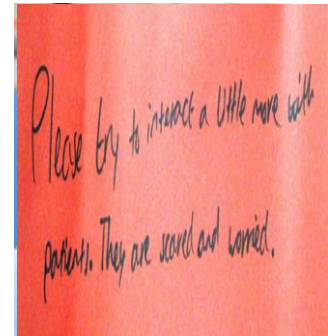


The power of narrative

in transforming practice....let me tell you a story...



Kath Evans,

**Head of Patient Experience
for Maternity, Newborn,
Children and Young People,
NHS England**



“...Place the oxygen mask on yourself first before helping small children or others who may need your assistance.”



Care for the Caretaker

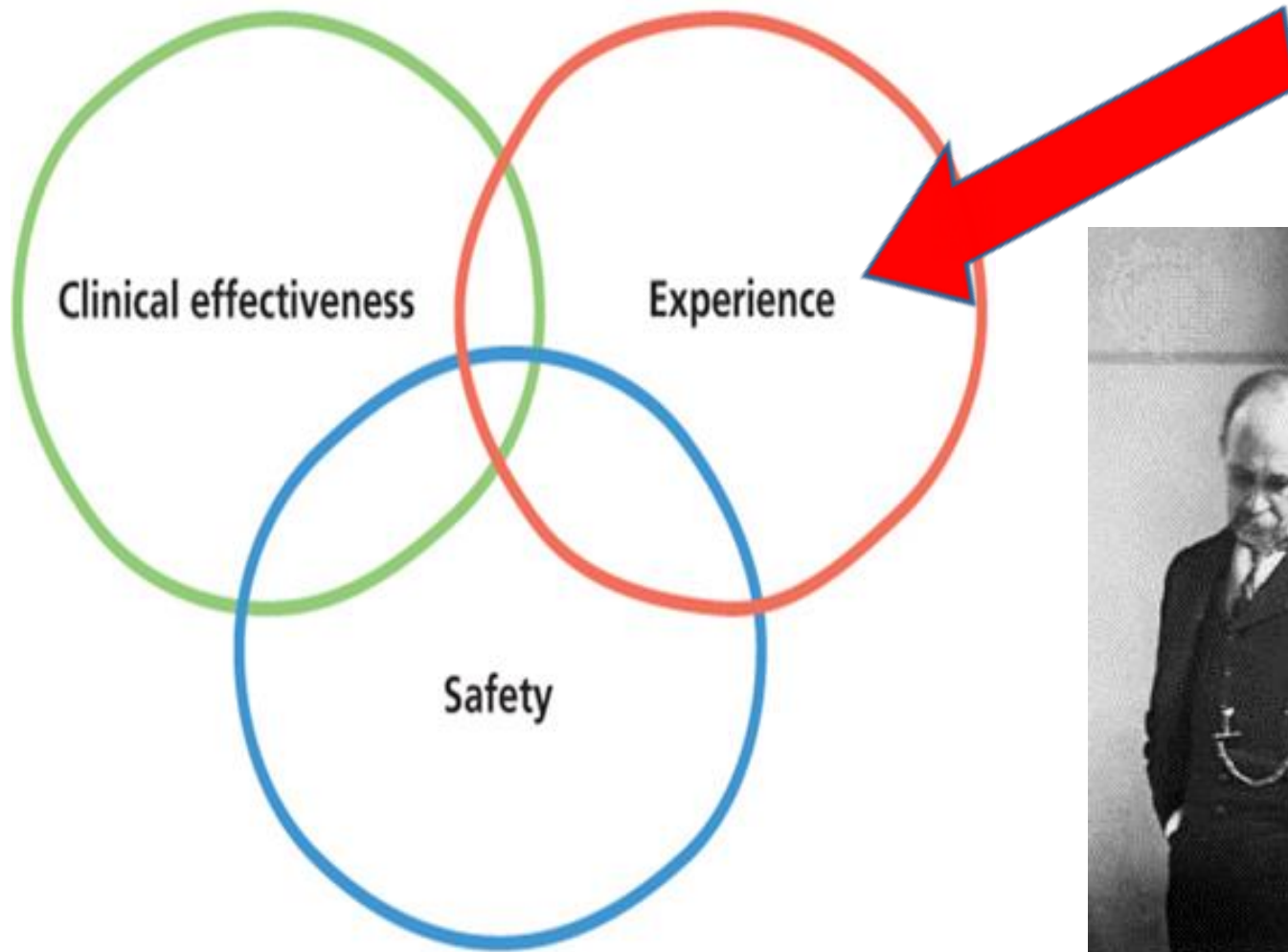
- Be gentle with yourself.
- Remind yourself you are an enabler not a magician. We cannot change anyone else – we can only change how we relate to them.
- Say 'I choose' rather than 'I should, I ought or I have to'.
- If you never say no – what is your yes worth?
- Aloofness and indifference are far more harmful than admitting an inability to do more.
- Change your routine often and your tasks when you can.
- Create some space - find a hermit spot, use it daily.
- Schedule withdrawal periods during the week – limit interruptions.
- Be a resource to yourself, get creative, try new approaches, be an artist as well as a technician.
- Use supervision, buddy, mentoring or coaching system regularly as a source of support, assurance and re-direction.
- Learn to recognise the difference between complaining that relieves and complaining that reinforces negative stress.
- Remember in the light of all the pain we see, we are bound to feel helpless sometimes . Admit it without shame. Caring and being there are sometimes more important than doing.
- Give support, encouragement and praise to peers and to management. Learn to accept it in return.
- On the way home, focus on a good thing that occurred during the day – if you can, jot it down and look at when things are tough, focus on the good stuff.
- Laugh, play, have fun
- If we care for ourselves we can care for others.....

