first exposure

Making Sense of Risk and Statistics

We live with risk in many daily decisions that we make. However, not all choices carry the same level of risk. In pregnancy, these choices feel more challenging; we are now responsible for making decisions that can affect a developing child. To make it all harder, the information can be confusing and is often described using statistical language, which can be hard to interpret.

It can feel like a lot of pressure to make the right decisions. It can feel overwhelming.

This website will provide you with the tools to help you with the decision-making process. Here you will find up-to-date research, and the opinion of experts balanced with the lived experiences of individuals from different backgrounds. There is much talk about risk, or the chance that something will happen, so let us explore some of the language of risk.

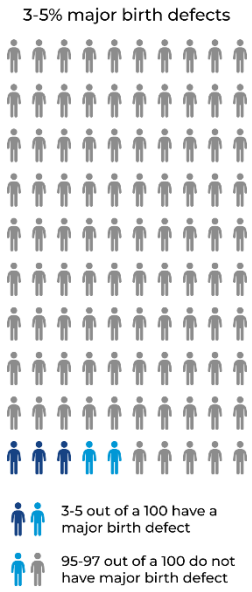
Baseline Risk

The baseline risk is the chance of a specific outcome occurring in a group, or a larger group of individuals (known as a population). This level of risk varies between groups, and in some situations the risk is higher than in others. For example, the baseline risk of catching a cold is higher for children compared to young adults. It's the "every day" risk of something happening.

In pregnancy, we know that there are chances of outcomes that we would want to avoid. Some of these outcomes include the risk of a miscarriage or a baby being born with a birth defect. This is also called a congenital malformation. The term birth defect seems harsh and scary until we remind ourselves that we all probably have some defect(s), most of them are minor, none of us is perfect.

Let us consider these examples.

A miscarriage is a loss of an early pregnancy, before 20 weeks (roughly 4 and a half months). The medical term for this is a 'spontaneous abortion". Most miscarriages occur before 12 weeks. Sadly, miscarriages are common. The baseline risk is between 15 and 25% (15-25 out of a 100 pregnancies). This translates into 1 in 4 pregnancies having a baseline risk of ending in a miscarriage.



The baseline risk for a baby being born with a major birth defect is 3-5%, meaning 3 to 5 babies in every 100 will be born with a genetic or physical problem that requires medical intervention or can have long-lasting effects upon their health. The number 3-5% makes this seem like a common occurrence, but it is important to remember that in 95-97% (95-97 of 100) pregnancies the baby develops well. In some cases, there are things that can be done to reduce the risk of a baby being born with a major problem. Taking folic acid supplements, for example, reduces the risk of having a baby with a spinal cord problem. Another helpful step is controlling blood sugars if you have diabetes and are pregnant.

The information provided on this website will let you know if taking this drug is likely to change your risk - either to a greater or smaller risk than the baseline risks.

How rare is rare?

Miscarriages are thought to be a common risk. In contrast, most birth defects are uncommon or rare. The most frequent birth defect is a problem with the heart, and that can occur in as many as 1 in 100 pregnancies. However, there are many different types of heart problems, and each such problem can be uncommon, rare or very rare.

Level Of Risk	*Frequency*	*Percentage*
Very Common	More than or equal to 1 in 10	10% or higher
Common	More than or equal to 1 in a 100 to less than 1 in 10	1% to under 10%
Uncommon	More than or equal to 1 in a 1,000 to less than 1 in 100	0.1% to under 1%
Rare	More than or equal to 1 in a 10,000 to less than 1 in 1,000	0.01% to under 0.1%
Very Rare	Less than 1 in 10,000	Less than 0.01%

