



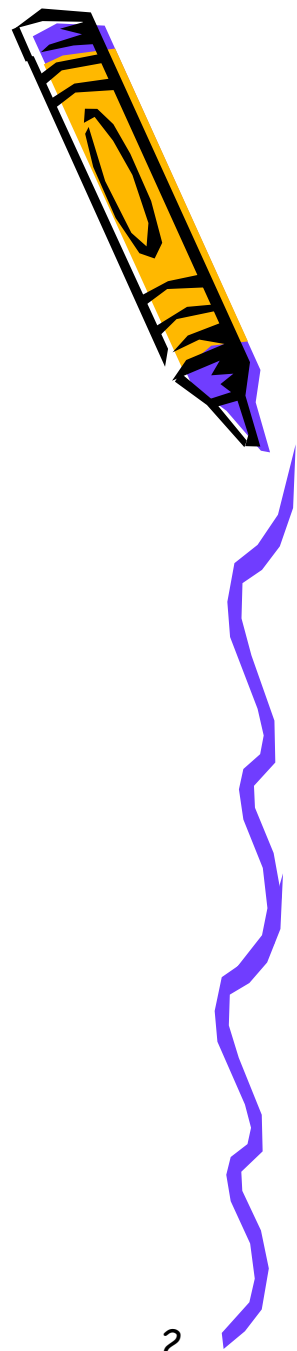
**Involving the public in research:  
Reflecting on the collaborative process from both  
a researcher and service user perspective**

**Liz Crathern: neonatal researcher and doctoral  
student DMed Sci Nursing and Midwifery  
University of Sheffield**

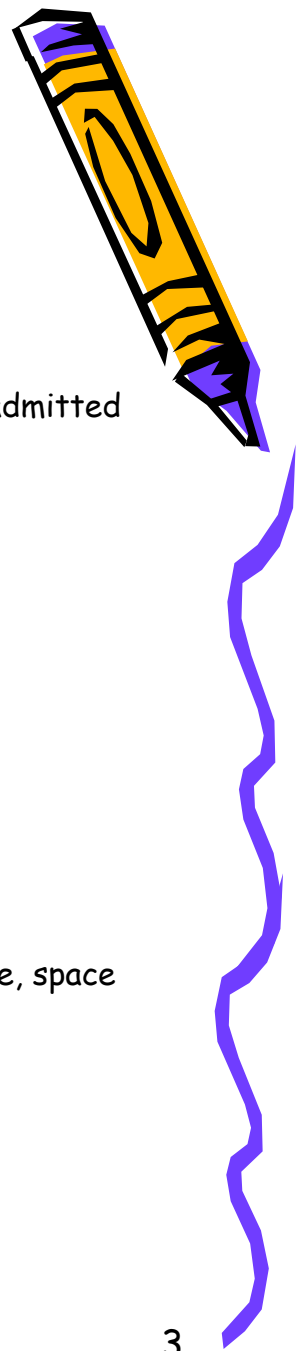
**Brett Jacob: father of preterm infants and  
member of research advisory panel**



Brett and Alicia



# Background to the study



The research aimed to explore the experiences of first time fathers who had a preterm infant admitted to neonatal intensive care (Crathern ref 1,2).

It had three broad objectives:

1. To explore the transition to first time fatherhood within NIC
2. To explore individual fathers' experiences over time
3. To extend the existing knowledge base for neonatal care.

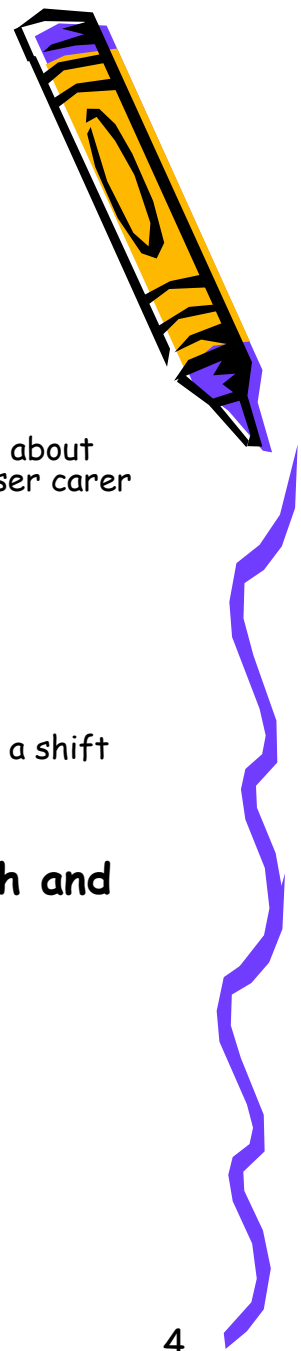
The three main themes emerged

- The uninvited self:
- The vulnerable self:
- The pragmatic self:

All three themes were inextricably lined to biographical disruption and Heidegger's notion of time, space and historicity and had resonance with Brett, the father on my advisory panel.



