





# Aim

To present an overview of the study undertaken with adults with an intellectual disability about their orthopaedic and trauma hospital experiences



# Background to the study

People with intellectual disabilities have a greater prevalence of musculoskeletal conditions and poorer bone health than the general population

Many reports, policies and legislation related to poor general hospital care for people with intellectual disabilities

The study was undertaken as part of a Professional Doctorate in Health and Wellbeing Award

Health and Learning Disabilities

Department of Health

Healthcare for people with learning disabilities

Closing the Gap

University of BRISTOL

Learning Disabilities Mortality Review (LeDeR) Programme

Background

- National reports and inquiries have said that people with learning disabilities are not getting good health and care
- Some people are dying too soon

The Learning Disabilities Mortality Review (LeDeR) Programme

# Integrative review (IR) of the literature

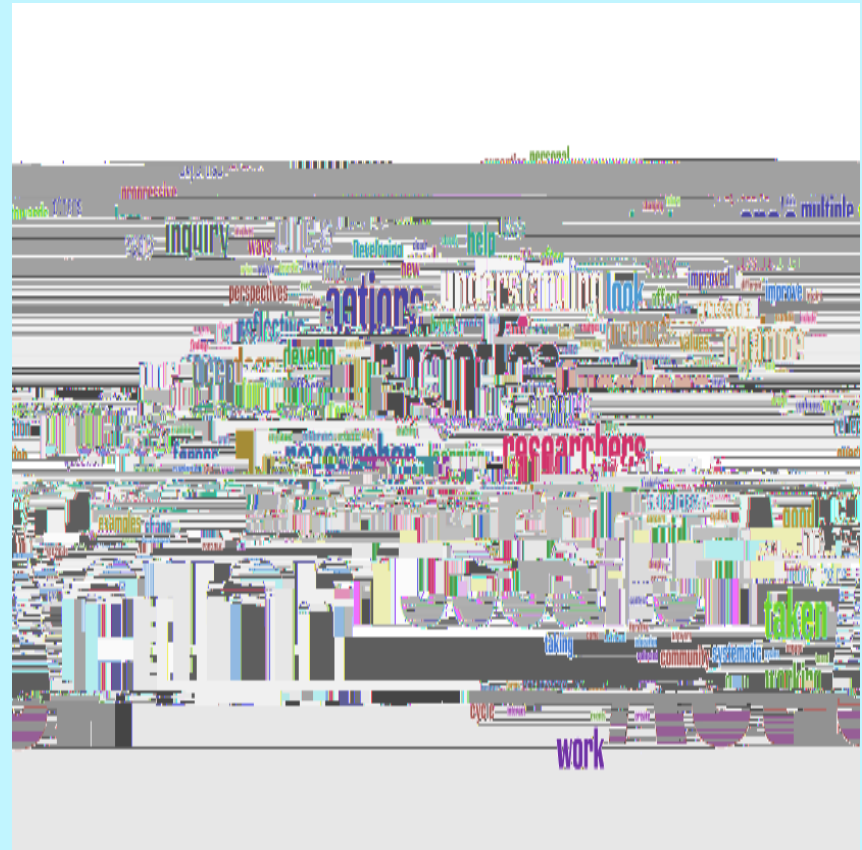
- Rationale for IR- broad review
- 2007-2018
- Literature used to present the background and context of the study
- Primary research studies (n=9) included in the final review
- No study focused on orthopaedic or trauma hospital care of people with an intellectual disability

# Research question

- How do adults with an intellectual disability describe their orthopaedic or trauma hospital experiences?

