



Patient Voices

Transforming healthcare through digital storytelling

5th February 2011

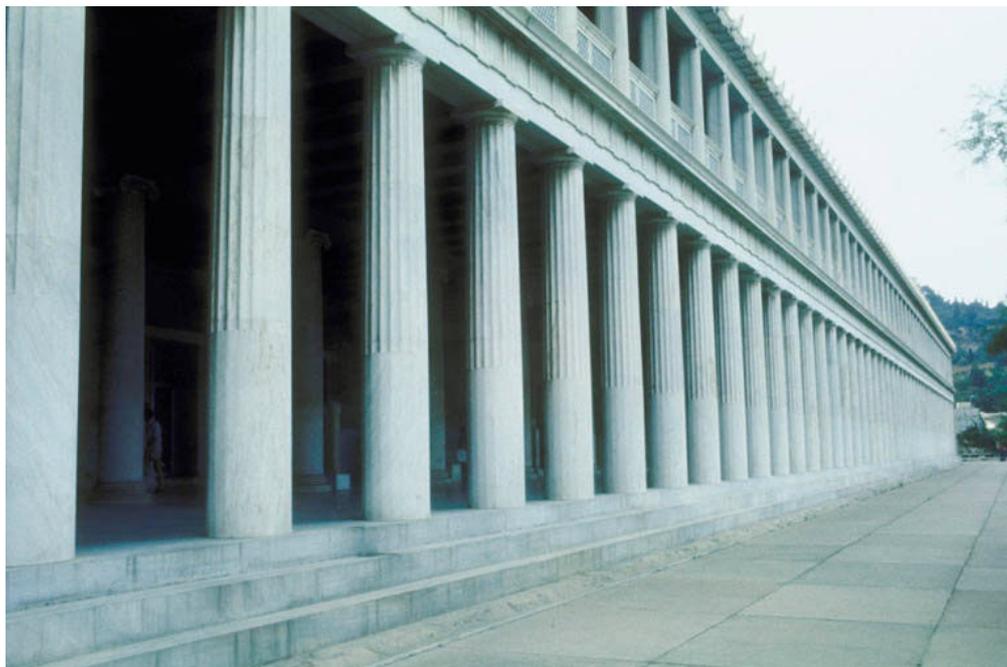
Create – Share – Listen
Lillehammer



Pip Hardy
Pilgrim Projects/Patient Voices
Cardiff University

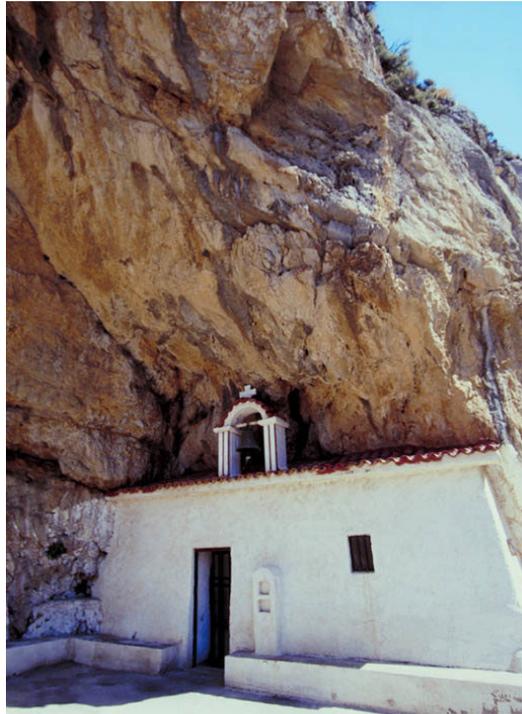


Ways of healing





Ways of healing

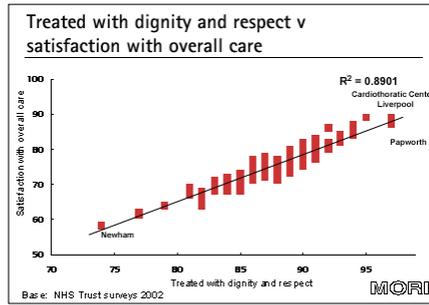
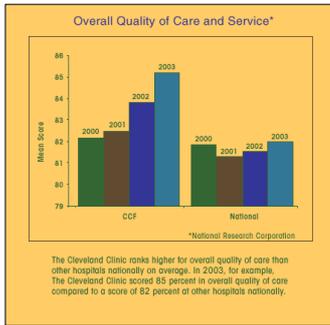