# Why involve the public in research in a more meaningful and representative way?



## Personal driver

- A personal belief system that reflects care and compassion for families using the NHS and about giving those families a voice. An overwhelming desire not to pay lip service to ticking the user carer box on the Ethics form!

## Why use the public?

- People who use services will be able to offer different perspectives.
  - Can help to ensure the issues, that are identified and prioritised, are important to them.
  - Involvement, if the research is done well, can help empower people who use the services.
  - Involving users in decisions about the research process - is about building a partnership and a shift in the balance of power. (*Steele / INVOLVE ref 3*)
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- **Political drivers: to engage with users and carers both in research and policy development**

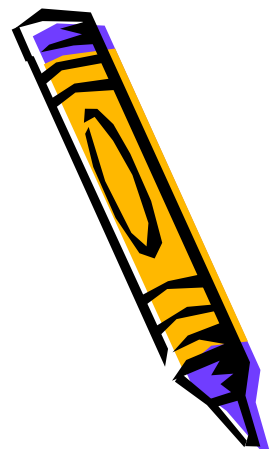


**INVOLVE: An advisory group promoting public involvement in in NHS, Public Health and Social Care research**

By public involvement in research they mean active involvement, where people involved are not just the 'subjects' of research but are active participants e.g. on a research steering committee.

If public involved – in the research process it leads to research that is more relevant to the public and more likely to be used. (ref 3)

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# Why did I chose to participate?



- Involved for a period of 6 years
- Follows birth of both my daughters and their period in neonatal care
- This had a major impact on my life and aware of impact on others
- A chance to assist with academic study from perspective of the experience of a parent in difficult circumstances
- An overwhelming sense of gratitude to staff who made a difference and chance to support future research



# *What did this mean at a practical level ?*



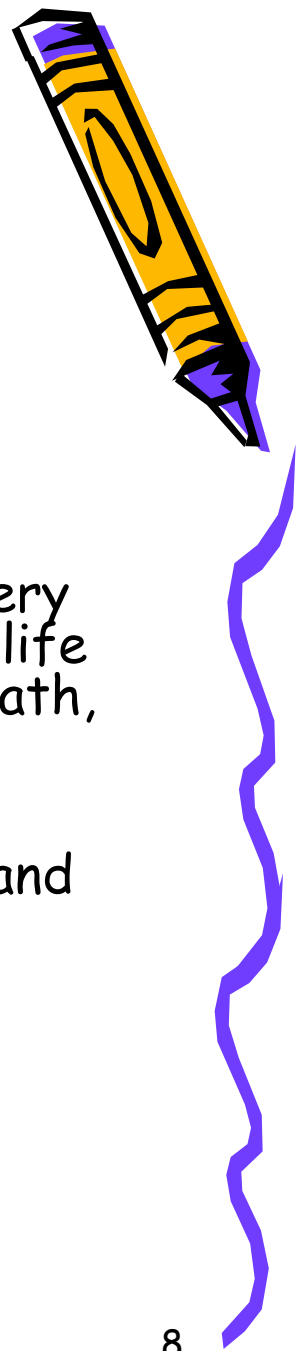
- On ensuring parent friendly wording in parent leaflets, posters and letters

On the research proposal: e.g.

- On interview process
- Asking challenging questions of the research process e.g
- What to do if a mum wants to come and sit in on discussion?
- What if a Dad just won't talk?
- How to best gain access to dads and being flexible about time of day



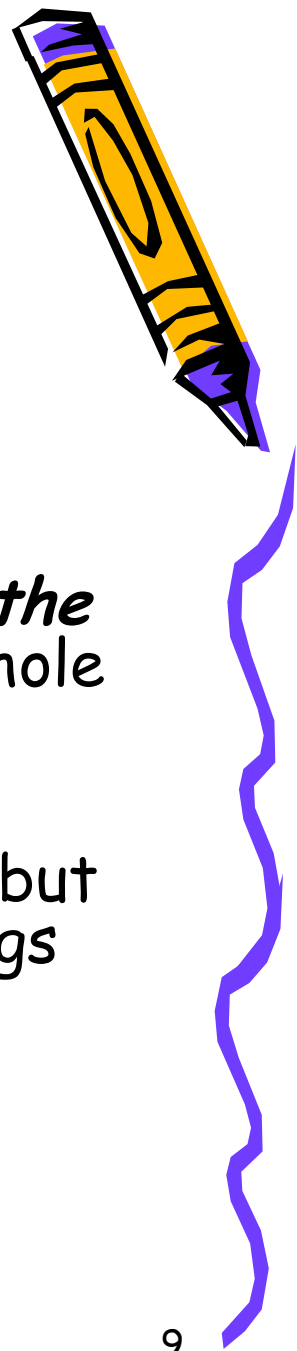
# The research findings: What did I find?