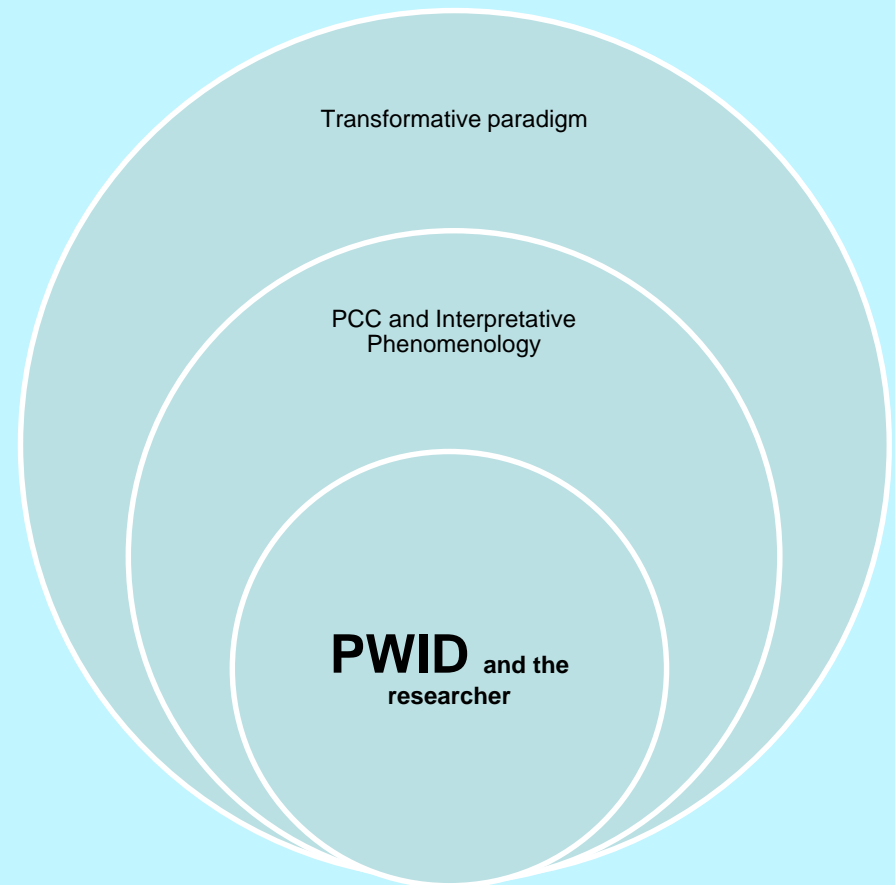
# Introduction to study

- Exploratory study
- 5 participants
- 4 with an intellectual disability
- 1 carer: Son had profound and multiple intellectual disability (PMID)



# The design of the study

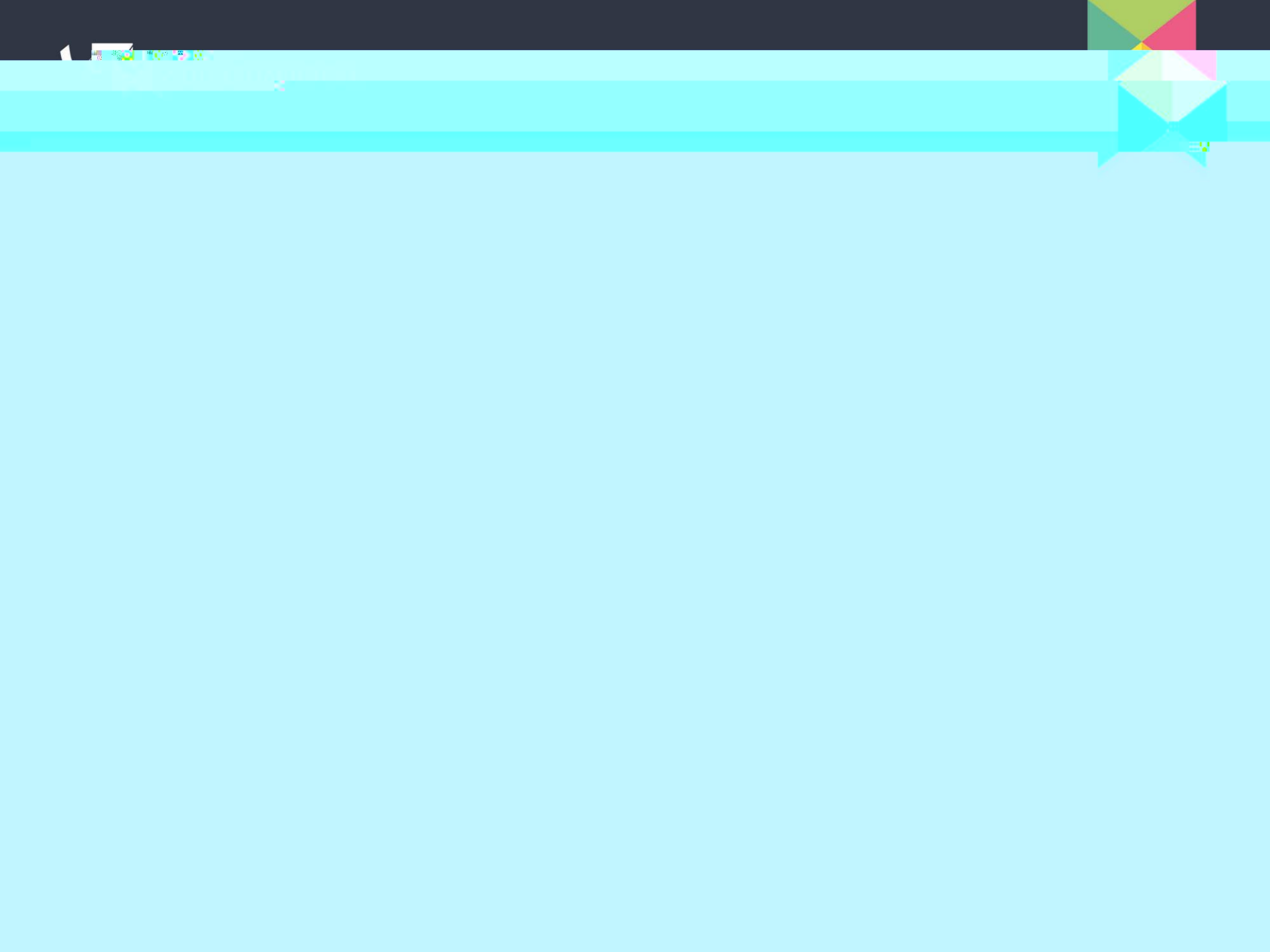
- Purposive sample
- Theoretical framework:  
Person-Centred Care  
(PCC)
- Interpretative  
Phenomenological  
Analysis (IPA)
- Transformative paradigm





