcare information, to examine how Irish people are accessing digital and online sources and identify what is driving their levels of trust in in those sources. It's such a fundamental challenge to anyone even remotely involved in the Irish healthcare landscape and, with always-on technology enabling access to online information at the touch of a button, it's a challenge that we need to meet head on if we are to ensure patients are empowered with the information they need to ensure they are accessing genuine, accredited sources and sites.

With trust a fundamental cornerstone of any health system, this report is intended to start a debate into this area and act as a framework for discussions as to how all of us in the healthcare industry and beyond can form partnerships to tackle new and future challenges in building trust. This will benefit not only patients but also healthcare professionals and providers, to ensure we're all making the right click when it comes to accessing online healthcare information correctly and responsibly.

MSD is committed to playing a role as a trusted provider in the Irish healthcare landscape and we hope the findings of the research inform this fascinating, thought-provoking public health debate.

The Right Click?

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Part of the *My Healthcare, My Future* Series

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Research Highlights

Over half of us have looked up healthcare or medical information online within the past year

53%
have looked up healthcare or medical information online within the past year

32%
looked up their symptoms online before their last GP visit

We tend to be less trusting of online sources for our healthcare information

15%
consider health websites in general to be very trustworthy

5%
consider online discussion boards to be very trustworthy

4%
consider social media to be very trustworthy

Going online for healthcare information can make some of us feel better, but make others feel worse

Before Diagnosis

40%
feel better when they go online before their diagnosis

46%
feel worse when they go online before their diagnosis

After Diagnosis

56%
feel better when they go online after their diagnosis

26%
feel worse when they go online after their diagnosis

Research Highlights

We are open to recommendation for our healthcare resources

77% would visit a website if recommended by their healthcare professional

86% would be likely to read an information booklet on a medical condition if given to them by a doctor or pharmacist

When it comes to visiting a health website, its source and ease of use are the top priorities for users

91% believe it is important that a health website comes from a recognised medical source

92% believe it is important that the content is easy to read and follow

91% believe it is important that it is easy to find the information one is looking for

There is an opportunity for a verified trust mark to indicate information is from a recognised, credible source

82% believe it is important that a health website has a quality mark that verifies it has been approved

73% are in favour of the introduction of a registered trust mark confirming that health information is from a recognised medical authority

Background And Objectives

We live in a world where technology is ever present and access to the internet is always-on. A wealth of information is available not only at the click of a mouse but in the palm of our hands, with the growth of smartphones in particular making information instantly available when required.

But with the enormous volume of healthcare content online, how can the public navigate the myriad of information that is available? Is having such an easily accessible resource a hindrance or a help when it comes to managing our health?

Does it provide reassurance or create concern? How do we discern between reputable sources and those that may contain misinformation? What sites can we trust and what are the cues that help us to do so?

As part of MSD Ireland's '*My Healthcare, My Future*' research series, this study sought to examine the experiences, perceptions and expectations of Irish people when going online for healthcare information.

The core objectives were, in summary:

- To understand the frequency and circumstances in which the public go online to search for healthcare information;

- To assess the impact these online experiences can have, both pre- and post-diagnosis;

- To establish the degree of trust the public have in online information sources, relative to other channels of healthcare information;

- To explore whether printed healthcare information can still play a role;

- To identify the drivers of trust in healthcare websites;

- To explore the merits of a validated trust mark to help the public identify a trusted online health information source.

The value of online information resources in helping us understand and manage our health generates significant debate and is yet to be fully understood. This report does not seek to provide all the answers. It does, however, allow the public voice to come to the fore in this fascinating debate.

Methodology

Ipsos MRBI conducted a programme of research on behalf of MSD Ireland over the course of 2018, consisting of three phases as follows:

Phase 1
Focus Group Discussions with the General Public

The initial phase involved in-depth qualitative research with the public to explore their perceptions and experiences when seeking out healthcare information online. The core objective was to understand the extent of trust that exists and what factors drive trust in these internet sources. This phase encompassed a series of four focus group discussions with a cross-section of Irish society, covering men and women across a range of ages in both urban and rural locations.

Phase 2
Telephone Survey with the General Public

The second phase sought to provide a comprehensive measure of both the experiences and the sense of trust the public had in online healthcare information sources. A total of 964 interviews were conducted via telephone with a nationally representative sample of Irish adults aged 18 years and over, with quota controls applied by gender, age, region and social class to ensure it reflected the Irish adult population.

Phase 3
In-Depth Interviews with Key Stakeholders

The final phase consisted of a series of in-depth interviews with a sample of key stakeholders with a relevant interest in this subject matter. These interviews provided the opportunity for open, free-flowing dialogue to better understand and provide context to the general public research findings. Contributors are acknowledged later in the report.

This report combines the results of all phases, focusing predominantly on the views of the general public from both the qualitative focus groups and quantitative survey, supplemented where appropriate with contributions from healthcare stakeholders.

The Internet as a
Healthcare Resource

Who is Going Online for Healthcare Information?

