

Patient Voices Protocol for Storytellers

'One of the hardest things in life is having words in your heart that you can't utter.'

James Earl Jones, actor (1931-)

Respect

Storytellers and their stories will be treated with respect at all times. We will try to interpret accurately the intentions of the storyteller and to preserve the integrity of the story. We will always try to be flexible and sensitive to the needs of storytellers with regard to the place and pace of recording.

Consent

We have a three-stage consent and release process. Before a storyteller participates in a Patient Voices digital storytelling workshop, we will obtain their informed written consent to take part. At the end of the workshop, storytellers will be invited to sign an interim release form. Various levels of release are available at this point.

Final control over what is included in the digital story will rest with the storyteller. A rough cut will be available for comment by storytellers and a final version will be sent for the storyteller's approval. Storytellers will then be invited to sign a final release form which will allow the use of the approved version of the story as a publicly available educational and learning resource.

Support

Storytellers will be offered emotional support during and after telling their stories. Many storytellers have commented on the therapeutic benefits of telling their stories in this way.

Storytellers' rights

Patient Voices plays an active part in the international digital storytelling movement. We subscribe to the core principles for ethical practice in digital storytelling, including the storytellers' rights, as outlined in the *Guidelines for Ethical Practice* developed by our colleagues at *Silence Speaks*.

Reimbursement

Storytellers who are patients or carers may be offered repayment for expenses incurred (including, where appropriate, reimbursement for respite care for people for whom they normally care).

Copyright

One of the primary goals of the Patient Voices programme is to build up a library of resources that can be shared for use in health and social care education and service improvement, while protecting the integrity of the stories and the contributions of those who created them. We expect storytellers to obtain permission from anyone else who appears in, or contributes to, their story.

To this end, when released by the storyteller, stories are distributed under the Creative Commons licence 2.5 (attribution-non-commercial-no derivatives), with copyright retained by Pilgrim Projects. This aims to ensure that:

- a) the stories are free for use in health and social care education and service improvement
- b) no profit can be made from the stories
- c) the integrity of the story, as told by the storyteller, is retained
- d) all who have contributed to the story are appropriately acknowledged.

Consent to participate in a Patient Voices digital storytelling workshop

- ☐ I have read the *Protocol for storytellers*.
- ☐ I understand the purpose of this Patient Voices digital storytelling workshop.
- ☐ I understand that I will have editorial control over my story or stories.
- ☐ I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational, research and learning resource.
- ☐ If my story is released, I understand that it will join the growing library of Patient Voices digital stories and may be made publicly available by Pilgrim Projects Limited, including via CD, DVD, the Internet and other means.
- ☐ I understand that, once a story is released, Pilgrim Projects Limited can have no control over, or liability for, how it is used.
- ☐ I consent to participating in a Patient Voices digital storytelling workshop.
- ☐ I consent to being contacted by Pilgrim Projects and its staff in relation to participating in future research projects.
- ☐ I consent to having my photograph taken during the course of the workshop and I give my consent to Pilgrim Projects Limited to use my photo for the purposes of promotion, education and research.

Storyteller	
Name	
Address	
Telephone	
Email	
Date of birth	
Signed	
Date	

Parent/Guardian (if storyteller under 18, or otherwise necessary)	
Name	
Address	
Telephone	
Email	
Signed	
Date	

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