

# NFTHD #61b: Patient stories; the whole ethical package

In this Note from the Help Desk, we consider the larger ethical conversation involved with storytelling. Our patients share some important – yet difficult – stories. What should we consider so that “story holders” feel protected and empowered to contribute to positive health outcomes?

Some common aspects that might hold story-holders back from sharing their lived experience can include:

- The story telling is being directed by and/or told by those with more power and control (companies/organisations in comparison to the individual), and the story is edited without the story-holders input,
- Little or no boundaries guiding the length of time the story can be used, and where it will/could be published. These aspects are usually outside the story-holders control and sometimes with no notification provided,
- Nervousness from story-holders when companies present them with long, complicated consent documents for signing, rich in legal jargon, and
- A fear that their engagement feels more like a consultancy rather than a collaboration, and perhaps that their personal stories could be used as commodities or instruments.

Just google ‘ethical storytelling’ and you’ll know this is not a unique concept to our industry, rather a well-established movement by and for social-impact professionals as we strive to understand and apply best-practice ethical principles. In a nutshell, its about power and control, and where there are significant differences (such as a large company in comparison to an individual patient), we need to actively and consciously set about ensuring the story-holder is centred as the creator and owner of their own story, and to rectify any power imbalances that may exist, even if only perceived.

Many companies will have internal policies and procedures for how to ethically and compliantly engage with patients in talking about their lived experience. If you don’t, then think about how you can develop one. It might be worth having a good look at your own approach in relation to free, prior and ongoing informed consent, resourcing and sensitivity, empowerment, co-design and collaboration, and the integrity of the story.

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And if you are not sure how your processes stack up, and suspect they could be improved, then reach out and consult with the story holders themselves. A good trusting and collaborative relationship will harvest honest and truthful feedback. Don't bypass the issue of remuneration for any service, time or advice provided.

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