Bridging the gap





The dominant paradigm



Case	Ref	ICD-10	ICD-9	ICD-10-CM	ICD-9-CM	ICD-10-PCS	ICD-9-CM-PCS	ICD-10-PCS	ICD-9-CM-PCS
111	111	ICD-10	ICD-9	ICD-10-CM	ICD-9-CM	ICD-10-PCS	ICD-9-CM-PCS	ICD-10-PCS	ICD-9-CM-PCS



effective
affective **Voices**
Patient
reflective



Ways of knowing

Empirical
knowing

Aesthetic
knowing

Authentic
presence

Personal
knowing

Moral
knowing



effective
affective **Voices**
Patient
reflective



'The care of the patient'

'One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.'

Francis Peabody (1927) *The care of the patient*



Reflection: learning from experience



'We learn not from experience but from reflecting on experience.'

John Dewey, 1938





Reflection: a valuable activity?

'We are asked to reflect all the time, and then to reflect on our reflection until we're sick of it.'

Matthew Critchfield,
2008



Matthew's story

'Yeah, I'll go'

www.patientvoices.org.uk/lssc.htm





Good stories are

Effective

Affective

Reflective

Tony Sumner, 2008





Stories and transformation



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

Schön, 1988



Stories or 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)





The stories: Patient Voices

A screenshot of the Patient Voices website displayed in a Windows Internet Explorer browser window. The browser address bar shows 'http://www.patientvoices.org.uk/'. The website header includes 'Patient Voices' and navigation links: 'About Patient Voices | The stories | Workshops | Resources'. Below the header, there is a 'Welcome to the Patient Voices programme' section with a paragraph of text and a bulleted list of elements. The list includes: 'the production and distribution of the Patient Voices digital stories themselves', 'workshops that enable healthcare professionals, carers and patients to develop their own stories and narratives', and 'consultancy and support on the integration and use of digital stories within healthcare development programmes'. The footer of the website shows 'Copyright 2007 Pilgrim Projects Limited' and 'Last updated: 07/06/2007'.



Patient Voices

patience, noun. calm endurance of pain or any provocation; perseverance

patient, adj. having or showing patience

voice, verb. give utterance to, express

Concise Oxford Dictionary, 1964





Facts and figures (and some statistics)

450+ stories facilitated/recorded

70+ workshops, plus some home visits!

350+ stories released via Patient Voices website

10+ Patient Voices stories WIP

550,000+ hits on the website in 2010

1100-2400 hits per working day on PV website

200 Gigabytes of data downloaded

35,000 stories viewed during the year



Patient Voices: a short history

- 2003 Patient Voices Programme founded by Pip Hardy and Tony Sumner
- 2004 Dartmouth Hitchcock Clinical Microsystems Film Festival 'People's Choice'
- 2005 First use of Patient Voices stories by UK National Audit Office VFM
- 2006 CDS workshops in California
- 2007 MSc research into digital storytelling in healthcare complete
- 2008 Creating an Inter-professional workforce Innovation award
- 2009 .5 million hits on Patient Voices website
- 2010 BMJ award for Excellence in Healthcare Education
Shortlisted for BMJ Health Communicator of the Year *and*
MJA Healthcare Champion of the Year
- 2010 Three papers published
PHD research into impact of digital storytelling on healthcare and reflective potential of technology





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 will not record a story for use as part of the Patient Voices programme unless we have informed and valid written consent from storytellers; we will provide whatever information is necessary about the process and the existing stories to enable such consent to be given.
Storytellers will be asked to sign a consent form which will allow the use of the final version of the story as a publicly available educational and learning resource intended to improve the quality and responsiveness of healthcare services for patients and carers.

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.

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 healthcare education and quality improvement, while protecting the integrity of the stories and the contributions of those who created the stories.
To this end, completed and approved stories are released 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 freely useable by anyone involved in healthcare education and quality 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.
Final content over what is included in the digital story will rest with the storyteller. A rough out will be sent for comment and a final version will be sent for the storyteller's approval before the story is released.

www.patientvoices.org.uk © Pilgrim Projects Limited (2012) www.pilgrimprojects.co.uk

Patient Voices

Consent form

I, _____, have read the Protocol for storytellers and other information relating to the creation and use of digital patient stories for the Patient Voices programme.

I understand that I will have editorial control over my story or stories, but that copyright will be held by Pilgrim Projects Limited.