(adapted from words shared by Marilyn Goodhew, Play Specialist, who I believe obtained the original words from a local children's hospice)

"Education is the most
powerful weapon
we can use to
change the world."

— Nelson Mandela





'he who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all.'

Sir William Osler (1849 – 1919)

Start with 'why'?

- **Why** is patient experience so important?
- **Frightened, disempowered**, lacking in knowledge/experience/information, **unfamiliar language, intimidated** by knowledge/skills (or not) of staff/uniform, smell, sights e.g. surrounded by sick people, worried about how health issues will impact on rest of life/finance/family, who will care for them, frustration, access

....loss of control/choice



Defining CYP Experience

- *The child/young person/family/carer's experience is the sum of all interactions, shaped by an organisation's culture, that influence their perceptions across the continuum of care* (Adapted from Beryl Institute's 2014 definition)
- *What matters to children and young people*
(NHS England, Children's takeover day 2014)
 - *Communication, Information*
 - *Pain*
 - *Access*
 - *Environment, Food, WiFi*

'Often it's the small things that will make the biggest difference'



What are the drivers for involving children, young people and families..?

Audience participation please....?!

Why.....?

- Right thing to do
- A legal requirement
- Better outcomes
- All

When...?

- At the start
- At the end
- Throughout the process



1.

The Health and Social Care Act 2012 introduced significant amendments to the NHS Act 2006, emphasising the ***importance of patients and carers participating in planning, managing and making decisions about their care and treatment and the effective participation of the public in the commissioning process itself, so that services reflect the needs of local people.***

Transforming Participation in Health and Care, Guidance for Commissioners

<http://www.england.nhs.uk/2013/09/25/trans-part/> provides the scaffolding on which to build effective engagement to deliver personalised care and true co-production in the design and delivery of health care.

A Rights Based Approach?

UN Convention Rights of the Child

- Article 12 'every Child has the right to say what they think in all matters affecting them, and to have their views taken seriously '
- Article 13 'every child must be free to say what they think and to seek and receive information of any kind as long as it is within the law'
- Article 23 'A child with a disability has the right to live a full and decent life in conditions that promote dignity, independence and an active role'
- Article 24 'Every child has the right to the best possible health'
- Article 31 'Every child has the right to play'

Children and Young People with Special Educational Needs or Disabilities (#SENDReforms)

Children and Families Act 2004

Section 19: Supporting and Involving children and young people

‘...Ensure local authorities place children, young people and families are at the centre of decision making, enable them to participate in a fully informed way and with a focus on achieving the best possible outcomes’

CMO Report

CYP Health Manifesto for Health and Wellbeing

To improve their health and wellbeing, children and young people want:

1. to be informed and have a say in decisions about their care,
2. to have personalised, child-friendly care from people they know and trust and who treat them with respect,
3. to have access to age-appropriate services where and when they need them,
4. to be supported through the transition to adult health and social care services
5. to understand their rights and responsibilities,
6. for schools to play a greater role in health and wellbeing.