- **The unwanted self** - a good term for the unreal and unwanted nature of the overall situation
- **The vulnerable self** - absolutely. For me personally a very clear feeling of the reality of how precious and fragile life is. The sub themes have real resonance - fear about death, acute emotional fragility, needing to know more.
- **The pragmatic self** - captures the getting on with it and our ability to normalise a situation that is far from normal.



# Biographical disruption



- I agree the immediate pragmatic day to day impact is disruptive, however in terms of the broader life history I would suggest that as a result of disruption there is also, in terms of *the vulnerable self*, - a positive impact on your whole life, certainly in our experience.
- Everyone's experiences are personal to them but the value of the research shows overall feelings can be similar.



# What have we learnt from this collaborative process?

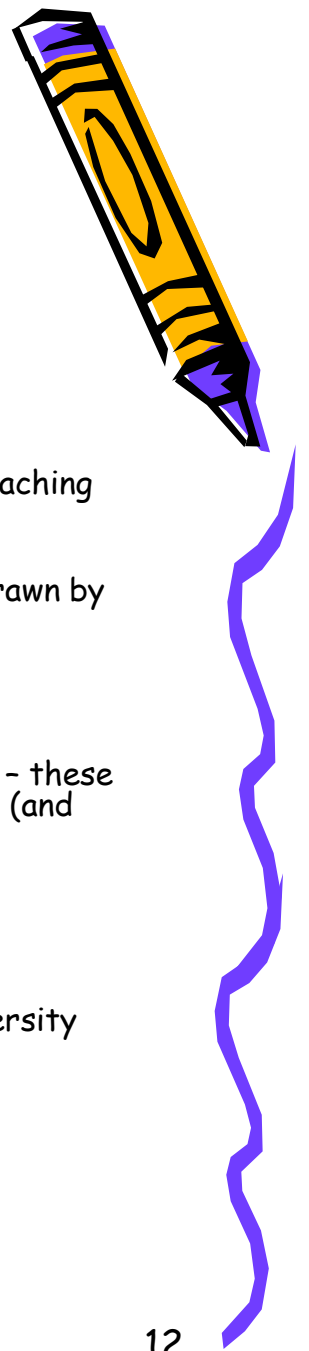


# What have I learnt as a researcher ?



- It is a rewarding experience.
- Commitment to a doctoral study - time involved not discussed at beginning.
- Neither of us really knew what to expect - our roles kind of emerged as a process of building a relationship and collaboration.
- It kept me grounded - helped me see how it really must be - feedback on my emergent themes rallied me when I got and get those writing dips!
- Concern for Brett and revisiting his own experiences, in terms of reading the labelling and emotive nature of transcripts -Space and support for Brett to reflect on his own experiences.
- Managing transparency of user carer involvement in the data analysis - must be captured within the write up of the study ( see Grant 2006)
- Bigger studies may benefit from 2 or more users and carers and a more structured approach





# Have I gained anything from being involved in this research?

- It is a rewarding experience
- A feeling of real contribution in assisting with the process of designing the questions, approaching fathers, dealing with staff in a stressful time for all concerned
- Real resonance gained from the themes that emerged from the study and the conclusions drawn by Liz
- Interest in the academic approach to the subject matter
- A chance to ensure the academic context is grounded to reflect the reality of the situation - these are sensitive issues being dealt with in often emotional circumstances and this needed to be (and was) reflected in the approach to the study
- Enjoyed the working relationship with Liz - felt she really sought my views, listened to the perspective offered and reflected that in her approach and interpretation
- In a small way, a chance to give something back building on my broader support for the university and neonatal nurses





- " When the public get involved in research, it becomes more relevant to people's needs, more reliable , and more likely to be used"



- *Nick Partridge chief Executive of Terrence Higgins Trust and Chair of INVOLVE Sept 2003 Involve D o H leaflet*



# Real world research



Any questions?

- "When you come down from your ivory tower you will see how it really must be - to be like me, to see like me, to feel like me" *Van Morrison*

Images [www.flickr.com](http://www.flickr.com)





1. **Crathern L 2009a** Men becoming fathers: from the perspective of transition to fatherhood in a neonatal intensive care environment *MIDIRS Midwifery Digest* 19:4 555 - 561
2. **Crathern L 2009b** Dads matter too: a review of the literature focusing on the experiences of fathers of preterm infants *MIDIRS Midwifery digest* 19:2 159 - 167
3. **Steele R 2004** ed **INVOLVE** - Involving the public in NHS, public health and social care research : Briefing notes for researching 2nd ed Eastleigh
4. **CEDSI 2002** Project 27/28. TSO London
5. **DOH. 1999** Making a difference: Strengthening Nursing, Midwifery and Health Visiting contributions to health and health care. Department of health London
6. **DOH. 2003** **Getting the right start - NSF for children: Emerging findings.** DOH April 2003 HMSO
7. **Grant G 2006** The reality of user and care involvement in research - NHS and research development forum event , Leamington Spa
8. **INVOLVE 2003** Promoting public involvement in NHS, public health and social research D o H leaflet