I agree to the inclusion of my story/stories in the growing library of Patient Voices digital stories and may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

I have obtained all appropriate permissions for materials used in the story.

Signed: _____ Date: _____
Email: _____ Tel: _____

Name: _____
Address: _____

Pilgrim Projects Limited
The Barn, 1 Corbett Street
Cotterham
Cambridge CB24 8DX

Tel: +44 1954 202158
Email: pp@pilgrimprojects.co.uk

www.patientvoices.org.uk © Pilgrim Projects Limited (2012) www.pilgrimprojects.co.uk




PILGRIM PROJECTS

Digital Stories Release Consent Form

The title of my story is: _____

I wish my story to remain confidential.

I am happy for my story to be shared with other members of my own workshop group.

I am happy for my story to be shared with the growing community of Pilgrim digital storytellers and future workshop groups, including via a private page on our website.

I am happy for my story to be used in future storytelling workshops.

I am happy for my story to be used in other workshops and presentations.

I am happy for my story to be put up on one of Pilgrim Projects' publicly accessible websites (such as www.patientvoices.org.uk), following a review to ensure that the story is free of any copyright restrictions.

I am happy for my story to be used under the following conditions:

Name: _____ Signature: _____

Email: _____ Phone: _____

Address: _____

Date: _____

Please return to: Pilgrim Projects, The Barn, 1 Corbett Street, Cotterham, Cambridge CB24 8DX

Patient Voices

Final release approval

I have seen a draft version of the story entitled _____ and I am happy for the story to be finalised and released under the Creative Commons licence.

I agree to the inclusion of my story in the growing library of Patient Voices digital stories and it may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

OR

I would like you to make the following changes to my story before it is finalised. I understand that I will be able to see another draft incorporating the changes.

(Please continue on the other side if necessary.)

Name: _____ Signed: _____

Address: _____ Date: _____

Please return to:
The Patient Voices Programme Tel: +44 1954 202158
Pilgrim Projects Limited Email: pp@pilgrimprojects.co.uk
The Barn, 1 Corbett Street
Cotterham,
Cambridge CB24 8DX
UK

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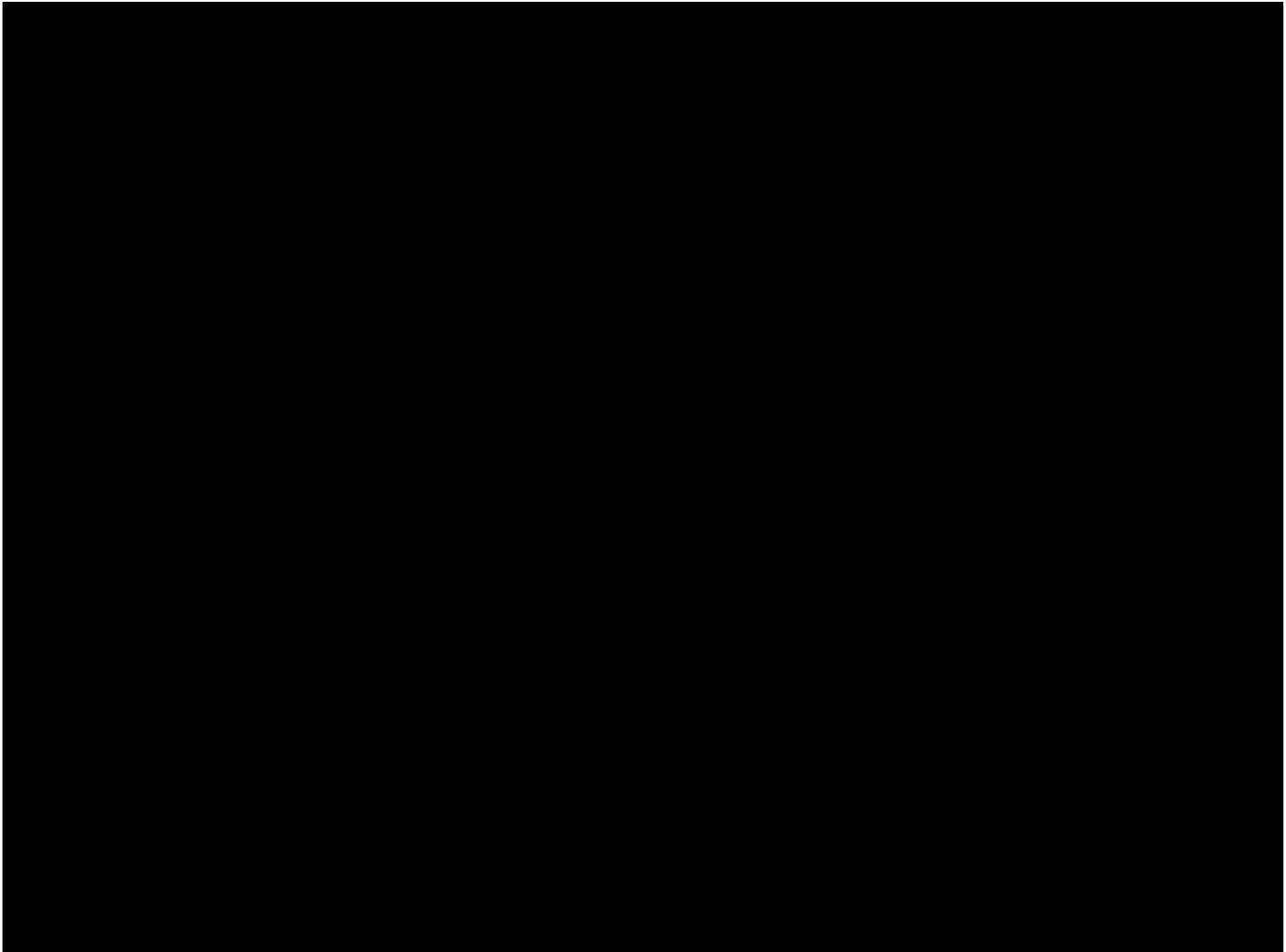