Annual Report of the
Chief Medical Officer 2012

**Our Children Deserve Better:
Prevention Pays**



Hart's Ladder

Key Questions

Which level of Hart's Ladder is our project on?

Which level of Hart's Ladder should our project be on?

What do we need to do to move to the right level on the ladder for our project?

NON-PARTICIPATION

It is important to remember that tokenism, decoration and manipulation are not examples of youth participation. You do have the choice to move away from these methods towards more meaningful participation.

QUALITY OF PARTICIPATION

EXAMPLES

Young people and adults share decision-making

Young people have the ideas, set up the project and invite adults to join them in making decisions throughout the project. They are equal partners.

Young people decide they need a one-stop shop in their community. They partner with adults in different youth organisations and together lobby the government for resources.

Young people lead and initiate action

Young people have the initial idea and decide how the project is to be carried out. Adults are available and trust in the leadership of young people.

A group of students get permission from their principal to run an environmental day. The students make the decisions, and the school provides support.

Adult-initiated, shared decisions with young people

Adults have the initial idea, and young people are involved in making decisions, planning and implementing the project.

A community co-ordinator asks young people for event ideas for Youth Week. The young people suggest having a skating event. The co-ordinator and young people work together to make decisions and apply for funding.

Young people are consulted and informed

Adults design and facilitate the project, and young people's opinions are given weight in decision-making. Young people receive feedback about their opinions.

A local council runs several consultations to get young people's input about a recreation park. Young people tell the council about features in the park they want changed. The council provides feedback to the young people about how their views affected decision-making.

Young people assigned but informed

Adults decide on the project and young people volunteer for it. Young people understand the project and adults respect their views.

A conference creates positions for two young people on a panel of speakers. Young people decide how to select their representatives and work with adults to understand their role.

Tokenism

Young people are given a limited voice and little choice about what they can say and how they can communicate.

A young person is asked by adults to be on a panel and represent 'youth'. The young person is not given the opportunity to consult with peers or understand the role.

Decoration

Young people take part in an event in a very limited capacity and have no role in decision-making.

A group of young people are given a script by adults about 'youth problems' to present to adults attending a youth conference.

Manipulation

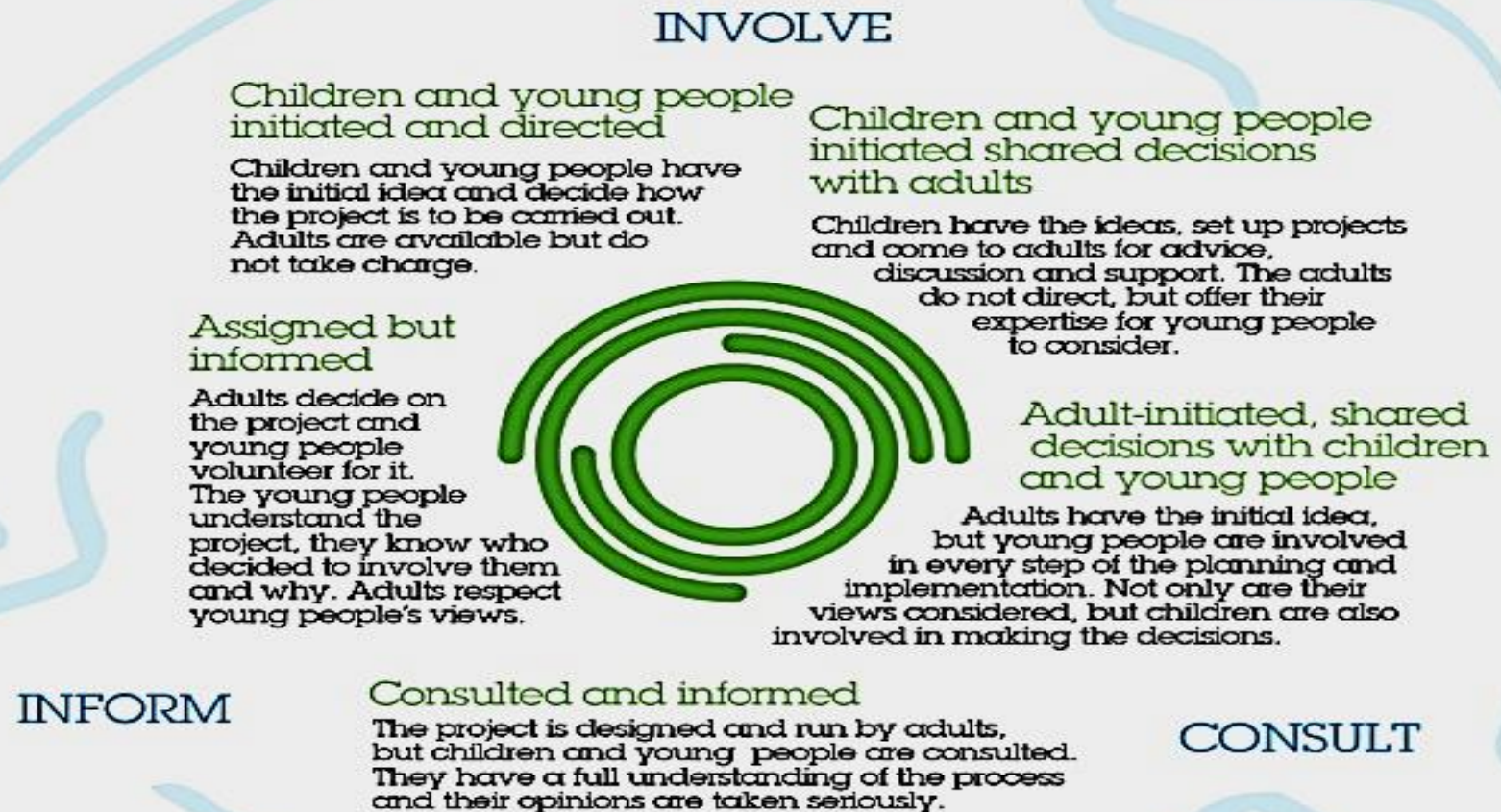
Adults have complete and unchallenged authority and abuse their power. They use young people's ideas and voices for their own gain.