A useful starting point for this study is to understand the extent to which the public is going online to look up medical or healthcare information. Our survey suggests that just over half (53%) of the adult population have gone online to seek out medical or healthcare information in the past 12 months, either for themselves or for a relative. One in four (25%) have also looked at online discussion boards about health in the past year.
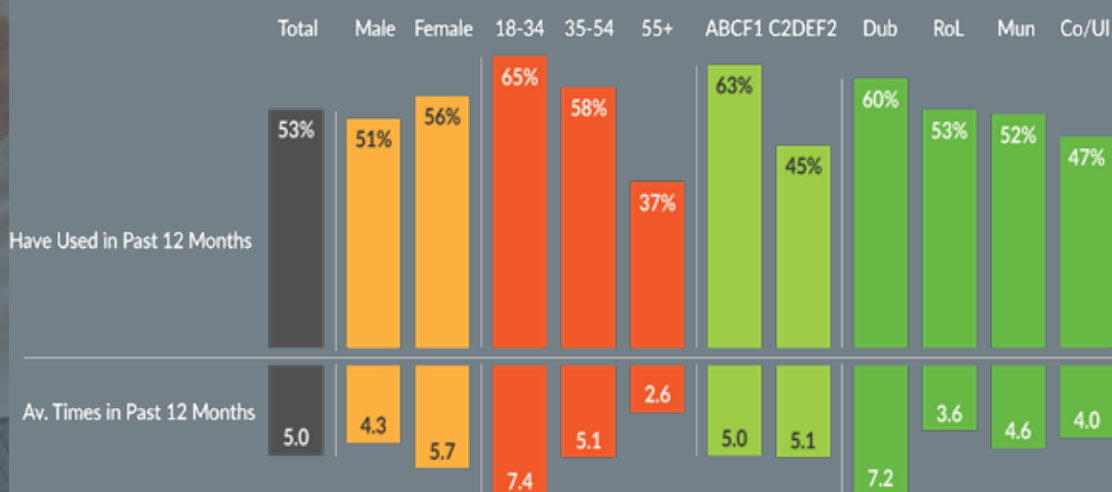
Many respondents suggest that the internet is their first port of call when seeking health information, in advance of visiting a healthcare professional, given its ease of access. In terms of frequency, the average number of times the public have gone online for health information was five times in the last 12 months.

When this data is sub-analysed across demographic groupings, clear differences emerge. Certain groupings such as younger people and those from higher socio-economic groupings are more likely to go online for their healthcare information needs.

Almost two-thirds (65%) of younger people aged 18-34 have gone online for medical or healthcare information in the past year compared to just over one-third (37%) of those aged 55 and over. The younger cohort also tend to go online more often for such information, an average of 7.4 times per annum.

In terms of social class, the ABC1F1 higher socio-economic group are also more likely to go online for health information (63% vs. 45% of the C2DEF2 class), while females are marginally more likely to do so than males (56% vs. 51%). Some regional differences are also apparent, with those in Dublin (60%) the most likely to go online for health information, doing so with greater frequency.

Use and Frequency of Online Sources for Healthcare Information

	Total	Male	Female	18-34	35-54	55+	ABCF1	C2DEF2	Dub	RoL	Mun	Co/Ul
Have Used in Past 12 Months	53%	51%	56%	65%	58%	37%	63%	45%	60%	53%	52%	47%
Av. Times in Past 12 Months	5.0	4.3	5.7	7.4	5.1	2.6	5.0	5.1	7.2	3.6	4.6	4.0

"The positive thing is that patients can use the internet to get information and it's far more efficient than the old way of having a medical encyclopaedia in your house. That's the positive. The negative is your ability to understand what you are reading diminishes the more complex it gets. So the advantage is access to information, the disadvantage is the inability to process and understand the information you are getting."
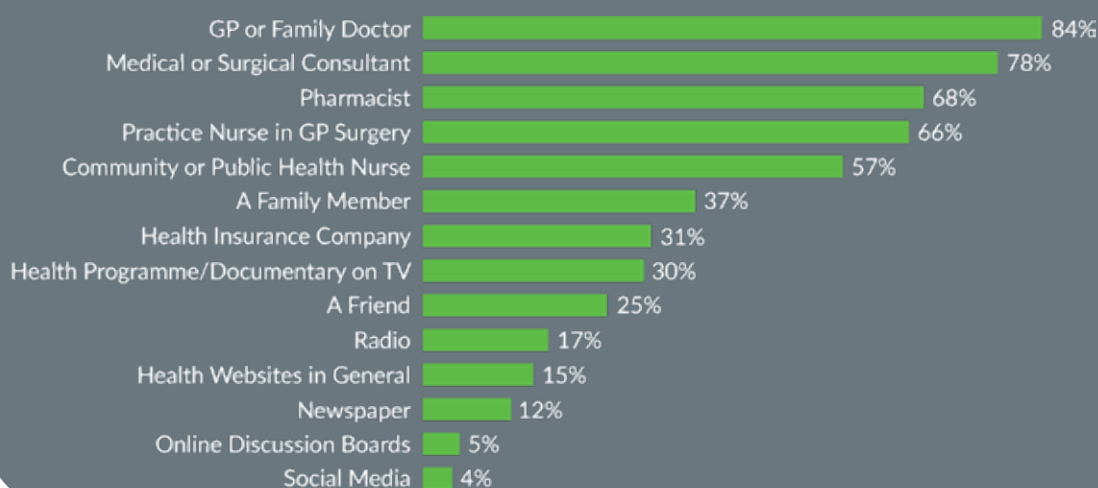
Peter Feeney, Press Ombudsman

Who is Most Trusted as a Source for Healthcare Information?

While online sources are readily available to anyone with internet access, they are only one of many information sources that the public could use for their health information needs.

With this in mind, our survey sought to measure the degree of trust the public has in a variety of healthcare information sources, regardless of how often or not they are being used. This was measured by asking whether each named source was considered trustworthy or not in terms of the healthcare information it provides, on a scale of 1-10, with a score of one meaning very untrustworthy and a score of ten meaning very trustworthy. The results herein show the proportions that gave a "top-three box" rating of 8, 9 or 10 indicating a positive level of trust.

