

International Digital Storytelling Conference
Current Trends in Digital Storytelling
 21-24 September 2018, Stavros Niarchos Foundation Cultural Center, Athens, Greece

effective
Voices
 affective Patient
 reflective

*Beyond Both Sides Now:
 Bringing Patients and Parents together*

Tony Sumner
 Patient Voices and University of Manchester Medical School

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

You've heard this one before, but...

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If your only tool is quantitative...

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It's a start....

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 affective Patient
 reflective

Resource and intellectual flows in the Patient Voices reflective digital storytelling process
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It's a start....

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 affective Patient
 reflective


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You go back, Jack, do it again...

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More elephants, more rooms



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...finally




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The elephant's story



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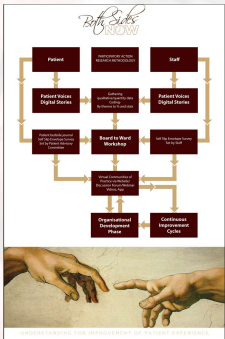
Hearing both sides of the story



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Both Sides Now: shared stories

“...evidence-based Patient Voices digital storytelling techniques to find the stories behind the data and the data behind the stories, **building common cause** between **staff** and **patient** groups from Board to Ward to drive improvement across a range of key metrics such as Hospital Standardised Mortality Ratio (HSMR) and the number and complexity of complaints.”
(NHS Institute for Innovation and Improvement, 2013)



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Terrific Teens: a shared experience

Moving forward from *Both Sides Now* approach of separate, uncoordinated workshops (albeit around same issue/condition), with stories used in another process.

Two conditions:
Complex life-threatening allergies
Sickle Cell Anaemia

Separate, but simultaneous, parallel DS workshops for:
Young people
Parents
Siblings (in the case of Sickle Cell)

Story sharing and reflection:
All participants
All stories
One room

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Parents on young peoples' stories

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"More respect for me, myself, my daughter and others in the same situation."

"She turned into another person - amazing that she showed her feet with the worst of the skin in her video. I forgot where she put it. She put that picture up - she did it herself."

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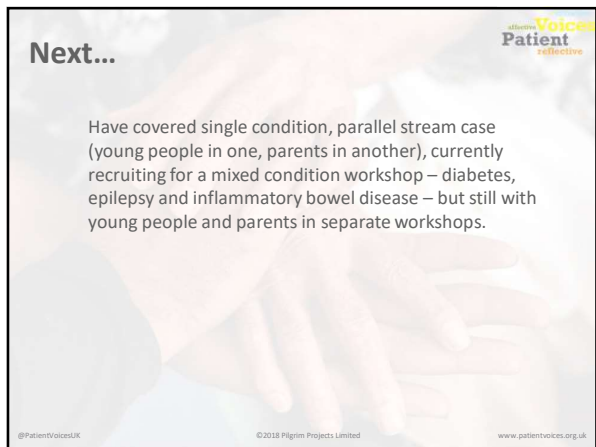
On the process...

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"It was good to have the stories separate." (A young person)

"We had to be separate in the pods and the best things have come out of the separation." (A parent)

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Next...

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Have covered single condition, parallel stream case (young people in one, parents in another), currently recruiting for a mixed condition workshop – diabetes, epilepsy and inflammatory bowel disease – but still with young people and parents in separate workshops.

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Thank you

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