A publication uses young people's cartoons; however, the publication is written by adults.

Figure 1.1 OCC's Wheel of Participation

Involving children and young people in decision making...

Based on the 'Degrees of Participation' by Phil Treseder



Degrees of participation by Phil Treseder

Complexity of CYP & families we serve

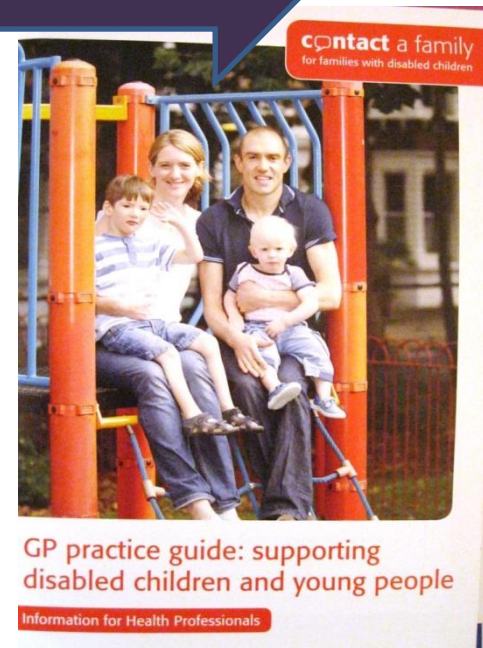
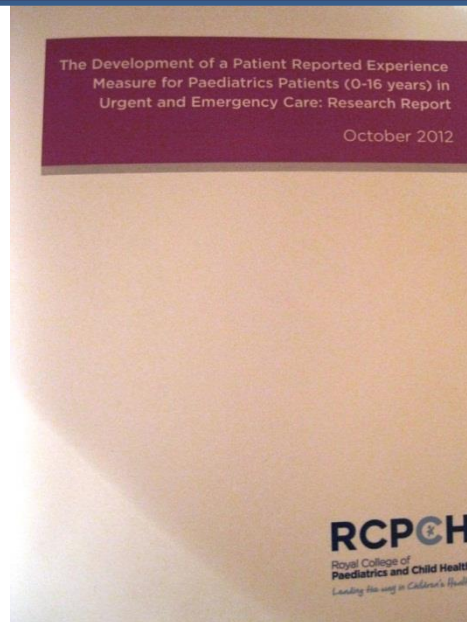
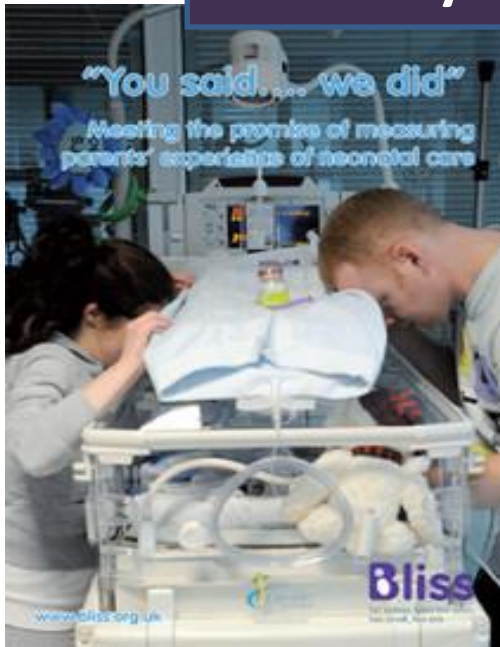
Neonatal
Care