% Who Believe Each Source is Very Trustworthy (Rating 8/10 on 10 Point Scale)

| Source	%
GP or Family Doctor	84%
Medical or Surgical Consultant	78%
Pharmacist	68%
Practice Nurse in GP Surgery	66%
Community or Public Health Nurse	57%
A Family Member	37%
Health Insurance Company	31%
Health Programme/Documentary on TV	30%
A Friend	25%
Radio	17%
Health Websites in General	15%
Newspaper	12%
Online Discussion Boards	5%
Social Media	4%

The results show that traditional, inter-personal sources tend to be the ones that are most trusted, with 84% trusting a GP for healthcare information and 78% trusting a consultant. Though results for other healthcare professionals are marginally lower, perhaps due to a lack of familiarity or experience among the public, there is trust amongst the public in information from the pharmacist (68%), the practice nurse (66%) and the community or public health nurse (57%). Common to all of these sources is the fact that they are regulated professionals that have an ethical obligation to be factual, present evidence and maintain a duty of care to their patients.

On the other hand, despite the high level of use of online sources, as outlined previously, trust in these sources is far lower. Only 15% say they trust information from health websites in general and fewer still say they would trust health information from online discussion boards (5%) or social media (4%).

In summary, trust levels appear to be lower in sources that are unverified or unqualified; not only online resources but also family and friends.

> *"I think the public have an unquenchable thirst for information. People want to lead healthier lifestyles, they want to be informed, they want to be able to make informed decisions and if you can provide readers with quality journalism around healthcare, then they will certainly use it to make decisions. It's vitally important that the media maintains its bond of trust with readers and only publishes content that is verified."*
>
> Stephen Rae, then group Editor-in-Chief, Independent News & Media PLC
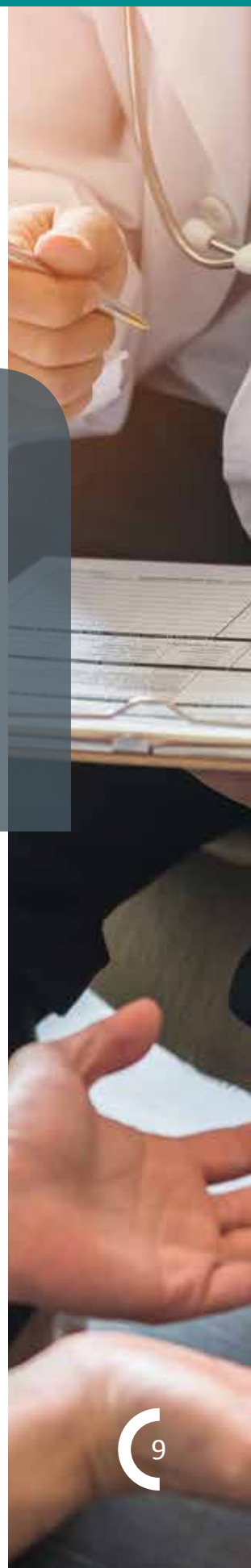
Online Experiences are Variable Dependent on the Scenario

> *"It's a bit of a minefield, you are hoping to find what you need but you don't always know how to get there."*
> Focus Group Participant

Our focus group discussions explored the experiences of those going online for healthcare information to better understand the circumstances in which this behaviour took place.

For many, going online to seek out information on a healthcare issue or concern was a natural, preliminary investigative step that is simply taken when required. Internet sources are readily available and convenient, arguably almost a default source for some when a medical query arises.

> *"I think we are all inclined to go on the first page of Google, if it's not on the first page of Google you tend not to go any further."*
> Focus Group Participant

However, one's experience with online sources and the extent to which they are trusted can vary considerably based on several factors, such as;

- **Timing of the search**
  Whether it is before or after a formal diagnosis has been provided by a healthcare professional.

- **Search parameters**
  Whether the search is exploratory (e.g. describing a set of symptoms) or specific (e.g. searching for a named condition).

- **Description of symptoms**
  Whether the search terms being used are vague and broad or specific and definitive.

- **Severity of condition**
  Whether the issue for which the information being sought is perceived to be mild, moderate or severe by the person.

- **Who the patient is**
  Whether the search is on behalf of oneself or on behalf of another (e.g. a dependent or relative, where arguably the concern can sometimes be greater).

- **The websites themselves**
  Many will not limit their online search to one single website, but may visit multiple sites to gather information from a variety of sources and cross-verify their findings.

The degree to which different health websites can be trusted and what influences this is examined in detail later in this report.

> *"I think it's really important for us that we never take agency away from people, so no matter how disadvantaged or challenged people are around their health, I think we should always have a focus on empowerment and that they should be part of the solution or part of the improvements that can be made."*
> Kate O'Flaherty, Director, Health and Wellbeing Programme, Department of Health

Having Gone Online,
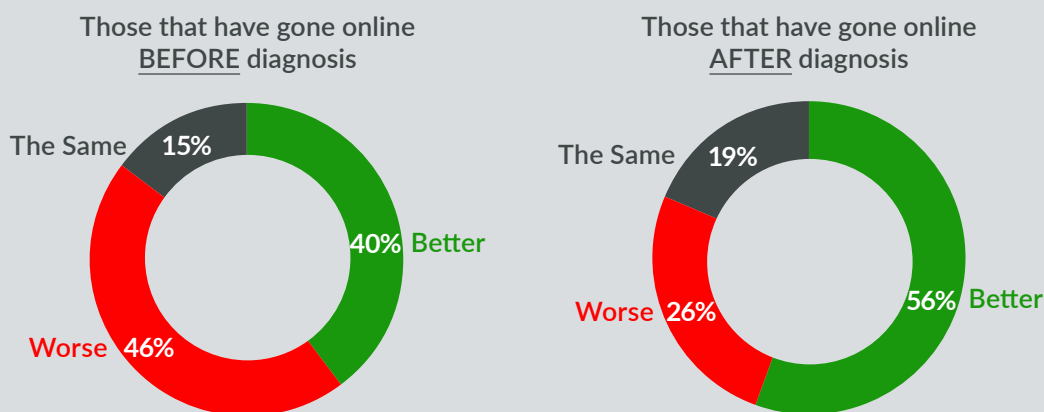# Do we Feel Better or Worse?

