








Making the big picture personal:
opportunities, challenges and some
ethical issues

Pip Hardy
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A tale of two storytellers

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Patient Voices ethical principles

- Acknowledgement (of storytellers)
- Integrity (of stories)
- Not-for-profit
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Ethical principles of biomedical ethics

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice

Beauchamp and Childress 2001



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Common ethical issues

- Confidentiality/anonymity
- Credit/acknowledgement
- Re-presentation/representation
- Consent and release
- Power or protection?
- Who benefits?



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Ethical issues for storytelling

- consent, approval and release
- confidentiality, anonymity vs having a voice
- briefing
- representation / re-presentation
- support (for storytellers)
- supervision (for facilitators)
- therapy or therapeutic?
- editorial control
- power/empowerment



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Practical issues for storytelling

- purpose and uses of story/ies
- resources
- recruiting storytellers – who, how and when?
- respite care
- remuneration
- conflicts of interest (storytellers and ‘clients’)
- expectations



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Editorial issues for storytelling

- what makes a good story?
- who decides?
- briefing storytellers
- images (selection and copyright)
- music (selection and copyright)
- attribution
- what to take out, what to leave in?
- facilitation and empowerment
- editorial control



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General issues for storytelling

- stewardship
- quality – of the process and the stories
- training, practice, supervision, integrity
- accessibility
- using the stories
- publication
- copyright and ownership
- ‘readiness’



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‘Readiness’

- not just about storytellers!
- supportive management/organisational buy-in
- resources
- understanding the process – from experience!
- time to recruit
- importance of briefing
- process *and* product
- mutual trust
- recognising the double win (good for the storyteller *and* the organisation)

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Benefits for storytellers

‘I feel like I’ve had a weight lifted from my shoulders. It’s been really therapeutic and it’s been really good to get everything down on paper and put it behind me and get some closure.’

A storyteller

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Benefits for organisations

‘If there is one lesson to be learnt, I suggest it is that people must always come before numbers. It is the individual experiences that lie behind statistics and benchmarks and action plans that really matter, and that is what must never be forgotten when policies are being made and implemented.’

Francis, 2010

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Thank you.

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Over to you...

A few questions to ask yourselves:

- *Why* do we want stories?
- *What* will we do with them?
- *When* are they needed?
- *Who* will tell them?
- *How* will the stories be made/funded/supported/shared/stored?

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