Patient Information Forum

For everyone involved in health information and support

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Best practice

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Communicating benefits, risks and uncertainties in a non-judgmental and unbiased way

Risks and statistics are an essential part of patient information. What is a person's risk of developing a particular condition in their lifetime, or of having a certain symptom if they have that condition? What are the risk factors for a disease, and can people change these? What is the chance of a treatment or procedure working? And what is the risk of getting the different side-effects and complications that can come with it?

Many patients are unable to comprehend basic statistics, never mind navigate their way through the reams of data that may come with health information to compare treatment options.[1]   As information producers, our job is to make sure we can guide patients through the minefield of data and figures to help them feel confident in making their own decisions.

The practical resources below highlight a range of approaches and tools for unbiased communication.

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Communicating risk checklist

☐ Be cautious using verbal descriptors of risk. If used, ensure these are accompanied by statistical information.

☐ Use absolute risk rather than relative risk.

☐ Use natural frequencies (i.e. x in 100) as well as percentages.

☐ Consider using both positive and negative framing for risk.

☐ Communicate uncertainty of data; explain the effect confidence intervals (or deeper uncertainties) have on data.

☐ Consider using a mix of numerical and pictorial formats to communicate risk.

☐ Make risks relevant. Consider using examples as a comparator.

This resource covers the following topics:

- Illustrating risk
- Perceptions of risk
- Know your numbers
- Explaining uncertainty
- Useful resources
- References
- Further evidence

Too much information?

Before we even think about how we talk about risk, it's worth asking the question – do we really need to discuss it at all? There are many reasons not to:

• Statistics are hard to understand.
• Risks can also vary considerably between individuals, procedures, doctors and hospitals.
• Statistics can feel so specific, and there is a danger of generalising information so much that it is not really relevant to anyone.
• There is also the issue of creating extra worry for patients by stating figures.

Presenting information in a non-neutral manner can affect a user's understanding and preferences. Clear consensus is that 'honesty is the best policy' and that glossing over or ignoring uncertainty can be deceptive.

Shared decision making

It is important to give patients the full picture if they are going to make an informed choice. This is fundamental to shared decision-making.

This means discussing and providing the potential benefits and harms with equal weight using language and graphics patients understand.

The Montgomery case in 2015 was a landmark for informed consent in the UK. This legal judgement defines how risks and benefits should be discussed with patients by healthcare professionals.[2]

While patients need to be fully informed, there is a danger of providing too much data.[1] It is important to strike a balance between overwhelming patients and giving them enough information to make fully informed choices. When you are producing your content, think about what information is most critical to help your readers make a choice.[1]

There will always be some people who don't wish to know this level of information. But it is better to have it available for those who do, while taking care to explain potentially upsetting statistics sensitively, and giving practical advice or reassurance when necessary.

Where to find information on risk

You may want to include statistics in your information, but as with anything, you need a reliable source. If you cannot back it up with a solid reference, it is better not to include this information at all. Information from hospitals or individual doctors is likely to be specific to that institution or individual, so is not an adequate source of information.

Look for systematic reviews (including Cochrane reviews) research summaries (such as BMJ Best Practice) or recent, large-scale clinical trials. If another organisation has quoted a statistic, trace it back to the original source. If you can't find a reliable source, don't include it.

Bear in mind too that you need to keep your information balanced. So, if you are discussing several treatment options and you are including statistics for one option, make sure you have the equivalent information for all.[4]

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Illustrating risk

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A great way to help improve your users' understanding of risk and statistics is to use visual aids in your content.[1,7] However, there are a few things to bear in mind before you go ahead.

Don't forget the numbers…

First of all, it's important to realise that people vary in their ability to understand visual information.[7] It can be easy to assume that adding in a visual will automatically make your information easier to understand – but bear in mind that some people may find graphs and illustrations harder to comprehend than the actual numbers.

It has been suggested that visual displays may be most helpful for giving people the general 'gist' or overall pattern, whereas including actual numbers is better if you want to communicate more of the detail.[7] You may find you need to do a combination of both to get your message across, and understood, by as many of your users as possible.