Discussions with the public reveal that the mindset can be different depending on whether one is searching for information either before or after a formal diagnosis of one's medical concern has been made by a healthcare professional.

Of those that looked up healthcare information online before getting a diagnosis, a higher proportion stated that they felt worse (46%), rather than better (40%), after doing so, indicating that such behaviour can add to the worry of a prospective patient.

Further investigation reveals that an online search for information in advance of diagnosis or a visit to a healthcare professional can sometimes result in the individual randomly searching symptoms and trying to determine their medical issue themselves. The search parameters are often poorly defined and somewhat vague, which can lead to uncertainty or in some cases raise concerns about the worst-case scenario that is found.

Many will need to visit a healthcare professional to ultimately resolve their medical query and get a definitive diagnosis. Although some admit they feel worse having conducted their own online investigation in advance of diagnosis, it is worth noting that such activity can also help the patient by making them better informed about what their medical ailment could be and also building their confidence to allow them to better describe their symptoms upon presentation.

Response to Going Online for Information Before/After Diagnosis

Those that have gone online BEFORE diagnosis

The Same **15%**
40% Better
Worse **46%**

Those that have gone online AFTER diagnosis

The Same **19%**
56% Better
Worse **26%**

Of those that looked up healthcare information online after getting a diagnosis, a higher proportion stated that they felt better (56%), rather than worse (26%), after doing so. Following a visit to their healthcare professional, it is easier to go online and conduct a more rational, informed search for a specific, named illness. At this stage, the online search is defined and therefore it becomes an exercise to learn more about one's diagnosis. This can also lead one to visit online discussion boards where other patients are sharing their experiences, despite the fact that trust in this source is lower.

The Role of Healthcare Professionals in Guiding Patients

The Internet Can Play a Role Before and After a Medical Consultation

How many of us go online to investigate our medical issue before visiting our GP? Of all those who had visited their family doctor in the past 12 months, almost a third (32%) said that they had looked up their symptoms online before their visit.

This figure rises to 42% among those aged 18-34 years, while it is lower for those aged 55 years and over (23%). Some of these patients may print out content from the internet and bring it with them to a medical consultation to get the healthcare professional's perspective.

Despite the fact that many of us regularly use the internet as a source of information for our health, our ability to interpret the content can vary. This is known as our health literacy, or our ability to make sense of health-related materials.

> *"We all need a level of health literacy in order to be able to understand and control information that pertains to our health. There's recognition that as part of health policy in Ireland, under Healthy Ireland, we all need to develop our health literacy."*
>
> Inez Bailey, CEO, National Adult Literacy Agency

Our research suggests that the public are open to being pointed in the right direction when it comes to their online searches. When asked if they would visit a website if recommended by their healthcare professional for information on their medical issue, over three in four (77%) said they would be likely to do so. This rises to 86% of those in the 35-54 year age group.

These results indicate an appetite among the public to be helped navigate the online space and to be directed towards websites that their healthcare professional has faith in.

Some doctors will recommend specific websites or even provide patients with printouts of content from websites they recommend. Indeed, given the likelihood that many patients will go online for information following delivery of a medical diagnosis, it could be argued that healthcare professionals should proactively direct patients towards specific sites that they know to be reliable and trustworthy, which does happen on occasion but not as standard.

> *"If they could all link in, a bit more continuity between doctors and the websites in an ideal world but that might be impossible."*
>
> Focus Group Participant

32%

LOOKED UP THEIR SYMPTOMS ONLINE BEFORE THEIR LAST GP VISIT

77%

WOULD VISIT A WEBSITE IF RECOMMENDED BY THEIR HEALTHCARE PROFESSIONAL FOR INFORMATION ON THEIR MEDICAL ISSUE

Printed Information Still has a Role in the Digital Age

While online sources are readily available, they are not necessarily accessible or preferred by all. The research also investigated the role that print materials can play for the public in informing them about health and medical issues.

All prescribed medicines come with a detailed patient information leaflet as standard. However, most focus group participants admitted that they rarely read this important document. While most patients will take note of the dosing instructions for their prescription, many do not appear to read the other important information that comes with their medicine.

When surveyed, just under three in five (58%) claim that they read the rest of the patient information leaflet from their last prescription (aside from the dosing instructions). However, anecdotal evidence from our focus groups and discussion with other stakeholders suggest that this result may be higher than would be expected, perhaps due to a reluctance on some people's part to admit they do not read it.

Among the reasons that respondents gave for not reading a patient information leaflet were its length and level of detail; a concern it may not be understood due to the complexity of its content; a belief that their doctor can be trusted to prescribe a medication that is suitable and that the doctor or pharmacist will pick up on any potential drug interactions that could occur.

"[Reading a patient information leaflet] I wouldn't understand 90% of it"

Focus Group Participant

58%

SAID THEY READ THE REST OF THE PATIENT INFORMATION LEAFLET FROM THEIR LAST PRESCRIPTION (ASIDE FROM THE DOSING INSTRUCTIONS)

Information Provided by a Healthcare Professional is More Likely to be Valued

Aside from information about one's medicine, this study explored the public's appetite for print materials relating to their condition or illness.

The direct provision of such materials from the healthcare professional to the patient is important, as many people admit they rarely read information leaflets in the waiting room, despite their availability. This is not surprising given the patient may not know their diagnosis in advance of their consultation and may be waiting for advice from their medical practitioner.

Our survey presents strong evidence that printed healthcare content continues to play an important role in the digital age. A majority (86%) suggest they would be likely to read an information booklet on a medical condition if given to them by a doctor or pharmacist.

Females (90%) and those aged 55 years and over (90%) are the most likely to do so. Providing such information to the patient can give them a sense of autonomy and may also result in fewer follow-up queries or repeat visits to the healthcare professional.