# Some of the ethical issues and challenges

- Access to people with an intellectual disability
- Perceived to be more vulnerable participants
- Informed consent
- Ethical approval received





## Data collection: semi-structured interviews

- Interviews conducted, audio recorded and transcribed by the same researcher
- Face-to-face, telephone, email
- Analysis and interpretation using approach advocated by Smith, Flowers and Larkin (2009)

# Quotations from Kay

*õ I found it hard to understandõ ermõ long wordsõ (Kay, line 373)*

*õ when I don't understand long wordsõ sometimes the^ have to tell m^ mom and then m^ mom tells me what it meansõ*

*(Kay, line 220-226)*

*õ sometimes ^ou have to wait ages forõ tabletsõ when ^ou sa^ ^ou're in painõ the^ sa^ the^ 're gonna get tabletsõ the^ don't come back for agesõ and then I end up cr^ingõ because I'm in a lot of painõ (Kay, line 228-233)*

*õ what the^ used to do is sa^ õ in the morning was have a wash, get read^ õ but I was scared to ask um to help meõ so I just waited for m^ Mom to comeõ it was about how bus^ the^ areõ (Kay, line 278-281)*

# Quotations from Ted

*õ some said things what made sense but sometimes the^ said things which were not true or (did) not make senseõ I was not alwa^s aware what was happening (Ted Email 13.6.16 at 21:27)*

*õ in a room on m^ ownõ I had blood in m^ mouthõ but no-one came inõ it went on for 14 hoursõ ^eah ever^ person had a nurse after their operation... right but I was left for 14 hours õ 14 hours I didnq see an^ oneõ (Ted line 133-141)*

*õ He was the onl^ one who even thought, I will tr^ õ I might not be walking now if he didnq tr^ õ (Ted, line 123-125)*

# Quotations from Kelly

*õ I had 30 clips in m^ hipõ I was shouting, screaming and cr^ingõ I want m^ Mom and Dadõ the nurse did itõ*

(Kelly, line 266-269)