Children's
Care

Young
People's
Care

Families/
Carers

Priority: those who are underserved/vulnerable



Audience participation?!

- Who are our underserved groups – those who are most vulnerable..?



The Challenge of measurement/feedback

A person wearing a dark suit and white shirt is sitting on a wooden bench. They are holding a newspaper in their lap. Their feet are wearing black loafers. The background is a wooden wall and a carpeted floor.

**‘If you want to know
how well a pair of
shoes fit ask the person
wearing them not the
person who made
them.’**

Anon



Feedback Station

We would really like to hear your thoughts about your visit to the Children's Emergency Department today.

Please take a token and place it in a box that you feel is suitable.

As a service we value your views, if you are unhappy with your experience today please ask to speak to the Nurse in Charge.

Thank you

What you said to us!

SOUTHAMPTON Children's Hospital
Your Feedback is Important to us

What we did!

- It's too hot!
- No baby changing facility
- Waiting room looks tacky
- Wait too long to see doctor
- New baby changer installed in kitchen
- Waiting room chairs replaced
- Double door cover in entrance when it is at its busiest
- Currently raising money with Aids (Southampton) so they have more fans

Your feedback is important to us,

Feedback from patients and families is collected in a 'Sunny or Cloudy' display. The display features a green background with yellow suns and white clouds. Each sun or cloud contains a handwritten note from a patient or family member.

Examples of feedback:

- "The doctors & nurses were nice. Can't wait to see how they help explain things to you and make you feel better."
- "Thanks for nice lunch."
- "The friendliest ward I have ever been to."
- "Nice Hospital and Staff."
- "Good Doctors and Nurses - just what I needed and very caring and friendly."
- "Thank you for all making me so much better and being so nice. Love you."

Please tell us if your care was sunny or cloudy!

Tell us about your stay

Feedback from patients and families is collected in a 'Tell us about your stay' display. The display features a blue background with colorful clothes hanging on a line. Each piece of clothing contains a handwritten note from a patient or family member.

Examples of feedback:

- "I was very happy with the care I received from the staff. They were very friendly and helpful."
- "The food was very good and the staff were very helpful."
- "I was very happy with the care I received from the staff. They were very friendly and helpful."
- "The food was very good and the staff were very helpful."

Was there anything about your stay that you were happy with?

Was there anything about your stay that you were not happy with?

Thank you.

Listen with Compassion



When you listen generously to people,
they can hear the truth in themselves,
often for the first time.

~ Rachel Naomi Remen ~

Empathy the critical tool,
in our toolkits?



