



Patient Information Forum

For Professionals Working in Consumer Health Information

Communicating risk: introduction

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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?

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's a danger of generalising information so much that it's not really relevant to anyone. There's also the issue of creating extra worry for patients by stating figures.

Yet, many patients are unable to comprehend basic statistics, never mind navigate their way through the reams of data that may come with health information comparing 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.

However, it is important to give patients the full picture if they are going to make an informed choice. And this means discussing the potential benefits and harms with equal weight – as well as using the same kind of language and level of graphics.

There will always be some people who don't wish to know this level of information. But it's 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. For instance, if the risk of a particular side-effect is high, you might include advice about what patients should do if they get it. If discussing a complication of surgery, you might say medical staff will be on hand should that complication arise.

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.²

Where to find risk information?

You may want to include stats in your information, but as with anything, you need a reliable source. If you can't back it up with a solid reference, it's 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 isn't an adequate source of information.

Look for systematic reviews (including [Cochrane reviews](#)), research summaries (such as [BMJ Clinical Evidence](#)) or recent, large-scale clinical

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

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.³⁻⁵ If you can, it's better to avoid using descriptive terms like these at all;^{5,6} but if you do use them, make sure you also include relevant figures or values.

trials. If another organisation has quoted a statistic, trace it back to the original source. And 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're discussing several treatment options and you're including statistics for one option, make sure you have the equivalent information for all.

PIF Toolkit: risk checklist

www.pifonline.org.uk/toolkit

PIF Toolkit key step	Covered here
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 numbers rather than percentages.	
Consider using both positive and negative framing for risk.	
Communicate uncertainty of data; explain the effect confidence intervals have on data.	
Consider using a mix of numerical and pictorial formats to communicate risk.	
Make risks relevant. Consider using examples as a comparator.	

References

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About the author and contributors

This fact sheet was written and produced for PiF by Pippa Coulter. Pippa is a specialist in the production of consumer health content, with 15 years of experience in medical publishing and communications. She has extensive experience in producing high-quality, reliable and evidence-based health content for consumers. Pippa currently manages the health content library at Bupa. View Pippa's profile on [Linkedin](#).

The factsheet was kindly reviewed by David Spiegelhalter, Winton Professor for the Public Understanding of Risk in the Statistical Laboratory, Centre for Mathematical Sciences, University of Cambridge.

Hannah Bridges, HB Healthcare Comms, edited the factsheet.

About PiF

PiF is a non-profit organisations working to improve the quality and accessibility of health information for patients and public across the UK. Our work involves: delivering resources and events for information producers; influencing to raise the profile of health information; and bringing together those interested in the field of health information via the PiF network. You can find out more at www.pifonline.org.uk .