*õ lqñ 32õ and lqñ not a child, lqñ an adult (Kelly, line 291-293)*

*õ I used to facetime m^ Dadõ and m^ Momõ and m^ Sisterõ (Kelly, line 212-216)*

# Quotations from Len

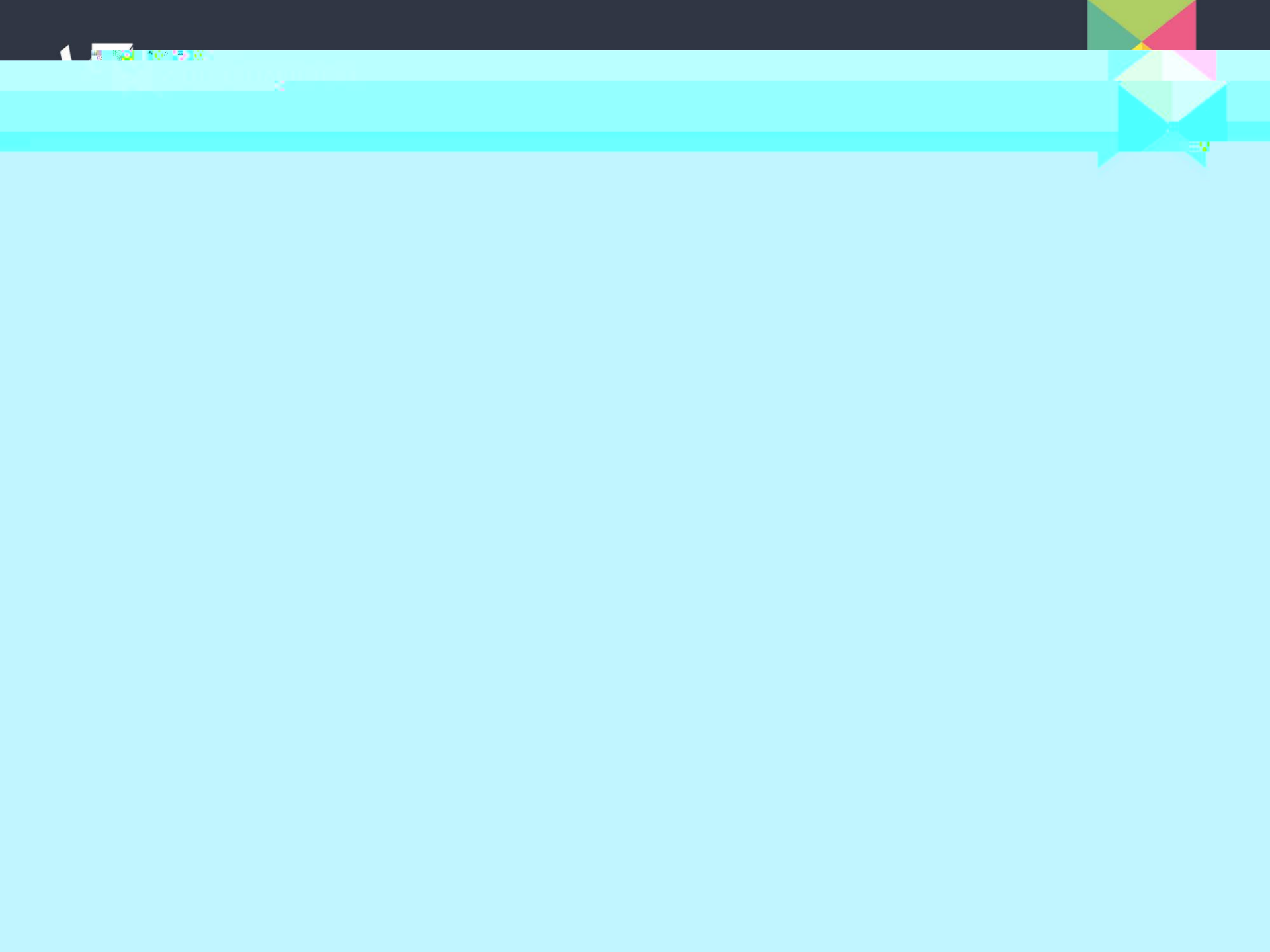
*õ horribleõ what was it likeõ absolutel^ horrible (Len, line 34)*

*...it was coldõ and not too much privac^ neitherõ nois^ (Len, line 90)*

*...it was reall^, reall^, nois^ õ .^ou know what hospitals are likeõ q(Len, line 200)*

*õ ermõ listen to what we sa^ õ more about our rightsõ that weqe disabledõ and understand (Len, line 180-186)*