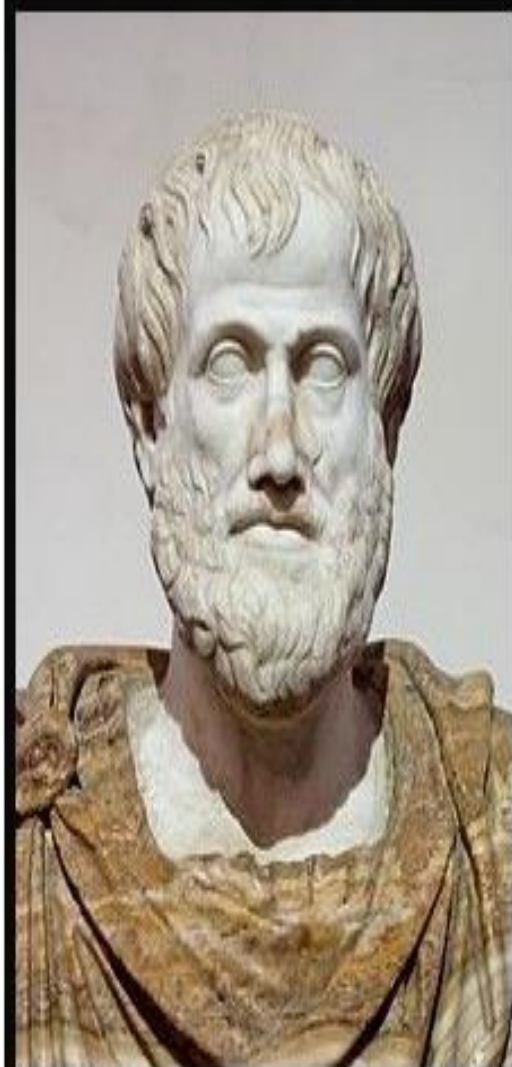
Hey!



I'm stuck
IT'S DARK
I'M OVERWHELMED



Disney · PIXAR
MONSTERS, INC.



Educating the mind without educating the heart is
no education at all.

(Aristotle)

“ You may tell a tale that takes up residence in someone's soul, becomes their blood and self and purpose. That tale will move them and drive them and who knows that they might do because of it, because of your words. That is your role, your gift.

Erin Morgenstern, The Night Circus

**'No story lives unless
someone wants to listen.'**

– J.K. Rowling



Please try to interact a little more with patients. They are scared and worried.



Angelina's Story !!!!

When I was nine I became incontinent. My GP sent me and my parents to the hospital.

The immediate response was that I was probably 'seeking attention'. I can remember hearing them say it.

Trust me if I was going to seek attention it wouldn't be by wetting myself in school, it was just embarrassing, I felt so silly and sad.

At the hospital I was taken over to bed and the curtain was drawn round me. There was a doctor and a nurse, I don't know why but mum and dad weren't in that curtain area. I was really frightened.

The doctor had a really strong accent and I couldn't really understand him, you know, what he was saying, that sounds mean and I really don't want it to.

The doctor tested my reflexes while I sat on the bed and then told me to lie down, I didn't understand him at first and the nurse repeated it but like she was shouting at me. Then the doctor pulled down my trousers and pants down. I quickly tried to pull them back up. But the nurse told me they had to 'examine' me and pulled my trousers and pants back down again..... And then the doctor examined me.

I've never spoken about it to anyone until now and I don't really want to say anymore about it.

But I look back now and it still upsets me; I was nine, my mum wasn't with me, no one was introduced, no one told me what was happening. I was completely powerless, as a child I could do nothing, I had no control and I was scared.

Social Media

Seeing Care from the Patient's Perspective

Adam @Adsthepoet



*Social Learning accounts for 70%
of our learning – real life, on- the-job
experiences, tasks & problem solving @LnDave*

People will
forget
what you said ...
they will forget
what you did
but people will
NEVER FORGET
how you made them
FEEL



Maya Angelou

Victoria



Daniel



Peter

Lucie



The Patient Voices Mandala

Copyright 2007 Pip Hardy and Pilgrim Projects Limited

What Matters to Me



Justine Rodger, Julie Sharp, Nicola
Coyne, Improvement & Patient Safety, 2005



Aim

The Scottish Government's Healthcare Quality Strategy (2010) supports the development of person centredness and improved patient experience.

This led to me to ask the question 'Do we really know what matters to the children and young people we care for?' The aim is to provide truly person centred care by uncovering and addressing what is important to children and young people during their hospital stay.

Methodology

The Model for Improvement (Langley et al 2009) provided the methodology for the project. Three fundamental questions and answers which form the basis of this improvement are:

What are we trying to accomplish?

The initiative acknowledges the stress that both children (Coyne 2006) and their carers (Commodari 2010) experience whilst in hospital, and will aim to provide a vehicle to regain a sense of control during their stay. The project will develop a service that does not assume knowledge on the thoughts of patients but rather asks them directly and responds to their needs.

How will we know that a change is an improvement?