Types of graphics

There are many different types of formats for presenting risk. Which one is best for your content will depend on a number of factors. These include the type of statistics you are presenting and whether you are looking at how data changes over a period of time, or just describing it at a single time point.[1]

Some of the main types of graphics used to illustrate risk include the following:

Line graphs

A simple graph with the risk/chance of the event on the vertical (y) axis and time period on the horizontal (x) axis. These tend to be better at communicating trends over time.[7]

Bar graphs

Whether horizontal or vertical, bar graphs are useful for comparing two or more groups or scenarios.[7]

Pie charts

These are often used to give a quick overview of the frequency of a single, or multiple events. Take care when using them though – it can be easy for true proportions to appear distorted in pie charts, giving misleading messages.

Icon arrays/Pictographs

These use a matrix of icons (usually 100 or 1000) to represent the number of people at risk or the number of expected events, as well as the number not at risk or number of non-events. The icons can range from blocks to figures or smiley faces.

In general, icon arrays/pictographs are considered to be the most effective when communicating individual statistics (rather than comparing groups).[1] One of the plus points is that they convey the numerator (number of events) as well as the denominator (total number of people), and by showing both the positive and negative outcomes they avoid bias through 'framing'.[7, 8]

If you are unsure which type of graphic best suits your needs, try the Wizard on the Visualizing health website, or take a look at some of the ideas on the Understanding Uncertainty website.

Don't forget to user-test which visual aids work best for your content and target audience. This means not just looking at which type your users prefer, but more importantly, which one they understand the most and gives them the most accurate perception of risk.[7]

Perceptions of risk

How we talk about risk isn't just about including the right numbers. It is also about the language we use and how we describe it.

Framing

Framing means whether you describe something in a positive or negative way. This can make a huge difference to how it is perceived.[9,10]

For instance, saying "this procedure is effective in 95 in 100 people" is positive framing. Saying "the surgery doesn't work in 5 in 100 people" describes the same results, but with negative framing.

Reading each of these statements independently may give you a skewed view of the results – you are immediately either focused on the positive or negative findings. Different people may be influenced by one more than the other.

You might want to tell people about a particular side-effect of a treatment: "1 in 100 people who have this procedure may develop a severe complication" – but do you ever think to mention the 99 in 100 people who are absolutely fine?

When you next come to write about statistics and risk, think about how you describe them – are you unintentionally putting a positive or negative spin on them? If so, consider how you may be able to include both positive and negative framing in your content. It may not always be feasible to do so, but when you can, it is the most balanced way of presenting your information.

For the example above, you could say "1 in 100 people who have this procedure develop a severe complication. This means 99 in 100

recovers without any severe complications." It may seem obvious, but it gives the more balanced view of the numbers.

Risk taker or risk adverse?

People are not just influenced by how risk is presented; everyone will also have their own personal perception of risk.[9, 11]

Take the example above, in which 1 person in 100 may develop a severe complication. Some people may take the view that this is a very small risk – and one that's worth taking. Someone else however, may worry about being that one person who develops the complication and therefore consider the treatment too risky.

This is something very personal – it is down to your own views and values, and more generally, about how risk adverse you are. What is important when writing content is not to assume what the reader's perception of risk may be. So, stick to the numbers, rather than adding descriptions such as 'this is a very small risk'.

Making risks relevant

How useful is telling someone they have a "one in five" risk, if they can't visualise what this means? Adding some context to your statistics can make them more meaningful. It can help to compare rates to something else that your audience may be more familiar with – for example the chance of winning the lottery, or of being struck by lightning "e.g., you are more likely to win the lottery than die from X disease."

The drawback with this kind of comparison, is that your readers may not always be familiar with the comparators being used, so it is

important to also include the actual figures too.

You may also find it helpful to include more relevant examples, for instance comparing rates of incidence to those for similar

conditions, or comparing rates of side-effects for similar treatments.[9]

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Know your numbers

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Numbers not words

You may think it is more helpful to include verbal descriptions of risk, for instance, describing something as 'common' or 'rare'. Many medical organisations have adopted a scale originally developed by the European Medicines Agency (EMA), which categorises levels of risk into very rare, rare, uncommon, common and very common.[3]

The problem with these descriptive terms is that people's perception of what they mean varies enormously. People tend to overestimate the actual risk when terms such as 'common', as defined by the EMA, are used.[4-6] If you can, it's better to avoid using descriptive terms like these at all;[6,10] but if you do use them, make sure you also include relevant figures or values.

