


**Inverting the *Pyramid of Voice*:**  
digital storytellers creating *activist memes* of care experiences

Tony Sumner

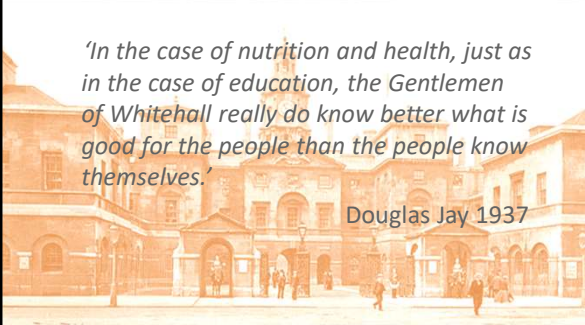
Pilgrim Projects / Patient Voices  
D59 Storytelling and Activism, University of South Wales, Cardiff, 24<sup>th</sup> April 2015



**Gentlemen of Whitehall**

*'In the case of nutrition and health, just as in the case of education, the Gentlemen of Whitehall really do know better what is good for the people than the people know themselves.'*

Douglas Jay 1937





**...are very well funded**

2012-13 Government marketing budget £285m

Health department's priorities:

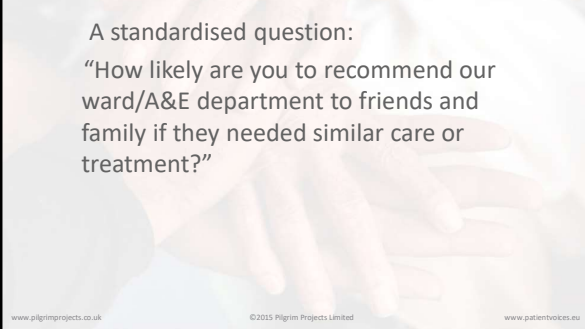
- long-running campaigns against smoking, obesity and other public health problems supporting the implementation of the NHS's efficiency and productivity challenge
- informing and engaging staff groups and stakeholders in the health and care reforms


**Friends and family test**

A standardised question:

"How likely are you to recommend our ward/A&E department to friends and family if they needed similar care or treatment?"



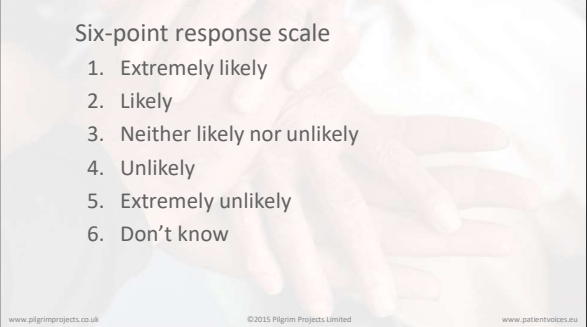
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**Friends and family test**

Six-point response scale

1. Extremely likely
2. Likely
3. Neither likely nor unlikely
4. Unlikely
5. Extremely unlikely
6. Don't know



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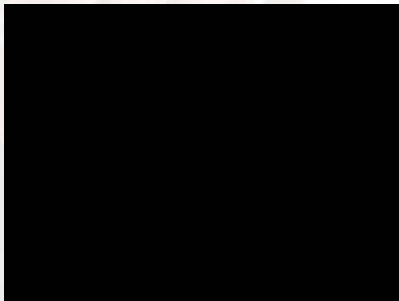


**Sue Archer's story**



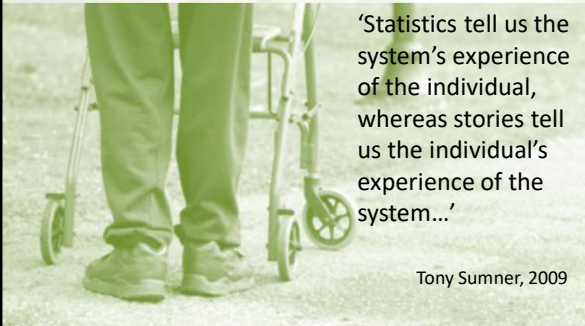
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### Sue Archer's story



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### Stories and statistics



'Statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system...'

Tony Sumner, 2009

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### Stories?

*'Storytelling is the mode of description best suited to transformation in new situations of action.'*

Schön, 1988

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### Patient Voices: a classic approach to creation

Flexible but typically:

- Small group process: 8 participants, 3 days.
- Carefully facilitated, safely bounded.
- Explore what makes a good story.
- Time for reflection.
- Write a script, edit down to 300 words
- Record voiceover, select or create own images
- Learn to use computer to assemble voice, images and music into digital story

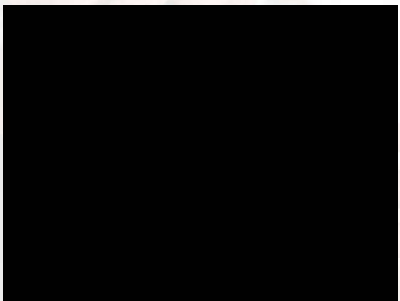
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### Brenda Cullen's story



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## So what? Manchester MHSC

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Patient  
Voices  
reflective

- Reduction in complaints related to care (45%)
- Reduction in complaints related to staff issues (9%)
- Reduction in complaints related to communication (22%)
- Reduction in CNST claims (50%)
- Reduction in management costs
- Patient-led 'dignity walks'
- More confident patients *and* staff, able to tell their stories
- Increased involvement of patients and carers in creation of care plans
- Greater recognition of 'experts by experience'
- More engagement with family members

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## Stories as memes

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An Internet meme (/ˈmi:m/ MEEM) is an activity, concept, catchphrase or piece of media which spreads, often as mimicry, from person to person via the Internet.

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## Stories, or autoethnography?

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A Patient Voices story is, effectively, a facilitated digital micro-autoethnography.

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## Patient Voices: some facts and figures

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- Established in 2003
- ~1000 stories facilitated/recorded
- ~125 workshops, plus some home visits!
- ~600 stories released via Patient Voices website
- ~35 Patient Voices stories WIP
- ~1 million hits on the website annually
- ~2000 hits per working day on PV website
- ~40,000 stories viewed during the year
- ~100 presentations
- 6 papers published
- 1 book written

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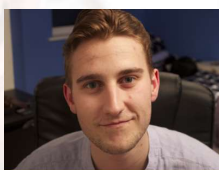
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## What story viewers say

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*'It strikes me that if all medical students could make these stories, or even just watch them, perhaps we would all feel more empowered and actually more energised to learn as we would feel part of a team, we would feel we had an important role and we would feel we could actually be "producers" of patients' good health and happiness.'*



David Gill, 2014

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## Sian's story

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# Sian's story



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# Thank you

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Winner  
Excellence in Healthcare Education  
Finalist  
Health Communicator of the Year

The **BMJ** Group Awards  
in association with **MDDUS**

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# References

Wheeler, B. (2012) Government marketing budget 'to increase' Retrieved 2<sup>nd</sup> March 2015 from <http://www.bbc.co.uk/news/uk-politics-18489251>

Sumner, T. (2009) Inspiring innovation through Patient Voices. Innovation Expo. Edeset London.

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