# Trust in personal experiences

From: Key Concepts for assessing claims about treatment effects and making well-informed treatment choices (Version 2022)

## 1.4a Do not assume that personal experiences alone are sufficient.

## Explanation

People can be led to believe that improvements in a health problem (for example, recovery from a disease) resulted from having received a treatment. Similarly, they might believe that an undesirable health <u>outcome</u> was due to having received a treatment. However, the fact that an individual recovered after receiving a treatment does not mean that the treatment caused the improvement, or that other people receiving the same treatment will also improve. The improvement (or the undesirable health outcome) might have occurred even without treatment.

One reason that personal experiences – including a series of personal experiences – are sometimes misleading is that experiences, such as pain, fluctuate and tend to return to a more normal or average level. This is sometimes referred to as "regression to the mean". For example, people often treat symptoms such as pain when they are very bad and would improve anyway without treatment. The same applies to a series of experiences. For example, if there is a spike in the number of traffic crashes someplace, traffic lights may be installed to reduce these. A subsequent reduction may leave the impression that the traffic lights caused this change. However, it is possible that the number of crashes would have returned to a more normal level without the traffic lights.

If you have a splinter that is causing pain and the pain goes away right away after you pull out the splinter, you can be confident that pulling out the splinter (the treatment) caused the outcome (no more pain). This is because the outcome happened right after the treatment and without the treatment the pain was constant and would very likely continue [Glasziou 2007]. However, few conditions are constant (unchanging without treatment) and respond quickly to treatment. So, for example, it is impossible to know based on your personal experience whether you did or did not have a stroke or cancer when you are 70 because of your diet when you were younger.

Unless an outcome rarely, if ever, occurs without treatment, it is not possible to know based on personal experience whether the treatment caused the outcome, even if the outcome occurs shortly after the treatment. For example, tension-type headaches are very common. In adults who have frequent headaches, about 5%, 20%, and 44% are likely to be pain-free within one, two, and four hours respectively without taking paracetamol (acetaminophen) [Stephens 2016 (SR)]. So, if an individual with frequent tension-type headaches took paracetamol and the headache went away, it would not be possible for that individual to know whether it was because of the medicine or if it would have gone away just as quickly without the medicine.

## Basis for this concept

Most treatments have at best modest effects [<u>Nagendran 2016 (SR)</u>, <u>Pereira 2012 (SR)</u>], which cannot be reliably detected by personal experience. For example, <u>randomized trials</u> have compared a <u>placebo</u> to "no treatment" for a variety of conditions, treatments, and outcomes. On average 41% of participants allocated to "no treatment" in these trials had a good outcome independent of a possible placebo effect [<u>Hróbjartsson 2010 (SR)</u>]. Based on personal experience, it would not have been possible for individuals in those trials to know whether a good outcome was because of the treatment or would have occurred without the treatment.

Personal experience can provide compelling evidence of beneficial effects for conditions that are constant (unchanging or consistent without treatment) and respond quickly to treatment [Glasziou 2007]. However, there are not many examples of conditions like that. Consequently, case reports (the experience of an individual) and case series (reports of several individuals) rarely provide a reliable basis for concluding that a treatment has a beneficial effect or is safe, and they can be misleading. For example, hundreds of case reports and series reported "successful" extracranial-intracranial arterial bypass surgery for stroke prevention, but a large randomized trial found that the surgery was ineffective and harmful [Haynes 1990]. Moreover, it appears likely that cases are reported selectively, they may represent outliers, and they are often poorly reported [Agha 2016 (SR), Albrecht 2005 (SR), Albrecht 2009 (SR), Oliveira 2006 (SR), Richason 2009 (SR)]. Case reports can generate hypotheses about the effects of treatments and lead to research to test those hypotheses, but it is uncertain how often those hypotheses turn out to be correct [Albrecht 2005 (SR), Dalziel 2005 (SR), Olaku 2011 (SR)].

Case reports and case series cannot establish causation for common outcomes, but they can provide compelling evidence for rare adverse events [Hauben 2007]. For example, sudden, unexplained perforation of the colon is extremely rare [Namikawa 2011 (RS)]. So, it is safe to assume that perforations following colonoscopy are caused by the colonoscopy and case series without a comparison group can provide reliable estimates of the risk of perforation [Lin 2021 (SR)]. There is very limited empirical evidence of how reliable case reports and case series are with respect to adverse effects [Vandenbroucke 2001]. A review of anecdotal reports of suspected adverse drug reactions published in four high-profile journals in 1963 found that 35 of 47 reports were clearly correct [Venning 1982 (SR)]. Modelling studies suggest that for rare events, coincidental associations between taking a medicine and the event are so unlikely that more than three reports constitute a strong warning requiring further investigation [Begaud 1994, Tubert 1992].

### Implications

If an individual improved after receiving a treatment it does not necessarily mean that the treatment caused the improvement, or that other people receiving the same treatment will also improve.

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### **Research studies**

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