It is important to note that these print materials can take many forms. A wealth of printed leaflets and booklets are available in GP surgeries and community pharmacies nationwide. It appears that any material provided directly by the healthcare professional to the patient suggests its content is vetted and recommended by that practitioner, thereby making it more likely to be read.

The public place a greater value in material that is directly provided rather than unsolicited. Indeed, over three in four (77%) say being given printed materials about a new medical issue that is diagnosed would be an important factor in helping them trust and have confidence in their healthcare professional.

However, it appears that provision of such printed material is not always occurring. Only 36% of those who saw their GP in the past year say their GP gave them printed information about a new medical issue that was diagnosed, while 46% of those who saw a specialist said they did so.
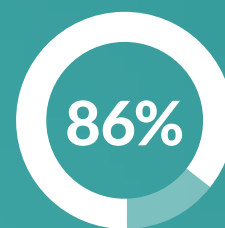
86%

WOULD BE LIKELY TO READ AN INFORMATION BOOKLET ON A MEDICAL CONDITION IF GIVEN TO THEM BY A DOCTOR OR PHARMACIST

What Drives Trust in Printed Healthcare Information?

As part of the focus group discussions, respondents reviewed a sample of randomly selected health information leaflets and booklets. The purpose of this exercise was to understand preferences in terms of content and style and, in particular, identify what factors were likely to drive trust in printed material.

There is no template or national standard that all health information leaflets and booklets must use or adhere to. However, this research identified five broad factors that drive public trust in health information leaflets, booklets and other print materials;

- *It should be accessible*
  The public want content that is simple, direct and easy to understand, including a title that is clearly recognisable and explains what the document entails.

- *It should be concise*
  The public want content that is relatively brief, to the point and not too text heavy, ideally broken up by bullet points to make it easier to read and digest.

- *It should be educational*
  The public want to read material that is informative and helps them understand the medical issue easily, with content such as checklists and 'Frequently Asked Questions' cited as useful in this regard.

- *It should be visually engaging*
  The public want content to be presented with relevant, realistic and relatable images to aid comprehension and help break up the text, which itself should be of a reasonable font size.

- *It should be impartial*
  The public want the content to ideally come from a neutral source that is recognised and relevant, though trust can be perceived as implicit if the material has been published and is available in a trusted location such as a healthcare setting.

There may also be an inherent understanding among some people that any publicly available printed material that comes from an identifiable source has already been through a rigorous approval and vetting process. Many are aware that healthcare and medical organisations are heavily regulated and the quality of their outputs are regularly monitored.

> *"Couch it in plain English, we'd all benefit from having information that is much more easily accessible and transparent."*
> Inez Bailey, CEO, National Adult Literacy Agency

What Drives Trust in Online Health Information?

How do we Search Online for Health Information?

In order to fully explore the reality of how the public search online for health information, live search exercises were conducted during the focus group discussions. These searches were directed by respondents, to try and replicate their actions and thought processes.

The circumstances under which an online search for health information is being conducted can vary. Searches can be pre or post diagnosis, as described earlier, with differing frames of mind as a result. The search terms used can vary across individuals and may depend on the circumstance in each case, for example; from looking for information on non-specific symptoms (e.g. "pain in stomach") to searching for a named condition (e.g. Type 2 Diabetes).

By their own admission, most people will start the process by entering a term or phrase they deem to be relevant into a search engine and then review the results. While user experience and online competence can vary, most admit that their searches are conducted intuitively without over-analysing their decisions. Once presented with the results of their search, many people will scan down through the options and may visit several sites in quick succession, scanning the content to determine its relevance and suitability for them.

"It's like doing the shopping, you try a few before you buy"

Focus Group Participant

Upon entering a specific website, users admit that they tend to make their minds up relatively quickly as to whether or not that site is going to meet their information needs. Web design theory for any subject matter, not just health, would suggest that there is limited time to engage the user's interest. If they believe their needs are not being met, users may leave a website within 10 or 20 seconds, knowing there are alternative sites for them to consider. However, web pages with a clear value proposition that meet the user's needs and expectations can hold their attention for much longer.

"The internet is a wonderful place to find information, but it's also a place of so much more misinformation than you would find traditionally in newspapers or magazines, radio or television. So the internet is obviously hugely important and hugely valuable but it is also a place where there's much misinformation including deliberately false information and information put there for commercial purposes."

Peter Feeney, Press Ombudsman

What Drives Trust in a Health Website?

This research identified five factors which the public believe have the potential to influence the degree to which they would trust a particular website when searching for health information online, which are outlined below.

- *Clarity of layout*
  Users want a professionally presented website with a strong first impression that generates interest. The home page must be clear, concise and easy to follow. We are less likely to trust a website that is perceived to be poorly constructed or have an amateur look and feel.

- *Ease of navigation*
  The presence of an intuitive menu system is important to all users, with section headings presented in a way that is easily understood. It is vital that the user can quickly find the specific information they are seeking. A "less is more" approach to content can be appealing, particularly for younger people who are often accessing such sites via mobile devices rather than traditional PCs or laptops.

- *Quality and accessibility of content*
  While the public accept that some health information websites may contain medical content that can at times be quite detailed, they also want answers to the most obvious questions that they are likely to ask, e.g. explanation of a condition, symptoms, treatment options and potential outcomes. The use of visuals and bullet points to break up text is generally welcomed, while brevity can also help as some users can find overlong content to be off-putting.

- *Recognised, evidence-based, impartial source*
  While a .ie or .com domain name is not always essential, the source of any health website is important. Many users suggest they are more likely to trust a site that comes from a recognised, evidence-based medical body or institution that is impartial. Users are often drawn to a site that is identifiable as Irish or locally relevant and that is recognised as a patient support organisation or is Government or state-sponsored (e.g. the Department of Health and Health Service Executive were cited as good examples of meeting these criteria in an Irish context). However, web content from the United Kingdom or United States of America can also be of value to Irish users, as they can often suggest a breadth of expertise. This can work in two ways, for example, the world-renowned Mayo Clinic in the USA may be recognisable to some, but could suggest a medical centre in the West of Ireland to others.

