

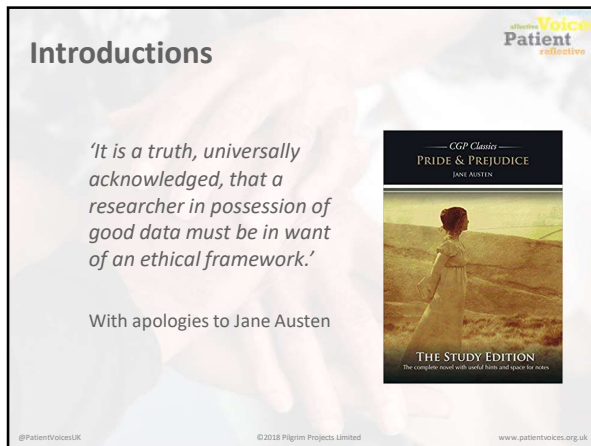


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Ethical digital storytelling in healthcare research: dilemmas and debates

Dr Carol Haigh, Manchester Metropolitan University
Dr Pip Hardy, Patient Voices

September 2018 'Current trends in digital storytelling research and practices'. Conference. Zakynthos, Greece

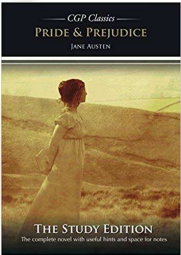


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Introductions

'It is a truth, universally acknowledged, that a researcher in possession of good data must be in want of an ethical framework.'

With apologies to Jane Austen



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Digital storytelling and product ethics

Protection and minimisation of harm has long been at the heart of the digital storytelling movement.

The immediacy and global reach of the technology that supports digital storytelling means that the ethical underpinning of digital stories has been a priority for all reputable story gatherers.

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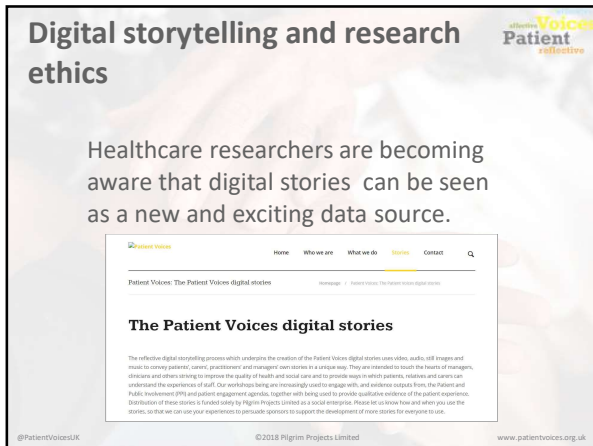
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Digital storytelling and product ethics

The creation of specific processes, such as consent, means that digital stories as 'products' are generally seen to have a robust and defensible ethical foundation.





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Digital storytelling and research ethics

Healthcare researchers are becoming aware that digital stories can be seen as a new and exciting data source.



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Digital storytelling and research ethics

Digital stories can be used as data

Questions

- Can digital stories be seen as the qualitative equivalent of Big Data?
- If so, why are researcher so slow to recognise and exploit this?

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Digital Storytelling and Research Ethics

Digital stories can be used as a research method.

Questions:

- Is it method or methodology?
- Is it an ideology?

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So far so good...

Case study 1: Doing research with vulnerable people

What could possibly go wrong?

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Ethical frameworks

Deontological ethics

- to be moral one must perform one's duties regardless of the consequence

Utilitarian ethics

- the moral worth of an action is determined solely by its utility in providing happiness or pleasure as summed among all people

Consequentialist ethics

- careful consideration of the risks and the potential benefits provided

Principlist ethics

- Self-direction (Autonomy)
 - This is seen as a norm that respects the decision-making capabilities of individuals
- Do no harm (Non-maleficence)
 - A norm that avoids the causation of harm or damage
- Actively do good (Beneficence)
 - A group of norms focused upon the provision of benefit and the balancing of risks and cost
- Fairness (Justice)
 - A group of norms that focuses upon distributing benefits, risks and costs fairly.