Qualitative data is collected from patient feedback questionnaires. The questionnaires are designed for three groups: parent/carer, young people and children. The data is reviewed every 2 weeks and comments linking to the initiative are recorded and displayed. Sound bites are also collected and displayed so the multidisciplinary team are able to collectively consider what is important to our patients. Staff feedback is also encouraged.

What change can we make that will result in an improvement?

Every child old enough to do so will be given the opportunity to draw or write a 'What Matters to Me' list which will be displayed close to their bed.

Results

Patient feedback has been positive. Often both children and their carers get involved which lends itself well to the family centred care model as well as person centred care. Older children and those with chronic conditions wrote very specific lists outlining personal preferences during their stay. Younger children enjoyed drawing pictures, and often described surprising likes, dislikes and

worries which may have went uncovered had it not been for the initiative.

Conclusion

For the cost of just pens and paper this initiative provides inspiration and insight for hospital staff caring for children and young people. Children and their carers can be confident that their individual preferences are being listened to and addressed. More research is required to analyse the impact of 'What Matters to Me' on psychological stress felt by carers, children and young people whilst in hospital.

References

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- Commodari, S. (2010) Children staying in hospital: a research on psychological stress of caregivers. Italian Journal of Paediatrics, Vol. 36 (40)
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Acknowledgments

A special thank you to Jane Craig, Linda Vaux, and Alison Jack who alongside the staff of ward 15, Royal Alexandra Hospital helped turn this idea into a reality. Also thank you to the staff and volunteers of the Yorkhill play service who are working hard to embed 'What Matters to Me' for all children throughout Yorkhill Hospital.

WS 262018



Case Study:

The Future is Membership, East and North Hertfordshire NHS Trust

The Future is Membership is an initiative designed to inspire and motivate young people to get involved with their local hospital. The Trust now has over 650 young members from 14-18 years engaging with the Trust (18months ago there were just 50 young members). The approach is to work with schools and their pupils in an interactive, fun way, free of jargon and management speak. The Future is Membership has delivered: intergenerational work using technology and social media to tackle isolation in the elderly; a Youth Health Champions conference for secondary schools; a workshop for young patients and members to develop a hospital complaints process specifically for young people and a short promotional film for young people that captures the essence of what we are about to inspire the next generation of young members and health champions; The Health Service Journal profiled the work

<http://www.hsj.co.uk/opinion/why-we-should-engage-young-people-in-the-nhs/5060112.article>

vimeo.com/m/108800527



Blackpool....



Blackpool Teaching Hospitals **NHS**
NHS Foundation Trust

TOP TIPS For talking to young patients

- Always check it's ok to come in
- **Don't lie** - Tell me if it might hurt or things might take a while
- It's hard for me to ask questions sometimes, please check with me if I have any
- I like to know the **REASON** for things, it helps me to understand
- Encourage me to speak for myself
- Offer me the chance to speak without my parents in the room
- If you have to pass on information, **please tell me!**

15 STEPS CHALLENGE



Shropshire Clinical Commissioning Group

- Young Health Champions



vimeo.com/m/110876365

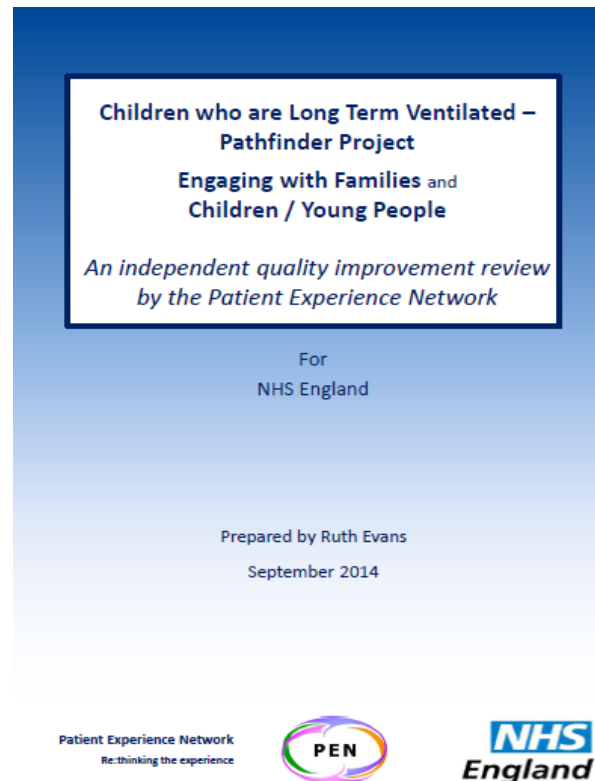
Children's Commissioner Take Over Day NHS England



