Rethinking Missing Data with Patients

FAQs

These questions were asked in previous work with other patients. We wrote them below to help you navigate queries you might have on missing data or giving your judgement on “missing data”. There is also an example given of missing data.

Any questions on this can be sent to email: s.greenwood.22@abdn.ac.uk

Glossary of terms

What is a "*health intervention*"?	A health intervention is something designed to improve a person health. They can be medical, surgical, or behavioural. Examples are weight loss application for the phone, vaccines or robotics for surgery.
What is a "*clinical trial*"?	Clinical trials are research studies that test a medical intervention in people. The intervention studied can be anything that is used to improve the health of people from fitness apps, to surgical equipment or vaccines! These studies are very common, and play a crucial part in determining what treatments are available to all of us, our friends and family, as future patients.
What do we mean by "*measurement*"?	To know how safe and effective that intervention is, researchers have to gather measurements that demonstrate how a participants medical condition changes over time. Examples could be questionnaires or blood pressure readings.
What do we mean by “*missing data*" in trials?	In trials there are *a set number* of measurements intended to be collected from all participants. Sometimes, for multiple reasons, they are not all the collected, and for that reason they are "missing".

Giving my judgements on “missing data”

What am I being asked to do?	You are being asked, as a patient, to make a judgements/ opinion/ give your thoughts on what the gaps in the puzzle are.
Can I give the wrong judgement?	Below is a quote from another patient who has worked on similar research. "*You're making a judgement with what you have. That information might not be enough, but that's the decision you've come to at that particular time with the information that you have. And that can't be wrong. It can't be wrong because that's your judgement.*"
Some might think this is fabrication of data. Am I making up patient data?	The puzzle with the gaps is our data, and we are asking you to help fill in the gaps. So at first glance you might worry that this is "*data fabrication*". This is not the case here for two reasons 1. Fabrication is when you try to pass off this filling in the gaps as real measurements that were taken from patients. Here we are clearly saying, this data is missing and this is our "judgement" of what we *think* the gaps are. 2. When we are filling in the gaps, we are not just thinking about one patient, but all of those who missed their measurements.
Should I do any preparation?	We encourage you to read and watch any of the resources given to you to help inform your judgements and make you feel more prepared.
Am I qualified?	Yes. You have been selected to complete this task and provide a judgement on the basis of your experiences as a patient.
Do I need to be accurate in my judgement?	No, this task is about trying to capture your general sense of the missing values. We want to know how *uncertain* you feel about the judgements you're making, and thoughts you have about it.

What if I am not sure?	If you're not very sure about your measurement that is good thing. Counter to what you might think, we want to capture that *uncertainty* in your judgements. Your judgement is not being used to accurately represent one patient's medical condition, it is about getting a general sense about all of those patients with missing measurements, and what their results might have been.

Do you have an example showing the impact of "missing data"?

- A doctor working palliative care wrote an article explaining what missing data means within the trials she works on.
    - Marie Curie article
- The same doctor worked with a group of researchers to explore what people's responsibilities are in clinical trials when it comes to missing data. They produced a cartoon of their work.
    - Cartoon - MarieCurie.png

Tell me more about "missing data"?

How much missing data is normal?	There is *no straight answer to this question*. Clinical trials can be used to any intervention for any health condition. So it really depends on the context. For example, a trial looking at substance-misuse expects to have high rates of missing data, as those patients may avoid going to health clinics. However in another trial where the patients are staying in a hospital for cancer treatment, they are likely to have all their measurements taken.
If a patient stops taking the medication on the trial does that lead to missing data?	Missing data comes from missing measurements from participant. A person can still give a measurement regardless of it they take their medication or not. Often in trials *it is expected that people don't follow treatment plans* perfectly.

How much missing data is due to process failure from the trial team, or the patient themselves?	*Data can be missing for many different reasons* and cannot always be clearly pointed directly at the patient or the trial team. The context of the individual trial very much impacts how and why it occurs.
Do trials try to over recruit the numbers patient because they know there will be missing data from patient who discontinue the trial?	Yes they do. They know that in some cases maybe 20% of the participants will withdraw before the end of the trial. So they over-recruit.
What information do trialist have about the missing data?	*Once a measurement is missing it is missing forever*. It is therefore a mystery with no perfect solutions and there is limited information about why it is missing. Sometimes it's very clear (e.g. a participant withdrew from the study and no longer attends appointments) or ambiguous (e.g. a participant filled in every question except one on their last questionnaire).
Why can patient help with missing data?	As there is no clear information available, so researchers look to get a range of judgements from those with relevant experience. *Patient can help*. They live day-to-day with condition, and increasingly in research they are beginning to take on representational roles, to bring the patient voices straight into research decisions like this one.
Can we use "incentives" to make patients stay to minimise missing data?	Given the *participation is voluntary* it is controversial to use incentives to keep participants in a trial. However the participant can have the trial's health intervention changed to meet their needs, e.g. if they want to stop using their medication they can and still continue to be part of the trial, giving their measurements.