

NFTHD #61a: Patient stories; what to consider?

In this Note from the Help Desk, we discuss what the Code says about capturing patient stories or testimonials. Whilst the Code doesn't call this material out specifically, there are a number of principles in the Code that work together to give you the guardrails you need before collecting and communicating a patient's perspective.

Context and audience are key considerations which shape your approach. For example:

- A disease awareness piece fit for consumers which is not promotional > Section 12.2 of the Code useful here.
- A promotional piece vetted healthcare professional audience > Sections 1 & 2 of the Code useful here.

One of the most important principles is that "information should be presented in a comprehensive, balanced and fair manner". Whilst it is not expected that each patient's story will be comprehensive, balanced and fair necessarily – the whole piece should be, which can be achieved through clever editing, captioning, top-and-tailing of messages, introductions, and key messages.

Disease awareness for the general public should be educational without emphasis on treatment options. It needs to be explicitly clear to the reader is encouraged "to seek further information or explanation from the appropriate healthcare professional". A patient can talk about the disease and their improvement of quality of life since receiving treatment. However, any detailed specifics about their own treatment runs a high risk of conveying an opinion that some treatments are better than others, which is not appropriate.

For a consumer disease awareness piece, consider:

- If a video features a patient talking about how wonderful the particular treatment/s are, think about how to mitigate any interpretation that the same treatment could also be wonderful for a viewer, or for each and every person with that condition. Think about how to insert balance into this message, perhaps with a qualifier.
- If a treatment manages the disease and not cures the disease, make sure the patient's story doesn't give an impression that they have been cured, or that treatment options present a cure for all people. Statements such as "I'm back to normal" run a risk of being interpreted as 'being cured', for example.

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- Ensure the message doesn't undermine the need for regular checks and the advice of a healthcare professional. Statements such as 'The new treatment I am on means I don't have to worry about monthly hospital visits'. Whilst this may be true for that particular person, could it give the impression there is no need for follow-up appointments? This can be better communicated.
- Avoid using statements, stories and overall impressions that might create unrealistic expectations. Impressions that treatments produced any magical, miraculous, infallible or unfailing changes are likely to be considered over-reach and unbalanced.
- Patient's perspectives when talking about a disease are best told in a tone that doesn't cause unnecessary alarm of fear in the community; whilst a patient might be talking about their own distressing health challenge, the take-away shouldn't be that everyone will suffer the same.

Above and beyond the Code, there is a larger ethical conversation involved with storytelling. Our patients share some important – yet difficult – stories. While these are important stories for the world to hear, inherent in undertaking these activities is a level of risk; both to the patient and the company involved in the collection and publishing of storytelling information.

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