There can be many ways to present the same type of data. Are you using the best method to communicate your information? You don't need to be a mathematician – a few simple tips can make your information instantly easier to understand.

Natural frequencies

One of the best ways to make statistics more meaningful is to use natural frequencies alongside their percentages. This is because some people find percentages a hard concept to understand.[1,12]

So, rather than just saying "Drug X reduces symptoms for 10% of people" you could add "or 1 in 10 people".

It is also important to make your numbers easy to understand. Obscure proportions, like "8 out of 27" are hard to picture. Try to either stick to using multiples of 10 as the denominator (3 in 10, 45 in 100 etc.); or alternatively saying "1 out of…" to make numbers more relevant.[9]

Finally, if you are comparing figures between groups, make sure they have the same denominator.[9,10] So, don't say 1 out of 6 for one group and 1 out of 8 for another – it's hard to tell quickly which one is larger. Instead, convert both figures so they use the same denominator.

> **How?**
> For the obscure proportion example above (8 out of 27), this is equivalent to 30% (8/27 x100).
>
> This could be expressed as "30 in 100 people", or "3 in 10 people". You could also describe this as "just under 1 in 3 people" (27/8 = 3.4).

> **How?**
> The simplest way to compare two fractions with different denominators is to convert both to percentages, and then use numbers out of 100.
>
> • 1/6 x 100 = 16.7%, or 17 out of 100 people
> • 1/8 x 100 = 12.5%, or 13 out of 100 people

Absolute risk describes the chance of an event happening over a specific time.

Relative risk describes how two risks compare; or in other words, how much more or less likely a particular event is in one group compared with another.

Risk reductions describes how these risks are reduced by a particular intervention.

The differences between these are best described using an example.

Imagine that you read a study on a new drug, which finds the risk of having a heart attack or stroke is 10% in people who did not have the treatment, compared with 5% in people who took the drug for 3 years.

This can be described as:

• An absolute risk reduction of 5% (10% minus 5%) – also sometimes referred to as 5 percentage points: "The number of people who had a heart attack or stroke after taking the drug dropped by 5 in 100".

• A relative risk reduction of 50% (5% divided by 10%): "The drug reduced the risk of heart attack or stroke by 50%".

Which would you find easiest to understand and which would you find more persuasive?

Relative risks tend to be misleading, by making any changes look bigger than they actually are.[12] They are often quoted in media stories as they add 'shock value'. However, if presented on its own, the relative risk does not actually tell you anything meaningful. You need to know what your baseline is to understand how it relates to you.

So, for the example above, someone who has a very small risk of heart attack to begin with will benefit much less from the drug than someone who has a high risk of heart attack.

• For someone with a low baseline risk of 1 in 100, a 50% relative risk reduction would mean their risk is now 0.5 in 100 (an absolute reduction of 0.5 percentage points).

• For someone with a high baseline risk of 80 in 100, a 50% relative risk reduction would mean their risk is now 40 in 100 (an absolute reduction of 40 percentage points).

You can see that in each example, the relative risk stayed exactly the same, whereas there is a huge difference in the absolute risk reductions.

When presented on their own, absolute risk reductions generally give readers a more accurate understanding of risk than relative risk reductions.[12,13]

There are sometimes occasions when it may be useful to include the relative risk – for example, if the absolute risks are very small and so the absolute numbers are difficult to comprehend (e.g. very rare complications),

The important point is the change that can be made to these by a treatment, but the absolute figures should still be used alongside them. Including the baseline figures[13] has been shown to significantly improve readers' estimate or interpretation of risk.[13]

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Explaining uncertainty

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Estimations of risk are just that – an estimate. Even with the most perfectly designed study, the results are always influenced by the play of chance and individual differences. [14]

This is where confidence intervals come in. Confidence intervals are a measure of how sure we can be about the estimates obtained from a study. They present a range of values; in which we can be fairly certain the true answer lies. The wider the confidence interval, the more uncertain we are. In most studies, results are expressed in terms of a 95% confidence interval (95% CI).