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Principles of bio-medical ethics

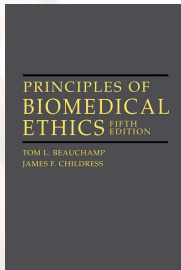
Despite the many reflexive ethical frameworks available to researchers today, the one that is still the most widely taught in universities and used by healthcare researchers is the Principlist approach, formally articulated by Beauchamp and Childress in 1979.



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The four principles

Principles
Principle 1 – Autonomy
Principle 2 – Beneficence
Principle 3 - Non-maleficence
Principle 4 – Justice



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The four principles +

However, these principles do not necessarily provide all the answers to some of the dilemmas facing digital storytellers, facilitators and researchers.

We suggest a subordinate principle for each which may contribute to the wider debate and to the ethical reflections of story tellers, story facilitators and digital story researchers.

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Subordinate principles: your thoughts?

Principles	Proposed subordinate principles
Principle 1 – Autonomy	
Principle 2 – Beneficence	
Principle 3 - Non-maleficence	
Principle 4 – Justice	

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Principles and subordinate principles (our thoughts)

Principles	Proposed subordinate principles
Principle 1 – Autonomy	Ownership
Principle 2 – Beneficence	Altruism
Principle 3 - Non-maleficence	Pragmatism
Principle 4 – Justice	Authenticity

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Group work

- 1 Please form small groups.
- 2 After each case example, please discuss which principles are most applicable to the situation and which subordinate principles you think would be most appropriate.
- 3 Are there more subordinate principles that should be added to the list?

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Some questions you might want to ask yourselves....

Should respect for a storyteller’s autonomy take precedence over the need to avoid harm to the storyteller or others in the story?

What happens when the beneficial effects of creating a story are threatened by a change in personal circumstances, e.g. death or divorce? Should the story be moved or changed? What are the implications for gathering (and presenting) data?

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Some questions you might want to ask yourselves....

What happens when justice and autonomy are threatened by members of a storyteller’s own family in an attempt to silence the storyteller?

How do we balance the risk-benefit equation, especially over time?



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Consent from others in the story



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Father in CAMHS

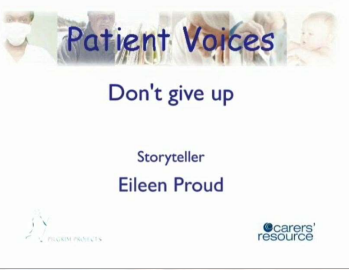
Storyteller
Ian Pickering

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A change in circumstances

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Don't give up

Storyteller
Eileen Proud

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Whose consent, whose approval?

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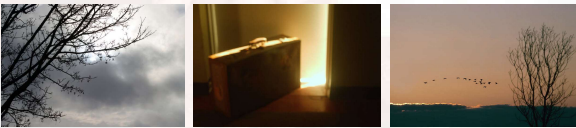


www.patientvoices.org.uk/flv/0857pv384.htm Barbara Clarke, 2015

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Safeguarding storytellers

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Safeguarding viewers

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www.patientvoices.org.uk/flv/0519pv384.htm Rose 2010

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Risk vs benefit

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Life is hard


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www.patientvoices.org.uk/flv/0795pv384.htm Habiba, 2014

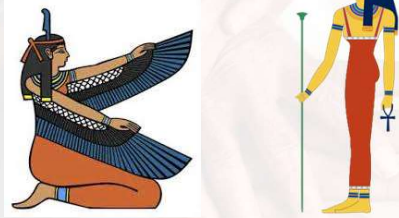
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Final thoughts and reflections?



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Ma'at: Goddess of universal harmony and balance



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Finally....

Thank you all for your participation and insights. The curated outcome of this workshop will be available at:
www.patientvoices.org.uk/what-we-do/qualitative-research

We would like to acknowledge everybody's input so, if you consent to having your name on our website as a participant in this workshop, please give us your name and affiliation.

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Thank you

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