



VIEWS AND REVIEWS

NO HOLDS BARRED

Margaret McCartney: Privacy is not secrecy

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Celebrities die, just like the rest of us. And—shock!—sometimes they do it without first making a public pronouncement. But, when a celebrity dies without an announcement of illness or a disclosure of the type of cancer, grieving family and friends are often accused of keeping the illness “secret.”

This, in the froth of social media and newspaper commentary, is seen as a “very bad thing.” Rather than mourning, I’ve read at least one person moaning about the loss of opportunity for “awareness raising” that might have been achieved had the celebrity in question gone public. Did we, the public, not have a right to know, the newspapers and social media masses ask? Just whose death is this, anyway?

This is crazy. We citizens have no right to know the details of anyone else’s diagnoses, prognoses, or reactions. Celebrities are entitled to close their doors and not share all of themselves. Privacy is not secrecy. Privacy means that the owner of the information retains some control: when, where, or how to share that information, how much, and why. For many people, dealing with illness also involves dealing with other people’s reactions.

Disclosure to others can be a source of strength but can also require reassurance or explanation, which may deploy energy that could be better spent elsewhere. Sharing with friends or colleagues might make life easier, but going full frontal in public is something different. Social media can be joyful and supportive but also cruel and anonymous.

Choosing privacy doesn’t equal shame or selfishness: this is about basic human dignity and care. Boundaries are often good. Feeling some influence over where these boundaries are placed

makes for trust, confidence, and a bit of control when it’s lacking elsewhere.

What the public seems to want others to do doesn’t match what we want for ourselves. Compare this situation with the rightful outcry about NHS England’s failing care.data project. I don’t believe that most of us want secrecy when it comes to our medical records—but most people do want privacy.

A feeling of control over information, and confidence that it’s being used anonymously, thoughtfully, and wisely, isn’t much to ask. At the heart of the care.data debacle, on “pause” for so long that I’m breathless with anticipation,¹ is a lack of trust. It uploaded data even when patients had objected.² And it has to draw a clear boundary of privacy against data dredging for exploitation or profit.³

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- 1 Praities N. Care.data paused yet again due to confidentiality review. *Pulse* 2015 Sep 4. www.pulsetoday.co.uk/your-practice/practice-topics/it/caredata-paused-yet-again-due-to-confidentiality-review/20020042.fullarticle.
- 2 Matthews-King A. 700 000 patients continue to have data sharing ignored. *Pulse* 2016 Feb 5. www.pulsetoday.co.uk/your-practice/practice-topics/it/700000-patients-continue-to-have-data-sharing-objections-ignored/20031072.article.
- 3 Pollock A. Care.data. 8 Apr 2014. www.allysonpollock.com/?page_id=1803.

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