

See the person not just the health problem: Guidance for creating and using case studies in learning

Background

This guidance has been created by the Brighton and Hove Common Ambition Lived Experience Steering Group, with support from Dr Kate Pitt at Arch Health CIC. This is a guidance for those who want to present case studies for the purpose of learning, for example teaching medical students or sharing learning with professionals at conferences.

For the context of this guidance, when we say case studies we mean presentations or studies of someone's personal experience, story or narrative. These are often used to show learning or service impact, or used as a teaching aid. These are different to case studies for academic research which will have research ethics in place already.

Brighton and Hove Common Ambition have attended many events where case studies have been presented. We have also discussed in detail how and when we should use case studies to support our work, particularly when designing training for medical students. We wanted to create this guidance to share our perspectives on their creation and use.

Overview

Case studies are regularly used in teaching and learning contexts. They differ from a clinical history where facts, for example age, blood pressure or physical symptoms, are included. Case studies share someone's story, they take into account the holistic narrative of someone's experiences.

Case studies can be a valuable asset to learning but Brighton and Hove Common Ambition have experienced case study presentations that have been disrespectful, upsetting and have questioned whether the patients have consented to their use. We hope that those who present case studies will have followed legal guidance and removed identifiable features as described in law, but using case studies still poses a moral dilemma.

On one hand, they serve to humanise learning. They challenge a potentially scientific or clinical approach, where traditionally only facts are used. They can also help to contextualise learning points in reality. On the other hand, personal experiences can be triggering to share and hear; we never know what experiences are in the room when they are being presented. It is also important to acknowledge these stories are owned by the people who have lived them. Finally, case studies risk perpetuating stereotypes or misconceptions.

Below we have co-developed a collaborative framework to follow when using case studies that puts the patient at the heart of learning.

Initial questions to consider when thinking about including a case study in your work

- What is the value and purpose of 'lived experience' stories?
- Can my work be done without someone sharing their personal challenging experiences?
- Do I have any biases that may affect which patient stories I use? And how can I ensure I do not perpetuate any negative stereotypes?
- Does the case study need to be a real life case study from one patient? Can it be created from several experiences?

In asking yourself these questions, you will ensure that there is a clear purpose to using a case study, you have considered any bias you might have and you know how you will create your case study.

If using real stories taken from the patient or patient files, even if you are combining several experiences and follow legal guidance to remove all identifiable features we want you to consider the following:

- Do you have consent to do so?
- How do you ensure you are working collaboratively and 'alongside' a patient detailing their experience.
- How will sharing stories and experience feel for the patient?

When and how to collect patient stories

Often when sharing a case study for learning purposes, teachers will use patient files to reflect personal points and remove identifiable features. Please ensure that when someone consents to being in your service they are aware that this may happen and they have consented to it. If possible when creating a case study, ask the patients involved for their consent to being a part of your lesson or presentation.

We encourage you to contact the patient/client whose story you would like to use, work alongside the patient as the case study evolves to check that they are happy with the outcome and ask them each time you would like to use it .

To make sure that they understand what you will be doing with their experience:

- Explain what you will be using a case study for
- Pinpoint what part of their experience you would like to use and why it is important for your work
- Share an example of a case study so they can see what it will look like
- If possible, provide examples of when you have used case studies before and what impact they had on learning and standard of care provided

When creating case studies

There are different ways a case study can be created, this could be:

- Using one patient's story, removing all identifiable features
- Using several patients' stories to create one unique, unidentifiable patient story
- Creating a case study from your professional experience

We suggest that the second option is the most respectful choice; using several patients' stories to create a new unidentifiable case study.

It is very important to consider bias here; what stories do you need for this case study and why? Are you picking patients' experiences that might perpetuate stigma? How can you use this case study to challenge misconceptions?

Brighton and Hove Common Ambition suggests this process:

1. Ask patients if they wish to share their experience to help further learning for professionals, ensure you explain that this experience will be put together with other stories so you can not be identified
 2. Ensure consent is obtained to use experience and that the patient understands where and why you will be using the case study
 3. Bring 3-4 experiences together to develop a new case study, ensuring the patient/s is/are completely unidentifiable
 4. Show the patient the final version of their experience
 5. Ask if the patient would like feedback around the impact the case study has
- Be mindful of language, ensure it is respectful and do not repeat triggering or upsetting words.

Presenting case studies

When you are presenting a case study that may include challenging experiences, which can sometimes be upsetting to share and hear, you must ensure that it is delivered safely.

Explain to those in the room how this case study was obtained or created, so that the audience will know if this is one patient's story, generated from several patients' stories, or created using your professional experience.

Explain why you have chosen these particular experiences and acknowledge any biases.

Ensure that you have told the audience you have consent to use this case study.

Add clear content warnings to each case study before they are used or presented; these can be words, themes or cases that may be upsetting to read or hear.

Make it clear the audience has a choice to opt out of engaging with case studies. That it is okay to leave the room before you start working through a story, after you have presented content warnings and at any time during the case study work if it becomes too upsetting, frustrating or difficult and there will be no judgement.

Start the presentation with a clinical history and then follow with the narrative, so that there is a choice for the audience if they want to leave the room before the narrative section.

Offer adequate aftercare if people become upset or triggered. Such as checking in with the person after the lesson/presentation, signposting to support or a follow up check-in phone call.

After the presentation

If possible, please follow up with the patients who contributed to the case study to let them know how the presentation went, how it supported learning, the impact it had on students and any feedback.

A final word from Common Ambition

Please remember safety, choice and respect for people's personal experiences should be the top priorities when using case studies. Together we can model a better way of working.

We hope you have found this useful.