

Everyday life of an adult with a single ventricle

Jara Weinkauff, PhD student

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About me

Name: Jara Weinkauff

Age: 37 years old

Diagnosis: Tricuspid atresia

Fontan surgery: In 1990, at 4 years old



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What is the PhD about?

- Lived experience of adults with Fontan circulation
- Impact of Fontan circulation on everyday life
- Enabling adult Fontan patients to express their experiences in their own voice



Why does this PhD matter?

- Global Fontan population is growing
- Gap in the literature
- Gap in knowledge of lived experience of adults with Fontan circulation
- No sufficient knowledge to support holistic management of this new generation of patients



What have I done so far?



Literature review



PPIE focus group



Interviews



Key Findings

Living Carefully

- Lower energy levels
- Impact on everyday life
- Less spontaneity and carefreeness but planning ahead
- Longer recovery required

Uncertainty

- Unknown future pathway causes anxiety
- First generation to reach adulthood. No studies of comparable cases.
- Unknown life expectancy

Identity

- Standing out due to heart condition
- Problems fitting in
- Feeling isolated / lonely



What is the aim?

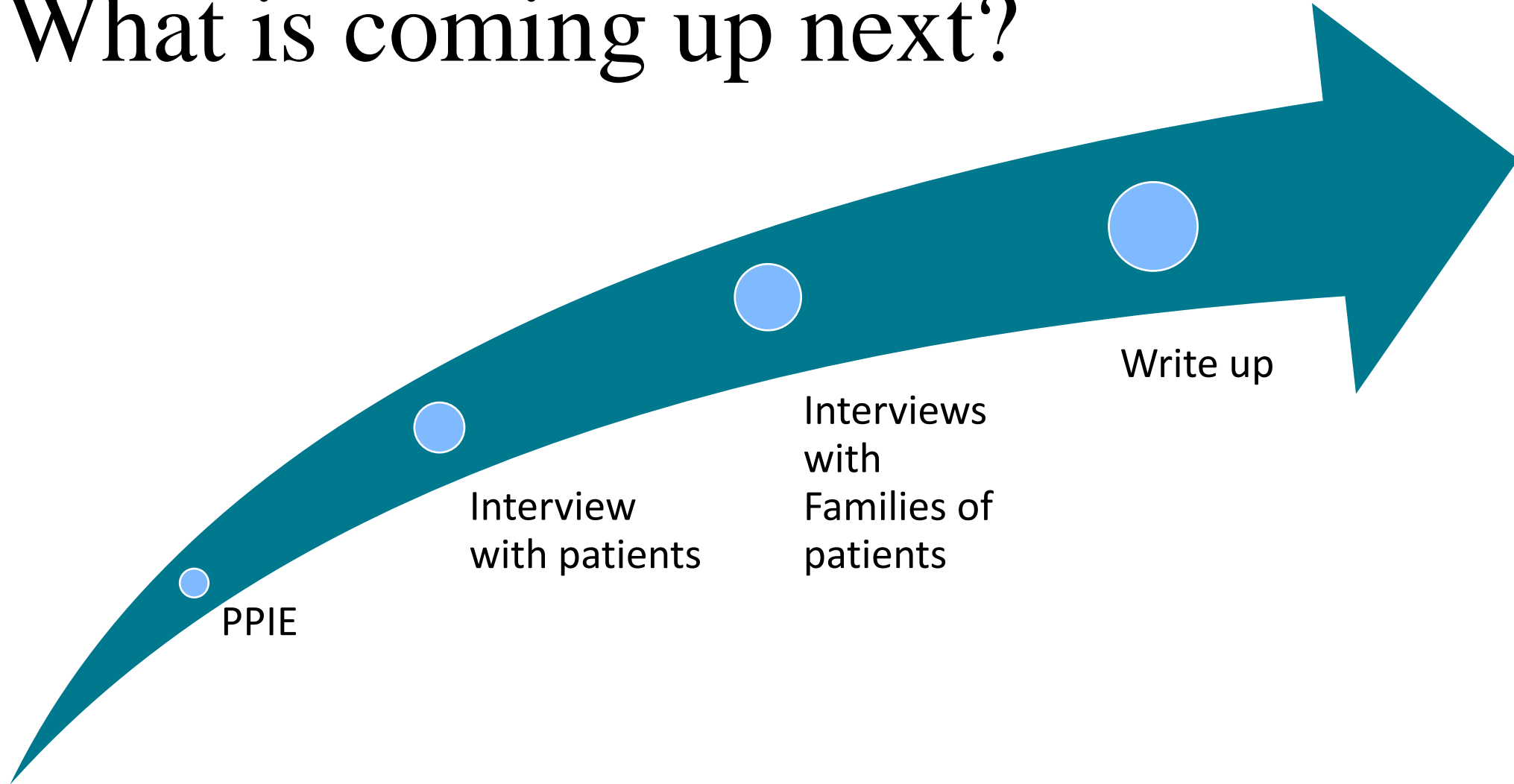
- Improve clinical and social care
- Inform clinical guidelines / adapt policy advice for Fontan patients
- Improve quality of life of adult Fontan patients
- Raise awareness



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What is coming up next?



Thank you

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