- *Subtle and unobtrusive visual cues*
  Subtle visual cues such as up-to-date content, recent news and the recency of posts on a discussion board can add credence to a health website's legitimacy. Furthermore, it is suggested that the presence of other elements such as advertising, pop-ups or overtly seeking donations also have the potential to erode trust levels.

"I just look at the first one in the search results because they pay to be there so they must be somewhat reliable if they have money to pay."
Focus Group Participant

"I always go to the Irish site because they might have a point of contact for where to go to next."
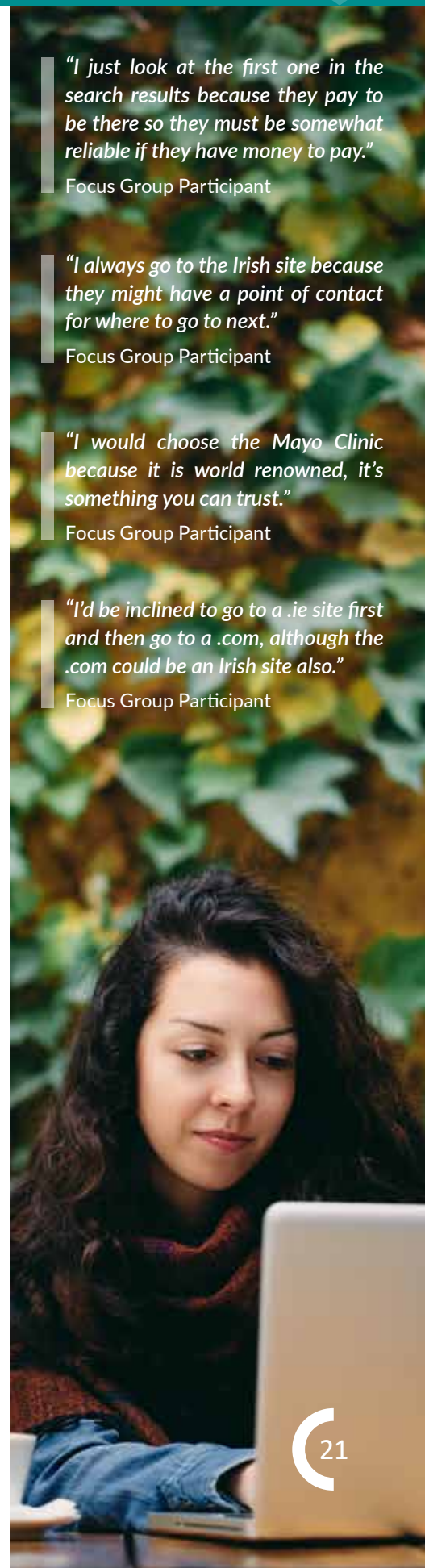Focus Group Participant

"I would choose the Mayo Clinic because it is world renowned, it's something you can trust."
Focus Group Participant

"I'd be inclined to go to a .ie site first and then go to a .com, although the .com could be an Irish site also."
Focus Group Participant

Trust in Online Discussion Boards & Social Media

The data presented earlier shows that social media is the least trusted source of medical information from those measured, with only 4% saying they would consider it trustworthy.

Given its content is often driven by individual, user-generated opinion which is unregulated, social media can sometimes feed suspicion of policy makers, health authorities and industry. This is not limited to the healthcare space, as many other institutions across other aspects of society can generate similar sentiment in the social media space.

Online discussion boards are also a source that, while commonly used, is a less trusted source of healthcare information. Our survey shows that only 5% believe that such forums are a trustworthy source for this type of content.

These online forums are often referred to as echo chambers, whereby beliefs and opinions can be amplified or reinforced by communication and repetition inside these closed systems. Furthermore, unlike published content which may come from a named organisation, the content on online forums is user-generated by individuals and can be posted without the need for formal review and verification. Negative opinions and experiences can often come to the fore on these discussion boards and be magnified, sometimes causing worry and fear for the user.

Despite this, online forums are used by the public as a means to gather information on health issues they may be encountering. While it can, in some cases, be beneficial and informative to hear from others who are experiencing similar health issues, this type of content can sometimes add to rather than alleviate their concerns.

"Individual media literacy should enable people to ask themselves: am I looking at the right thing? However, regulation, either direct, self- or co-regulation, could require online providers of health information to put in place some safeguards regarding information that is published on their platforms."

Stephanie Comey, Senior Manager in charge of Media Literacy, Broadcasting Authority of Ireland

