



Respecting the Voices of Children and Young People in Participatory Action Research

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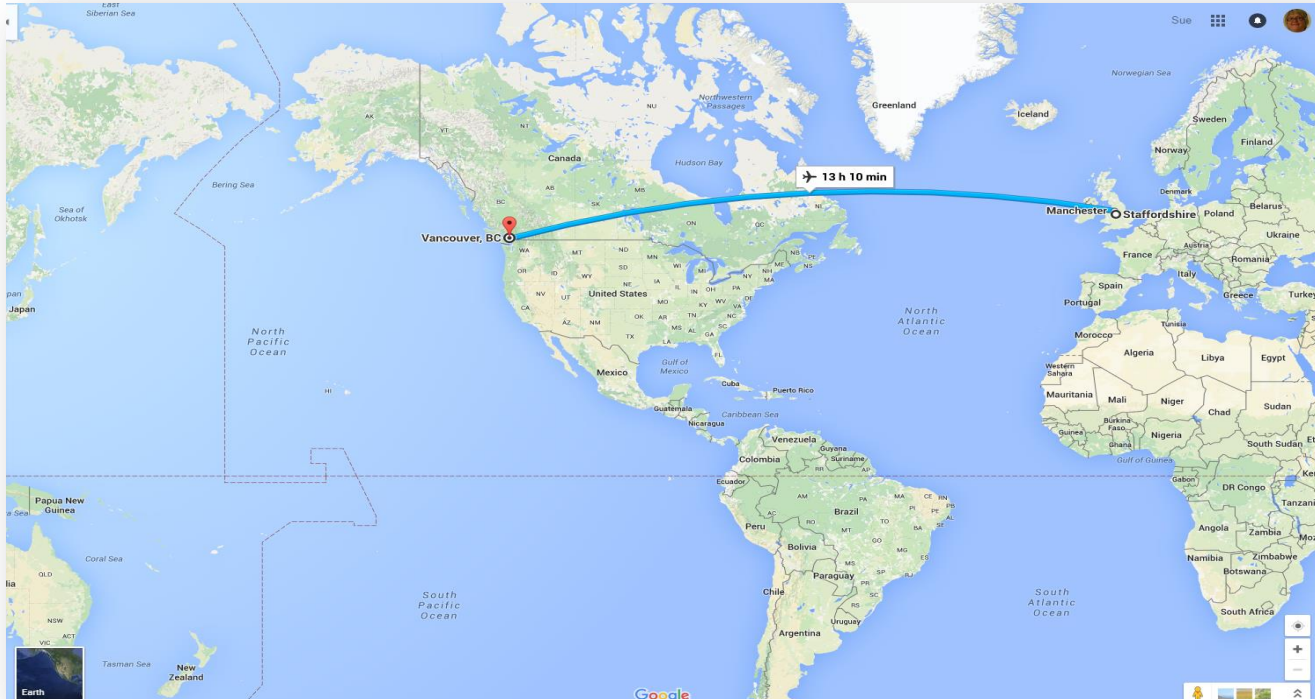


