

Understanding how risk is discussed in healthcare

Information for you



Royal College of
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Setting standards to improve women's health

What is risk?

Risk is the chance that any activity or action could happen and harm you. Almost everything we do has an associated risk. Living is a risky business. People will generally take risks if they feel that there is an advantage or benefit. We need to look at risks and benefits together. Normally the benefits of an action should outweigh the risks. There is no such thing as a zero risk. How you view risk depends to a large extent on your own circumstances and 'comfort zone'.

Why do I need to know about risk?

When you are considering having a procedure, intervention or screening test for yourself or someone else, you need to know about the benefits and risks or any uncertainties to help you to make an informed decision.

How you view a risk depends on one or more of the following:

- the chance of the event occurring (frequency)
- the chance of a condition being detected by a screening test (detection rate)
- the benefits of the treatment or screening
- how much harm may be caused:
 - if it is life-threatening
 - if it is short-term (temporary) or long-term (permanent)
- how much you feel in control of the decision
- how much you trust the person discussing the risk with you
- whether you feel you understand the situation sufficiently.

Some of these factors will be more important to you than others.

How is risk discussed?

Healthcare professionals use research evidence to describe the chance of an event occurring in the context of an entire population. So your healthcare professional can tell you one woman in nine (1 in 9) will develop breast cancer. What they cannot tell you is whether the 'one' woman who develops breast cancer will be you.

If you have a screening test for a particular condition or disease, the results tell you if you are at 'high risk' or 'low risk' for that condition or disease. For example, if you are pregnant you will be routinely offered a screening test for Down syndrome. The results of this test will show if your unborn baby has a 'high risk' or a 'low risk' of having Down syndrome. A high-risk result does not mean that your unborn baby definitely has Down syndrome. It means that the risk of Down syndrome is more than 1 in 250 (of 250 pregnant women, more than one woman has an unborn baby with Down syndrome). In this situation, you would be offered a further test to find out if your unborn baby is one of the babies with Down syndrome.

Even if you have a low-risk result, there is a chance that your unborn baby may have Down syndrome but it may be helpful to know that the chance is small.

Risk can be given as numbers or words, or both. This table below shows how risk should be described in healthcare:

Risk table		
Verbal description ^a	Risk	Risk description ^b
Very common	1/1 to 1/10	A person in family
Common	1/10 to 1/100	A person in street
Uncommon	1/100 to 1/1000	A person in village
Rare	1/1000 to 1/10 000	A person in small town
Very rare	Less than 1/100 000	A person in large town

^a EU-assigned frequency
^b Unit in which one adverse event would be expected

People's views of the descriptions of 'very rare' or 'common' regarding harm or satisfaction vary greatly concerning health care. Your concerns, anxieties and fears about the present and the future are very personal and may affect how you view risk. Some people find it is more useful to discuss risk using numbers or pictures rather than words.

How is risk presented in everyday life?

Health risks are talked about every day – sometimes well, sometimes poorly.

Often it can be difficult to sort out the real facts of a matter. Take, for example, the confusion over the 1995 'pill scare'. Scientists reported that some oral

contraceptives doubled the risk of thromboembolism (a blood clot) compared with other oral contraceptives. To say that something 'doubles' sounds a huge amount. What the initial report did not mention, however, was that the risks were only 1 in 6000 to start with – which is 'rare'. The new risk - 1 in 3000 (or 2 in 6000) - is still rare. In addition, the increased risk of death was only about one person in a million. The risk had not been put into context and a result there was panic in the media and among the public.

Sometimes percentages are used when the overall numbers are very small indeed. It is very important that the facts are explained in a meaningful way.

What are the best ways for risk to be explained?

Good communication between you and your healthcare professional promotes a trusting relationship and brings greater satisfaction to you both. It also helps you to take more responsibility for decisions about your own health care.

When explaining risk healthcare professionals should:

- involve you fully
- give you the opportunity to have someone with you (such as a friend, partner or relative)
- know and understand your circumstances and how this could affect you personally
- describe the risk in different ways; for example, 'your risk of breast cancer is 1 in 9 or your chance of never getting breast cancer is 8 in 9'
- give you correct and up-to-date information
- give you information that is relevant to you
- be honest, frank and open
- speak clearly
- have empathy
- listen to your concerns
- give you an opportunity to ask questions
- give you time
- provide sources of information such as leaflets or websites
- check that you have fully understood

...and on your part, you should:

- say if you don't understand
- ask if you want information presented in a different way
- say if you need more time.

Your healthcare professional may explain the information in a number of different ways, such as pictures, graphs and other tools to help you make a decision. These help to ensure a better understanding.

Understanding risk

Sometimes research evidence may not be clear about a particular risk or benefit. This is why you may receive different information from different healthcare professionals. It may be because of the situation in which your healthcare professional is working, their own personal experience, your personal situation or because the true risk is not known. Uncertainty exists.

Understanding risk can be difficult but it is helpful when you work in partnership with your healthcare professional.

Reference

Calman KC, Royston G. Personal paper: Risk language and dialects. British Medical Journal 1997; 315:939-42

A glossary of medical terms is available on the RCOG website:

www.rcog.org.uk/womens-health/patient-information/medical-terms-explained.

Sources and acknowledgements

This information is based on the Royal College of Obstetricians and Gynaecologists (RCOG) Clinical Governance Advice No. 7, *Presenting Information on Risk*, which was published in December 2008. This information will also be reviewed, and updated if necessary, once the Clinical Governance Advice has been reviewed. You can find the Advice online at:

www.rcog.org.uk/womens-health/clinical-guidance/presenting-information-risk. Clinical Governance Advice is intended to provide advice for clinicians. It is drawn up by teams of medical professionals and consumer representatives who look at the best research evidence available and make recommendations based on this evidence. This information has been developed by the Patient Information Subgroup of the RCOG Guidelines Committee, with input from the Consumers' Forum and the authors of the Clinical Governance Advice. It has been reviewed before publication by women attending clinics in Newcastle-upon-Tyne and Surrey. The final version is the responsibility of the Guidelines Committee of the RCOG. The RCOG consents to the reproduction of this document, provided that full acknowledgement is made.

A final note

The Royal College of Obstetricians and Gynaecologists produces patient information for the public. This information is based on guidelines which present recognised methods and techniques of clinical practice, based on published evidence. The ultimate judgement regarding a particular clinical procedure or treatment plan must be made by the doctor or other attendant in the light of the clinical data presented and the diagnostic and treatment options available