This means we can be 95% certain that the true answer will lie within that range.[14]

So, if a study tells us a drug works for 25% of people and the 95% confidence interval is 23–26%, the results are very precise and we can feel more confident that the true proportion of people who will benefit is close to 25%. If the confidence interval is 12–48% though, there is much more uncertainty around the results and it is questionable how useful they are.

On top of this, there are uncertainties that are not so easily quantified. Perhaps we are only relying on one study, which may not have been particularly well controlled. Perhaps the studies were on a particular group of patients, and in the 'real world', patients who take the drug may be very different from those in the study setting, and this may affect how well it works. So even the confidence interval does not fully express our uncertainty.

Of course, no estimates at all can say what will happen to an individual patient - only what has happened in the past to people like them.

> **How?**
> So, how to communicate uncertainty? As we know, more information is not always a good thing – aim to keep it as simple as possible.
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> For the example above, in which a drug worked in 25% of people and had a 95% confidence interval of 12–48%, you could explain this as follows:
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> "Results from the study suggest that the drug works in 25 in 100 people. The results weren't very precise though – between 12 and 48 in 100 people may benefit from the drug."
>
> If you do not need to discuss study results in depth in your information, it may be enough to be aware of how to interpret and convey this information.
>
> If the confidence intervals are very wide, should you be quoting those results at all? If there is a narrower range, you may simply want to add in suggestion of uncertainty in your content by using terms such as "Around", "Approximately" or "About". For example:
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> "Around 25 in 100 people may benefit from this drug".

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Useful resources

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BMJ Best Practice
A research base which allows decisions to be made on the best available evidence https://bestpractice.bmj.com/info/benefits-features/evidence-based/

Cochrane reviews
Cochrane is for anyone interested in using high-quality information to make health decisions. Cochrane evidence provides tools to enhance your healthcare knowledge and decision making.

International Patient Decision Aid Standards (IPDAS) 2005: Criteria for judging the quality of decision aids
This checklist specifies criteria for transparent, balanced and unbiased communication of health information to aid decision making. It covers: having a clear structure for layout; asks if resources help patients to make appropriate decisions; the need for planning and identifying objectives; and having a systematic development process

Making Sense of Statistics
This guide is not a lesson in statistics. It provides the questions to ask and identifies the pitfalls to avoid.

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services (2012) NICE (National Institute for Health and Care Excellence)
Principles for discussing risks and benefits with a patient (1.5.24).

'Does the patient decision aid… list the options; list the option of doing nothing; describe the natural course without options; describe positive features; describe negative features....'

Public engagement: a practical guide
This is a practical guide on involving the public in working out how to communicate research findings.

Spinning the Risk
This tool allows you to compare presentation of relative vs absolute risks, positive vs negative framing, natural frequencies vs percentages etc. It aims to help improve the way that uncertainty and risk are discussed.

Understanding Uncertainty
Website that tries to make sense of chance, risk, luck, uncertainty and probability.

Visualizing Health
Contains graphic displays of health information that we've validated through research among the general public

Winton Centre, Cambridge eLearning courses
Courses on risk communication for primary care clinicians and for perioperative specialists such as surgeons and anaesthetists.

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References
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1. *Helping patients decide: ten steps to better risk communication* Fagerlin A, Zikmund-Fisher BJ, Ubel PA (2011). J Natl Cancer Inst. 103(19):1436–43. doi: 10.1093/jnci/djr318 jnci.oxfordjournals.org/content/103/19/1436.long

2. *Montgomery v Lanarkshire Health Board judgment*
The Montgomery case in 2015 was a landmark for informed consent in the UK.

3. *Undesirable effects* European Medical Agency (2013)

4. *Perceived risk of medicine side effects in users of a patient information website: a study of the use of verbal descriptors, percentages and natural frequencies* Knapp P, Gardner PH, Carrigan N, Raynor DK, and Woolf E. (2009). British Journal of Health Psychology. 14:579–594. doi: 10.1348/135910708X375344

5. *Comparison of two methods of presenting risk information to patients about the side effects of medicines* Knapp P, Raynor D, and Berry D (2004). Quality and Safety in Health Care. 13:176-180. qualitysafety.bmj.com/content/13/3/176.full

6. *Combined verbal and numerical expressions increase perceived risk of medicine side-effects: a randomized controlled trial of EMA recommendations* Knapp P, Gardner P H, and Woolf E. (2015). Health Expectations. doi: 10.1111/hex.12344. 6. Royal College of Obstetricians and Gynaecologists (2008). Presenting information on risk.