Understanding Risk language

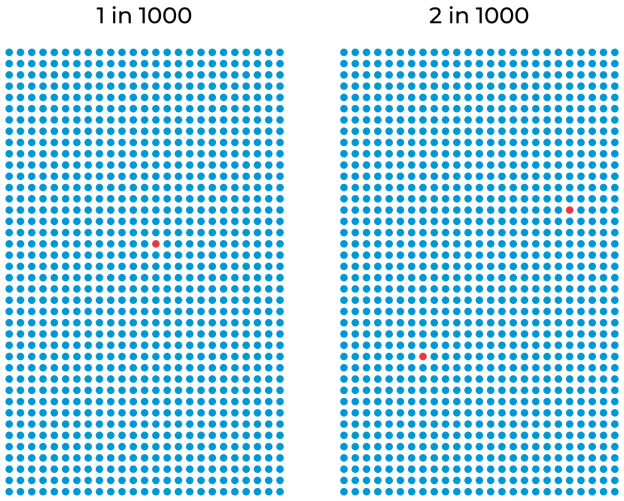
Understanding risk for ourselves is different than understanding risk for a larger group of people.

How do we know how likely is each outcome? To understand that, we need to know about the risk for people who are similar to us, and that gets us into the language of statistics.

Relative Risk and Absolute Risk

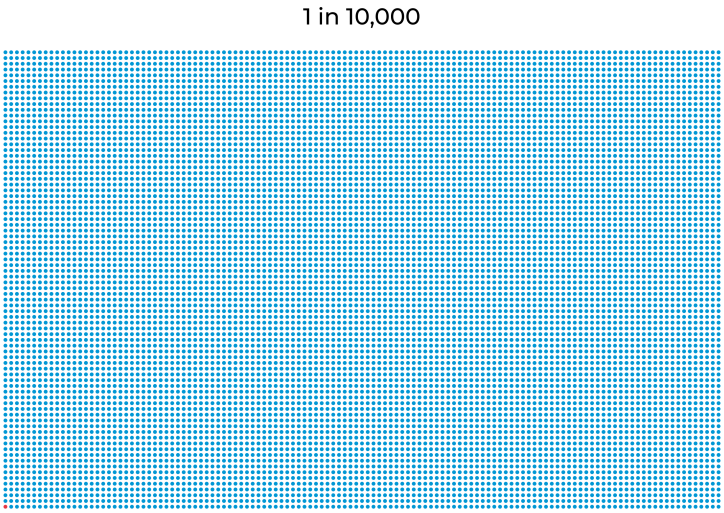
Every decision we make carries risk, for example, the decision to take medicine to treat depression, or to take nothing at all.

The term relative risk, RR, is used when we compare the risks of the same thing happening in different populations (groups of people) or compare the risks of various options (like different treatment options) within a population. Relative risk can be deceiving if you do not know the baseline risk. Relative risk is also distinct from the absolute risk. Here is an example of what we mean:



If the probability of having deafness is 1 in 1000 (written as 0.01) in one group of people, and 2 in 1000 (0.02) in another, the relative risk of deafness in the second group is 2 (2 times higher), which can seem very high. As seen in the image here, because the baseline risk in the first group is low/uncommon (1 in 1000) even risk that is twice as high (2 in 1000) results in a small (uncommon) absolute risk.

It is much harder for us to make sense of rare risks. In the image here, the risk of the outcome is 1 in 10,000. It is hard to even see the coloured dot in the bottom left. While it is harder to visualize this level of risk, these rare and very rare things still happen.



On this website, it may be reported that an exposure doubles the risk of a particular outcome. But it is important to always check for and the consider absolute risks, in addition to relative risks.

Odds Ratios

Odds refers to the chance of something happening compared to the chance that it would not happen. Odds Ratio, OR, is the comparison of the odds in two populations (groups of people). Odds ratios are always written as numbers; anything that reduces the odds of something happening will be expressed as a number smaller than 1, anything that increases the odds is a number bigger than 1, and when the odds remain the same it is 1.

Odds ratio and relative risks are similar concepts. In scenarios where the baseline rate is small (the risk of an outcome is rare), odds ratios and relative risks are nearly equal. Odds ratio and relative risk only measure association, or correlation. While they provide important information, it cannot be used to determine the cause.