Jean's story

Getting to the bottom of things

www.patientvoices.org.uk/rcnqip.htm





Passages past dragons

'No matter what form the dragon may take, it is of this mysterious passage past him, or into his jaws, that stories of any depth will always be concerned to tell....'

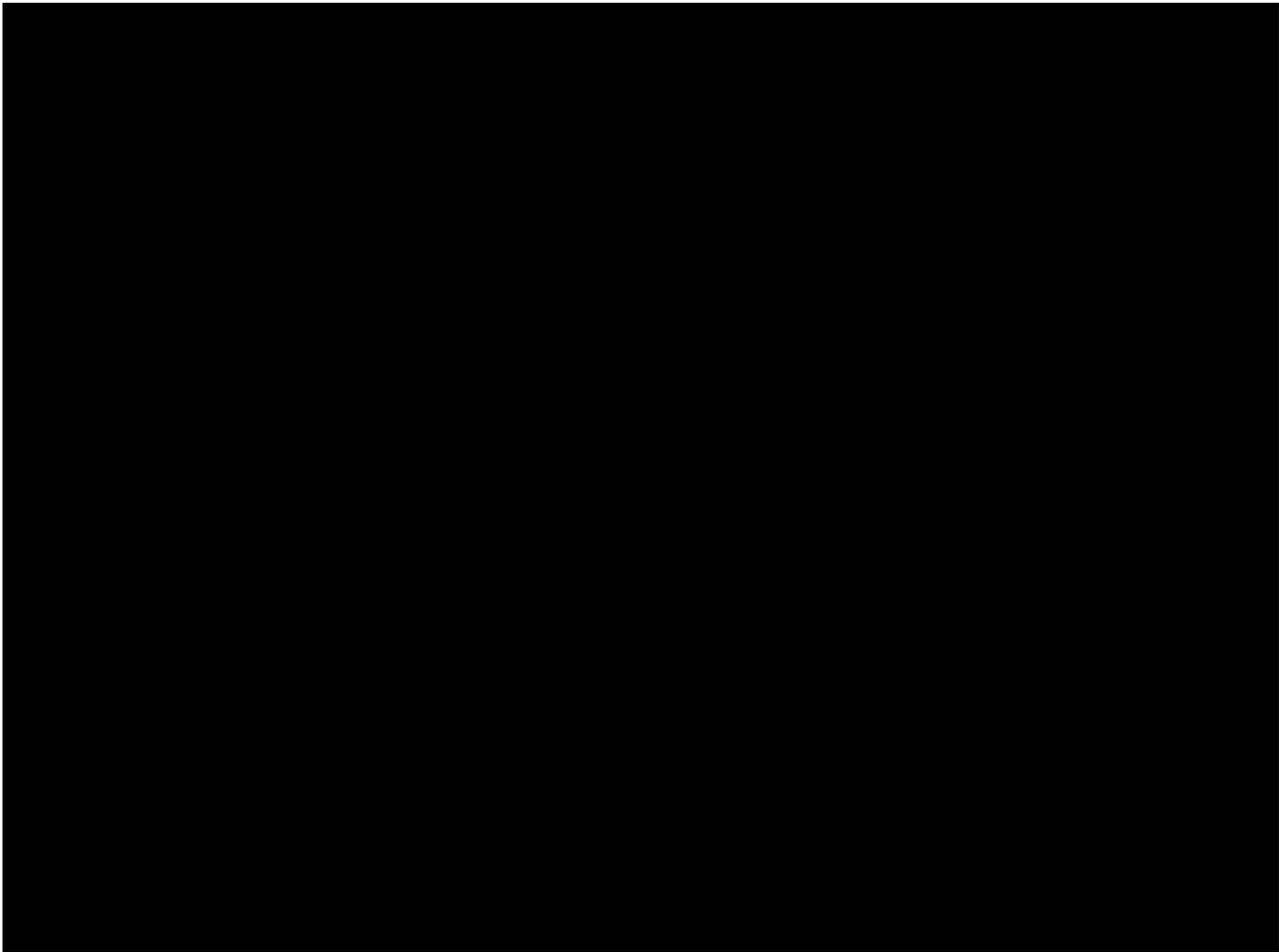
Flannery O'Connor



Vicky's story

Locked door





What research reveals

The stories are valued for their:

- authenticity
- veracity
- flexibility and versatility
- brevity and succinctness
- emotional power.....



What research reveals

...and for their ability to:

- prompt reflection
- stimulate discussion and debate
- promote empathy
- encourage creativity
- change practice.



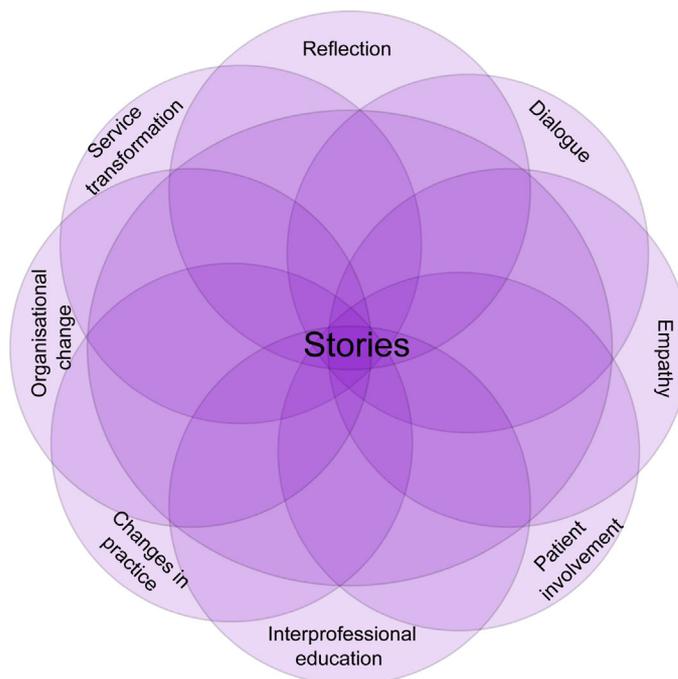
Hardy, 2007



From stories to transformation

Markers

Guides



Comfort

Warning





‘Stories work on many levels.’



Brian Clark, Storyteller



Reflection in action



‘But now, with the digital storytelling, I understand for the first time what it really means, and how powerful reflection can be for me, and as a way of sharing my experiences with others.’

Matthew Critchfield, 2008





Reflection and professional development



Evaluation and research





Health promotion



Involving patients





Creating a culture of safety



Improving the patient experience





Sharing understanding across cultures



Illuminating threshold concepts





Culture of the heart



Culture of the heart



'Behaviour change happens in highly successful situations mostly by speaking to people's feelings.'

Kotter and Cohen (2002)





Culture of the heart

'The culture of the mind must be subservient to the culture of the heart.'

Mahatma Gandhi



Thank you

pip@pilgrimprojects.co.uk

www.patientvoices.org.uk

Distribution of the Patient Voices digital stories
is funded by

www.pilgrimprojects.co.uk



Winner
Excellence in Healthcare Education
Finalist
Health Communicator of the Year





The lesson

'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.'

Robert Francis, QC