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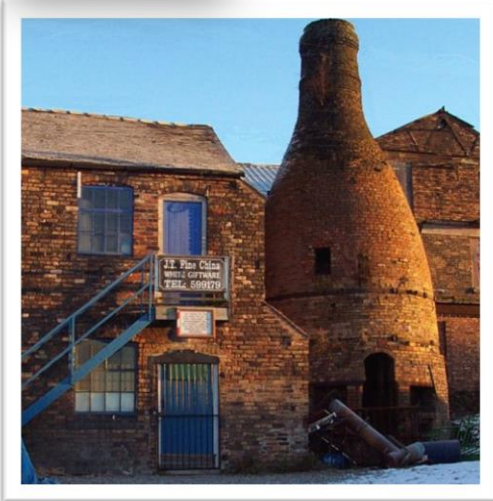
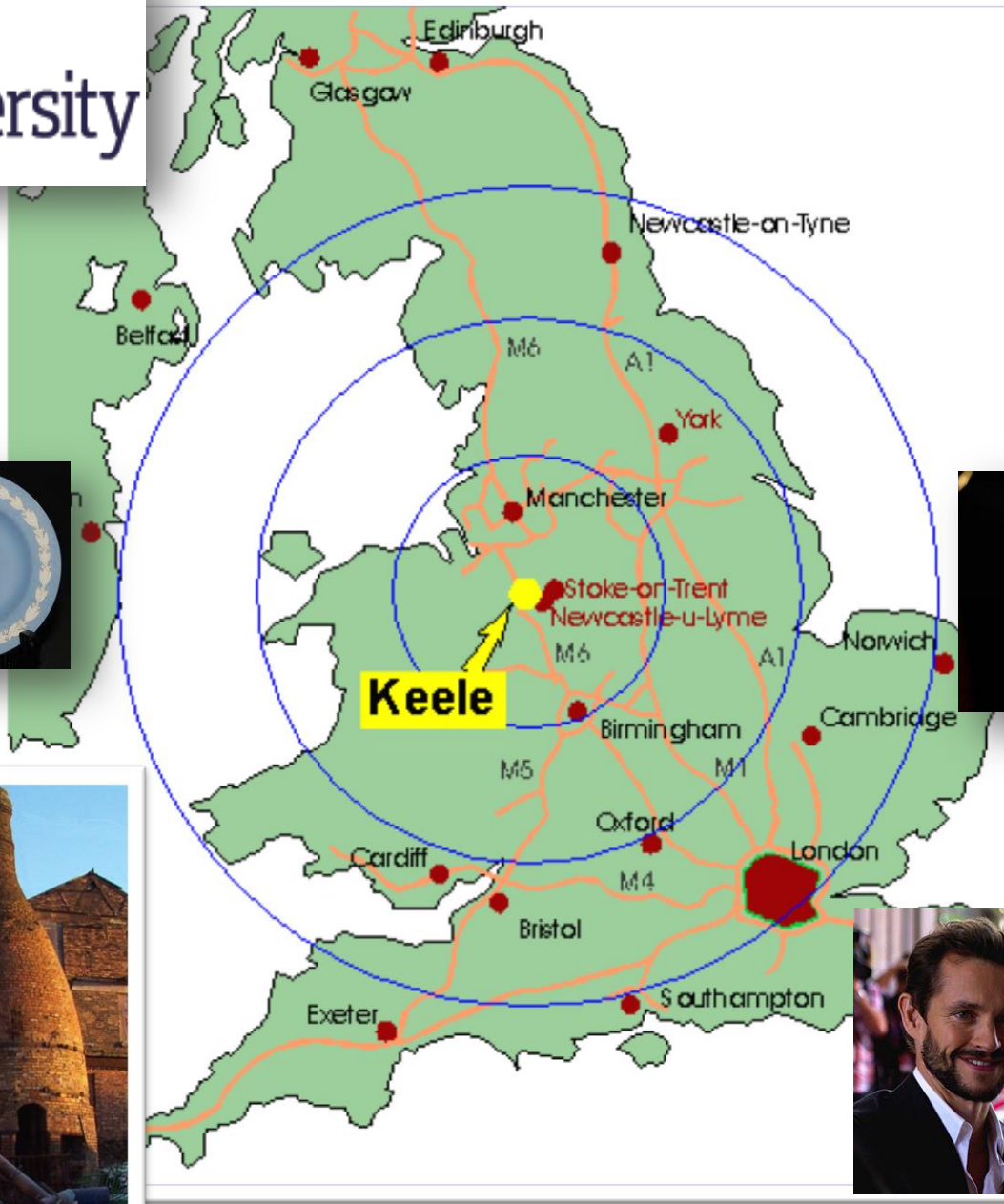
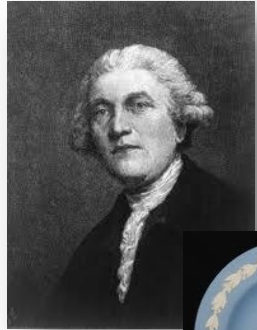
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Where am I from.....



Staffordshire is in the Midlands area of England.
It is 4581 miles from Vancouver.



Aims are to...

- Introduce the background and rationale for my PhD research project
- Discuss how children and young people were involved in the research
- Explore what was gained from this consultation and collaboration

‘Healthcare is everybody’s business’



My Journey...Towards the PhD



MSc – Children:
Critical Perspectives



Experience in MAU
& Cardiac Arrest Team



'Sudden Death' Chapters



PhD

PAR study to improve
support provided to
children and their families
when visiting relatives in
hospital

What did we know

Often *not included* in conversations at the hospital.

Leads to an increase in *anger and fear*.

Need information, reassurance, expression of feeling and the opportunity to be *involved*

Often *poorly informed*, unaware that death is anticipated, *poorly prepared*.

Study 5-15 year olds – questions to doctors were *seeking* reasons and cause for death (Thompson and Payne, 2000)

Involving children in research

Great importance on children's participation
in healthcare research (Fleming and Boeck, 2012)

Young people involved in the research process 'can offer
a different perspective' (Kirby, 2004).

User/carer involvement across the **research
continuum** is crucial to ensure it remains 'fit for
purpose' (Read, 2013).