For example, the odds of catching a cold are higher in winter. We can get a rough measure of the number of colds people have had and that may show us that when we compare the odds of catching a winter cold vs a summer cold, the odd ratio is 2 - meaning that they are twice as likely, but why is that? Is that because we are closer together indoors, or because the viruses prefer cold weather, or because our immune system is weaker? The odds ratio in this case tells us we are twice as likely to get a cold in the winter. It cannot tell us why it happens.

On this website you will sometime see us saying that although the study reported a link (association) between a drug and an outcome (like miscarriages) there may be other factors that explain this relationship and the outcome is not caused by the drug.

We often refer to these as “confounding” factors. A simple example are studies that show a relationship between stork population in a country and the birth rate in humans. But does it mean that storks deliver babies? As we know this is not true, there would be other factors that influence this relationship.

Multiple Comparisons

When researchers compare outcomes, they try to make the groups they are comparing as similar as possible, so they have a similar baseline risk. For example, the average age would be very important if the researchers were examining the risk of miscarriage, because we know that risk goes up with age regardless of the exposure. So, they try to compare groups with similar ages or if the groups are different in age, they will make a “statistical correction” to address the difference. This is simpler when you have one or two outcomes you are looking at but becomes more challenging when more outcomes are added until at some point you have so many outcomes and comparisons that some results may show differences between groups by chance alone. If no other researchers found that association when they looked specifically for it in a well-designed study, we have even more reason to doubt that the association found was a true association.

When our experts read and summarize the studies, they try to determine if the way the study was done and the way the outcomes were analysed is correct. In our summaries you will see this particular problem described as a weakness of research methodology - called “multiple comparisons”, it means that too many comparisons were done and some of these comparisons may have shown differences between the groups by chance alone. By conducting multiple experiments (comparisons) at the same time, there is a good chance you will find something unexpected purely at random, or by chance. There are statistical ways to try and correct for multiple testing, but in many studies these corrections are not done.

Severity, Benefit and Risk

Risk is a number that tells us the likelihood of something happening. But when we make decisions, we also look at the consequences of us taking the risk. When an undesired outcome is severe, we are more motivated to protect against it, even if the baseline risk of it occurring is low. But we may be more open to take a higher risk when the undesired

outcome can be relatively easily fixed or corrected. For example, starting folic acid before pregnancy reduces the risk of a developmental defect in the baby's spine (called neural tube defect) by up to 80%. However, the baseline risk for spina bifida is rare, 2-3 cases in 10,000 births. Despite this small baseline risk, folic acid is recommended because the benefits of supplementing has a large impact on occurrence of an outcome as severe as spina bifida. Ultimately, the benefits of supplementing with folic acid outweigh any risks (especially as there is essentially no risk).

Emotions

Risk can be calculated mathematically, but even the most logical individual is influenced by an emotional response when making a decision. When we think of risk, we try to decide how vulnerable we are to that risk. Are you the person who "whatever is going around, I will catch it" or the person who says "I am never sick - haven't missed a day of work in ten years"? We have an inborn sense of our vulnerability and personal risk tolerance, and it plays a role when we make decisions. When we are anxious and asked to make a decision, we are more likely to think of potential negative outcomes of a decision rather than the potential benefits and it may feel safer to not intervene and allow "nature to take its course". When we are calm and confident, we find it easier to consider all options in order to arrive at a decision. In reality, the best choice will be to carefully consider all options and take actions accordingly.

Here are some strategies to help with decision-making when we feel overwhelmed:

1. Get your information and advice from trustworthy professionals.
2. Ask someone who you know and trust to come with you to appointments and help listen and ask questions or write things down.
3. Take time to review all the options, and consider what factors there are in your situation that may make you more susceptible to a risk - or that may make you feel more concerned - even though the actual risk may be no different.
4. If you are doing your own research, keep an open but critical mind.
5. Write down your questions, and if time allows, re-visit the discussion at your next visit.

Summary

Understanding risks and how they are described can help estimate personal or individual risks. Recognizing when emotions may be at work, and having trust and confidence in your team can all help with making better decisions.

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