A Range of Factors Can Help Drive Trust in Online Sources

> *"You want a website that is easy to see, with a helpline, and information that is available straight away. I just want answers really quickly."*
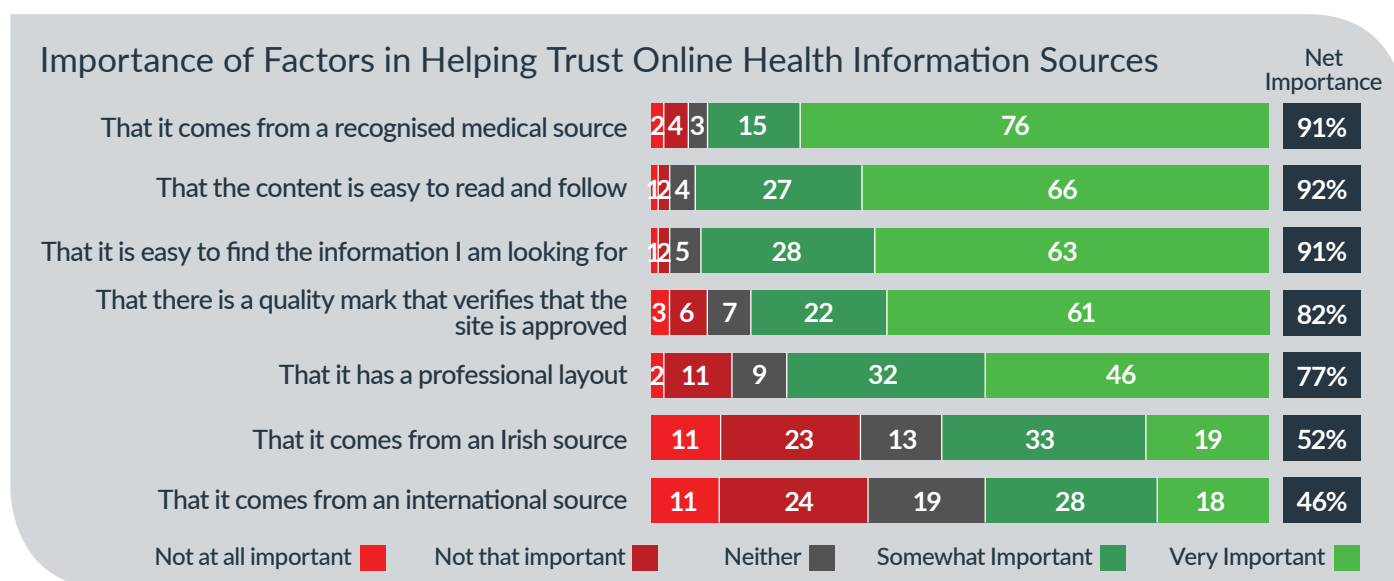>
> Focus Group Participant

Having explored the drivers of trust in online health information sources during the focus group phase, the subsequent survey then sought to measure the degree to which each of these factors were important to the public.

When asked how important a series of prompted factors were in helping one to trust and have confidence in a specific website, the most important factor at 91% is that it comes from a recognised medical source (76% saying this is very important and 15% saying it is somewhat important).

The next two highest ranked factors in helping the public trust a website relate to usability. 92% overall say that the content should be easy to read and follow (66% very important, 27% somewhat important), while 91% overall say it should be easy to find the information one is looking for (63% very important, 28% somewhat important).

82% believe that having a quality or trust mark that verifies that the website has been approved is important, while 77% believe having a professional layout would help them trust a website. 52% say it is important that the website comes from an Irish source, while 46% say it is important that it comes from an international source.

Importance of Factors in Helping Trust Online Health Information Sources

Factor	Not at all important	Not that important	Neither	Somewhat Important	Very Important	Net Importance
That it comes from a recognised medical source	2	4	3	15	76	91%
That the content is easy to read and follow	1	2	4	27	66	92%
That it is easy to find the information I am looking for	1	2	5	28	63	91%
That there is a quality mark that verifies that the site is approved	3	6	7	22	61	82%
That it has a professional layout	2	11	9	32	46	77%
That it comes from an Irish source	11	23	13	33	19	52%
That it comes from an international source	11	24	19	28	18	46%

It is worth noting that the user's own digital literacy and experience online, while not covered in the survey, is also likely to be influential in the level of trust they have in online health information sources.

There is an argument that the public should seek the opinion of a healthcare professional to help filter and interpret the online content they are reviewing. With so much information, the healthcare professional could provide guidance as to what sources may be more or less beneficial with regard to the condition the patient may have.

> *"It's to be welcomed that people are looking to inform themselves and get information on their conditions. What we as professionals need to say to people is 'Go to the library or to the internet, get good information and then bring it in to us and ask us questions… use a healthcare professional to filter and understand the information'. Healthcare professionals are no longer the gatekeepers to health information. People are now their own gatekeepers, but still need a guide."*
>
> Darragh O'Loughlin, Secretary General, Irish Pharmacy Union

Is There Merit in a Registered Trust Mark for Health Content?

This research has demonstrated that there are vast resources available for information on one's health that are widely used by the public, yet are fraught with challenges. There is no definitive accreditation process for online health information. How can the public make a conclusive determination as to whether or not the source they use is of benefit and that its content is accurate, relevant and can be trusted?

> *"With websites, my biggest concern is that it's impossible to tell the genuine ones from the non-genuine ones. I say to patients, if you want to look this up, I'll give you the names of some reliable websites. It's something that I think in many ways should be regulated, but will we ever see that become a reality?"*
>
> Dr. Maitiú Ó Tuathail, **President, National Association of General Practitioners**

The final theme covered by this research looked to investigate this question by putting forward the idea of a hypothetical "Trust Mark" for health information sources, i.e. a means by which any source could be readily identifiable as one that could be trusted. This concept was explored collaboratively with the public during the focus groups, while openness to it was also assessed in the survey phase. It is worth noting that similar certification systems operate in other countries, e.g. The Information Standard quality mark is an NHS certification programme for organisations whose main target audiences are in England.

The survey question asked the public if they were in favour or opposed to the introduction of a registered Trust Mark confirming that health information in relation to medical conditions, either in print or online, is from a recognised medical authority. In total, 55% were strongly in favour of this idea and a further 18% were somewhat in favour, giving a total of 73% in favour overall. Only 8% in total were opposed.

While these results are encouraging, it must be accepted that they are merely indicative of support for a theoretical concept. Furthermore, it is acknowledged that this question was presented in the context of a longer survey interview on trust in healthcare information. Meanwhile, the focus groups allowed time to explore this idea in greater depth and during these discussions, the public acknowledged that this would be a difficult idea to implement and appraise in practice. Respondents raised several valid questions around how such a Trust Mark might work in practice, which can be summarised under two broad headings as follows;

Oversight and governance
- What organisation would provide this trust mark and manage its authenticity and governance?
- Would this be overseen by an independent Irish body, or does the size of the task require it to be delivered by a European or global entity?