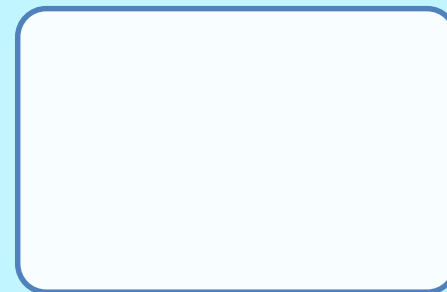
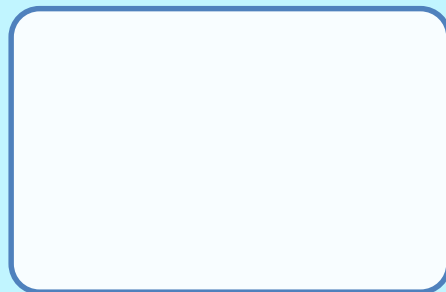
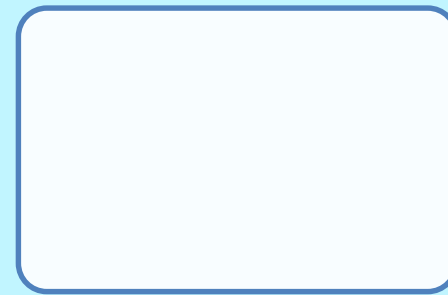
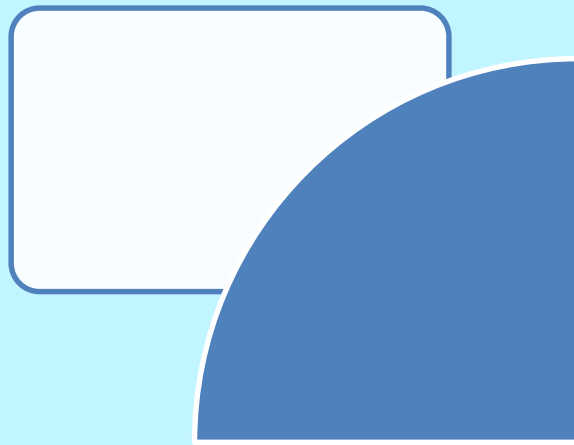




# Findings across the participants

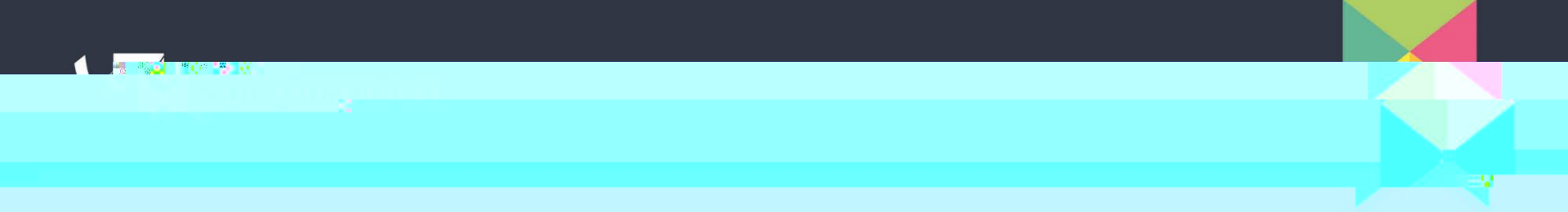
- Communication problems
- Lack of person-centred care
- Issues related to pain management
- Lack of confidence in hospital care
- The valuable support and expertise of carers
- Incompetence of hospital staff to make adjustments
- Isolation and loneliness

The themes derived from a cross case comparison situated within the domains of orthopaedic and trauma practice (RCN SOTN 2019)



# Conclusion

- The findings are confirmatory of other studies
- The majority of participant experiences were exceedingly poor
- The fundamental needs of PWID were not met
- Further empirical exploration of the reasons for these failings is required
- Addressing these issues might enhance the hospital experiences for PWID, their health outcomes and ultimately avoid premature deaths



# Tentative implications and recommendations

- Education and training
- Orthopaedic and trauma hospital practice
- Policy
- Further research

# Limitations and strengths of the study

- Novice researcher
- Small participant group to enable gathering of rich qualitative data and congruent with IPA
- Unique contribution to orthopaedic nursing knowledge
- Often a voiceless and overlooked group – this study begins to correct that oversight



# Acknowledgements

- Immense gratitude to the participants, carers and advocacy group managers
- Thank you to Dr Darren Chadwick & Professor Rebecca Jester and for their expertise, outstanding support and supervision
- Thank you for listening

# References

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