7. *Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers* Trevena L, Zikmund-Fisher B, Edwards A, et al (2013). BMC Medical Informatics and Decision Making. 13(Suppl 2)

8. *Decision tool to improve the quality of care in rheumatoid arthritis* Fraenkel L, Peters E, Charpentier P, et al (2012). Arthritis Care Res. 64(7):977–85. doi: 10.1002/acr.21657

9. *Presenting health risks honestly: mifepristone, a case in point*. Stewart FH, Shields WC, and Hwang AC (2004). Contraception (69):177–8.

10. *Presenting information on risk* Royal College of Obstetricians and Gynaecologists (2008).

11. *Always Read the Leaflet – getting the best information with every medicine* Committee on Safety of Medicines (2005). Report of the Working Group on Patient Information.

12. *Using alternative statistical formats for presenting risks and risk reductions* Akl EA, Oxman AD, Herrin J, et al. Cochrane Database of Systematic Reviews 2011, Issue 3. Art. No.: CD006776. DOI: 10.1002/14651858.CD006776.pub2.

13. *Expressing medicine side effects: assessing the effectiveness of absolute risk, relative risk, and number needed to harm, and the provision of baseline risk information*. Berry DC, Knapp P, Raynor T (2006). Patient Educ Couns;63(1-2):89–96.

14. *Smart Health Choices: Making Sense of Health Advice* Irwig L, Irwig J, Trevena L, Sweet M (2008). Hammersmith Press.

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Further evidence

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[Assessing the quality of information to support people in making decisions about their health and healthcare. (2006.) Picker Institute Europe](.).
These findings and results of previous research should encourage organizations communicating evidence communicating evidence from synthesized research to provide detailed information about effects and quality of evidence narratively using a standardized language and in a table.

[Balancing the presentation of information and options in patient decision aids: an updated review. (2013.) Abhyankar P, Volk R, Blumenthal-Barby J, et al., 13(Suppl 2). BMC Medical Informatics and Decision Making.](.)
When discussing risks and benefits with a patient… include both positive and negative framing (for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients.

[A Demonstration of "Less Can Be More" in Risk Graphics. 4b Zikmund-Fisher BJ, Fagerlin A, Ubel PA (2010). Med Decis Making. 30(6): 661–71](.)
Taking a ''less is more'' approach by omitting redundant mortality outcome statistics can be an effective method of risk communication and may be preferable when using visual formats such as pictographs.

[Symbols were superior to numbers for presenting strength of recommendations to health care consumers: a randomized trial. (2007.) Akl EA, Maroun N, Guyatt G, et al., 60: 1298-1305.. J Clin Epidemiol.](.)
Most participants were adamant that they did want to know the full picture...They indicated a preference for information that is balanced and includes a careful and honest assessment of the pros and cons of treatment.

[Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions. (2003.) Section 6 - producing the first draft. NHS Scotland.](.)
It is essential that patient information is explicit about the degree of uncertainty, as categorical statements and didactic recommendations that don't acknowledge scientific uncertainty are unreliable and help no one.

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Acknowledgements
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About the Patient Information Forum (PIF)
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The Patient Information Forum (PIF) is a not for profit, UK membership organisation and network for people working in and involved with healthcare information and support.

Our work involves: delivering resources and events for information producers and providers; influencing to raise the profile and quality of health information and bringing together those interested in the field of health information and support.

The PIF membership body come from across all sectors, representing every kind of information and support producer and provider, from the NHS to large international companies, health charities to national health departments, researchers to freelance medical writers.

PIF is committed to improving the healthcare experience for patients and the public by helping individuals and organisations to deliver high-quality, evidence-based, accessible information and support so that everyone can understand their care, and make informed decisions about their health and wellbeing choices.

You can find out more:

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