The Five Year Forward View sets out how the health service needs to change, it argues for a more engaged relationship with patients, carers and citizens, so that we can promote wellbeing and prevent ill-health. NHS Youth forum <http://www.england.nhs.uk/ourwork/patients/public-voice/yth-for/>

Specialised Commissioning

Embedding the voices of families caring for children who are ventilated long term



Building the Evidence Base



The provision of play in health service delivery

Fulfilling children's rights under Article 31 of the United Nations Convention on the Rights of the Child

A literature review

Summary overview



Improving Patient Experience for Children and Young People

*A Report prepared by
The Patient Experience Network*

For
NHS England

Patient Experience Network
Re:thinking the experience



NHS
England



Patient Information Forum

For Professionals Working in Consumer Health Information



- ****NEW** Guide to producing health information for children & young people from PiF.**
- **PiF is the UK network for professionals working to produce and deliver health information for patients and the public.**
- **If you are involved in creating health information for children and young people, then this guide is for you.**
- **It is full of practical information to help you produce results that are of high quality, appropriate and effective. The Guide brings together the experience of health information providers in the NHS, voluntary and private sectors, and there are many case studies that are examples of good practice.**
- **More information from www.pifonline.org.uk**

Two young people's stories about the effect
of participation on their lives

m.youtube.com/watch?sns=em&v=dr18QxY--Wc

**OH SO YOU LISTEN
TO YOUNG PEOPLE...**

**...TELL ME AGAIN ABOUT THE CHANGES
YOU MADE BASED ON WHAT THEY SAID**

With thanks to @grangerkate

A blue cartoon bird with its wings spread, winking, and smiling.

Hello fellow Tweeps!



NAHPS Committee

@nahpsofficial FOLLOWS YOU



What is the best way to spread new knowledge?

Social connection/discussion is
14 times more effective
than
written word/ best practice
databases/toolkits etc



Source of image: happiness-one-quote-time.blogspot.com

Source of data: Nick Milton
www.nickmilton.com/2/2tOjE



@Helen Bevan @hcvoices #newhcvoices



The Starfish Story

An old man was walking on the beach one morning after a storm. In the distance, he could see someone moving like a dancer.

As he came closer, he saw that it was a young woman picking up starfish and gently throwing them into the ocean. "Young lady, why are you throwing starfish into the ocean?"

"The sun is up, and the tide is going out, and if I do not throw them in they will die," she said.

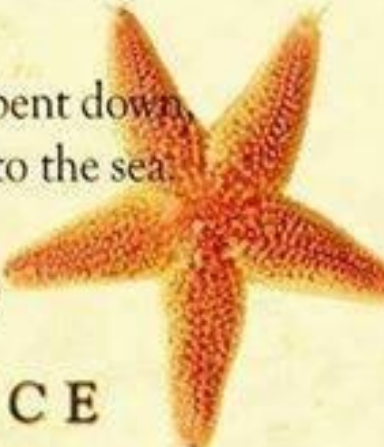
"But young lady, do you not realize that there are many miles of beach and thousands of starfish? You cannot possibly make a difference."

The young woman listened politely, then bent down, picked up another starfish and threw it into the sea.

"It made a difference for that one."

~ *Adapted from the original by Loren Eiseley*

LIFE'S A DANCE



**"NEVER UNDERESTIMATE
THE POWER OF A SMALL
GROUP OF COMMITTED PEOPLE
TO CHANGE THE WORLD.**

**IN FACT, IT IS THE ONLY
THING THAT EVER HAS."**

- MARGARET MEAD

**IF YOU THINK YOU ARE TOO
SMALL TO MAKE A DIFFERENCE,**

**TRY SLEEPING
WITH A MOSQUITO.**

- DALAI LAMA

ZERO DEAN

***As professionals we can all consider our
personal interactions with professionals as well
as patients***

- ➡ Take care of you....
- ➡ Recognise and appreciate the good stuff
- ➡ Interested in people – public as assets
- ➡ Readiness to listen *‘No story lives unless someone wants to listen’*
- ➡ Belief in potential/High expectations
- ➡ Embrace new communication strategies





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