The verification process
- What specific process would underpin this trust mark, i.e. how would a health information source be verified in practice?
- What specific medical criteria would need to be met?
- How long might the process take?
- What fee, if any, would be involved for websites to be verified as trustworthy?
- Would the entire process be secure or open to manipulation or fabrication?

73%

ARE IN FAVOUR OF THE INTRODUCTION OF A REGISTERED TRUST MARK CONFIRMING THAT HEALTH INFORMATION IS FROM A RECOGNISED MEDICAL AUTHORITY

In summary, while the theory of a registered trust mark is deemed to be laudable and of value by the public, it is also accepted that the design and implementation of such a process, particularly in the vast online space, would be a long-term, challenging undertaking.

Furthermore, for a registered trust mark to be truly successful, users must be aware of it and understand its purpose. Therefore, the roll-out of any verification process for online health information sources would require a significant and comprehensive marketing and promotional campaign, to make the public aware of its existence and rationale.

Many believe that for any healthcare information that is publicly available, the named source or organisation that is providing that information could itself be interpreted as an indicator of its quality and thereby be a marker of trust. Indeed, it is suggested that one means of verifying trusted sites is to have links to them on the website of a noted authority.

For example, if the website of a national Irish health body were to contain links to other websites with information on particular conditions, this is seen by some as a potential solution. Nonetheless, the need to avoid any conflict of interest around the suggested endorsement or recommendation of third-party websites by a national authority would of course need to be carefully considered.

Ultimately, the user's own health literacy, knowledge, intuition and previous experience all play their part in helping them determine whether or not a specific health information source can be trusted.

"I think a quality mark would be good because you know it's verified, you aren't left wondering if it might be a good website."
Focus Group Participant

"You would hope that there would be certain standards that you would have to meet across the board and that it would be validated and up-to-date."
Focus Group Participant

"If there was a quality mark it would depend on the criteria to attain it. I think it would take time for people to trust it."
Focus Group Participant

"A lot of this is about empowerment. How do you empower the user, or the searcher, or the seeker of information that what they seek is from a reliable source? Sometimes you have to use an intermediary to actually get to where you want to go. It's really got to do with signposting to those reliable, authoritative sources."
Stephen McMahon, Chairman and co-founder, Irish Patients' Association

Conclusions

Conclusions

We live in an era of consumer empowerment. The ease with which we can access information on our health anytime, anyplace, from any device would have been unthinkable in the pre-internet world.

The sheer breadth and variety of content that is available online about all matters to do with our health is generally welcomed. However, it makes it extremely challenging to manage, and sometimes overwhelming for the user.

There is undoubted variability in the quality of health information that exists online. The information available on a single health subject can sometimes be inconsistent across different websites.

Through our research we found:

1. The approach any individual takes to searching for this information varies considerably. **Online searches are far from linear and standardised**; one only has to type any symptom or medical condition into a search engine to be presented with numerous results, with the choice and sequencing of which sites to enter ultimately at the user's discretion. Moreover, the competence of the individual to interpret and make sense of the information they do find will also differ.

2. A standardised approach to assessing the veracity of health content on the internet does not appear to exist. **A verified trust mark** to help users determine the validity of the information they review is of interest to many. However, the practicalities of implementing and managing such a system would require a significant undertaking, with many unanswered questions remaining.

3. The public are **open to guidance** when searching for health information sources, whether online or in traditional printed format. The role of healthcare professionals is key in providing this guidance, with patients more likely to place value on materials directly recommended to them by an experienced practitioner.

Whether it makes us feel better or worse, the internet is here to stay and can be invaluable to the public when seeking information on their health. It is hoped that this research helps inform this debate and provides guidance in how best this invaluable resource can be utilised to the benefit of all stakeholders.

Acknowledgements

About Ipsos MRBI

Ipsos is a global independent market research company ranking third worldwide among research firms. At Ipsos, we are passionately curious about people, markets, brands and society. We make our changing world easier and faster to navigate, and inspire clients to make smarter decisions. Ipsos is represented in Ireland by Ipsos MRBI, Ireland's longest established research firm.

With a heritage stretching back over fifty years, Ipsos MRBI is renowned for delivering high quality, insight-driven, actionable research. We employ 35 full time employees, who are supported by a staff of over 200 experienced interviewers nationwide.

Ipsos MRBI interviewers abide by strict fieldwork quality standards set by the ESOMAR International Code of Marketing and Social Research Practice and AIMRO (Association of Irish Market Research Organisations). We are dedicated to ensuring quality throughout all elements of our research, and in order to demonstrate this we became the first research agency in Ireland to be certified to ISO quality standards.

MSD Ireland is one of the country's leading healthcare companies, having first established here over 50 years ago.

We currently employ approximately 2,000 employees, across five sites in Ballydine, Co Tipperary, Brinny, Co Cork, Carlow and Dublin and, in addition, operate substantial Human Health and Animal Health businesses. Early in 2018 the decision was made to base a new biotechnology facility – known as MSD Biotech, Dublin - in Ireland with the expected creation of up to 350 new jobs. In October 2018 we also announced plans to construct a second manufacturing facility at our existing site in Carlow with the creation of 170 new jobs.

In total to date, we have invested $2.5 billion in our Irish operations and our annual turnover ranks us as one of Ireland's top 20 companies.

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At MSD Ireland we firmly believe that the most important thing we make is a difference – to patients, to our employees, to our communities and to the Irish healthcare landscape generally. MSD Ireland is 100% committed to putting the patient at the heart of everything we do.   Significantly, our Irish sites manufacture approximately half of MSD's top twenty products, saving and enhancing lives in over sixty countries around the world.

The Right Click?

Exploring levels of trust in online healthcare information

Part of the My Healthcare, My Future Series

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