Research objective

A Participatory Action Research (PAR) study to improve the support provided to children and their families when visiting adult relatives in hospital.

My PhD dilemma

The main dilemma during the planning stages was whether to and where to include children in the research process.



Consultation and Inclusion

- Contact was established with the West Midlands Medicines for Children Research Network (MCRN) User Involvement Coordinator:
 - who asked the Young Persons Advisory Groups if they would provide consultation for my PhD research proposal
- Two consultations were held...

Process of inclusion

1. The first consultation was a focus group of young people from the West Midlands MCRN Young Persons Advisory Group (n=15; three boys and 12 girls, aged between 10 and 17 years).
2. The second focus group incorporated members of the London and South East MCRN Young Persons Advisory Group (n= 8, four girls and four boys aged between 8-17 years).

Process of inclusion

They were asked:

- What **experience** they had of visiting adult relatives in hospital
- What **support** might be required
- For suggestions regarding communicating with children and young people



Process of inclusion

They were asked:

- whether I should **approach** any children who visit an adult relative at the hospital
- whether I should use other children's groups (MCRN, schools, clubs) to receive **feedback** on plans/leaflets during my research.



Hospital experiences

Several young people had visited relatives in hospital. All were elderly and mostly Grandparents

Few had had explanations from medical staff about their relatives condition

Three had had no explanation from relatives or staff



Encounters with nurses/doctors

They sat down and talked to me, saying he (relative) was going to be alright. It made it easier when I had my mum with me

We felt in the way

They did not have time to talk to us



They were rude and showed no compassion

What did not help

When they said I
couldn't go in

Leave you waiting outside
getting panicked



Nobody spoke to me
about where to go

Process of inclusion: informing research methods

- After discharge would be better, but not if the relative had died
- Thought it best to speak to different groups, but be careful as some children may not wish to talk about their experiences
- Don't visit schools and pick out kids who have visited adult relative's as it is a sensitive topic



Process of inclusion: informing research methods

- Not when visiting relatives at the hospital
- After they have seen their family member if the child is emotionally stable
- Don't use questionnaires, ask questions face to face



Process of inclusion – An unexpected development

- Exciting
- Successful Focus Group
- Want further participation with the hospital....



Young people involved in the research process
'can offer a *different* perspective' (Kirby, 2004)



On reflection...

Engagement of children and young people in research is an important and expanding area

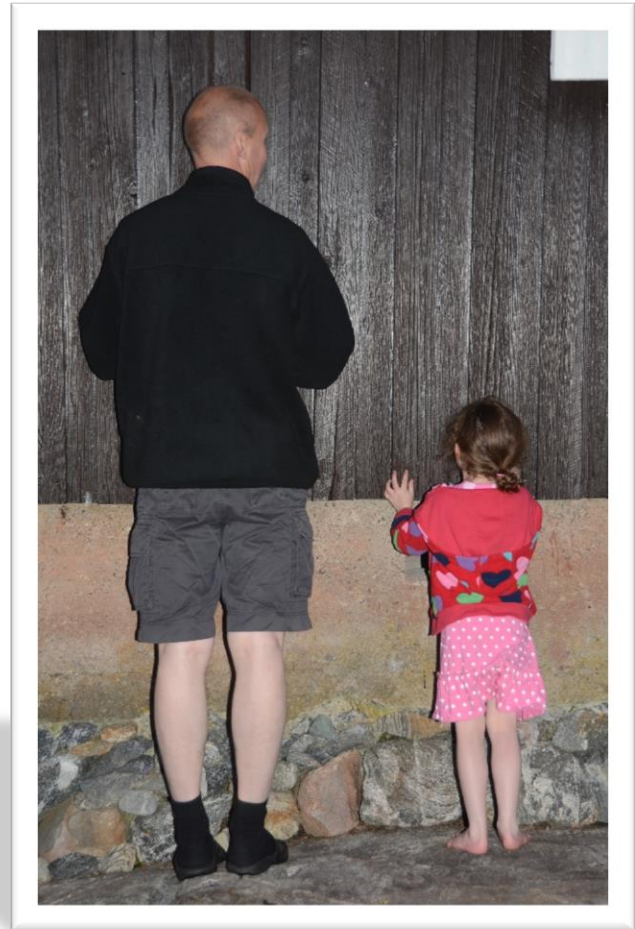
The experience has influenced my clinical practice and now my teaching practice

Care must be taken in relation to research design, the research process

Care is also required in the preparation of those children and professionals involved.

**“Children are a part of
the social world and
without their
perceptions and
experience's being
documented, we gain
a partial view, and
an inaccurate
perspective”**

(Butler, 2012, p72)



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Thank you for Listening.

Any questions ?



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