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# O02 It's time to talk about HIV – challenging stigma and reducing self-stigma

Katie Warburton

University of Central Lancashire



**IT'S TIME TO  
TALK ABOUT  
HIV:  
CHALLENGING  
STIGMA AND  
REDUCING  
SELF-STIGMA**

*Katie Warburton*

*PhD student*

*Senior Lecturer in CYP Nursing*

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## PLAN

- Introduce the SKETCH Study
- Explore specific data
- Discuss future practice



# NATIONAL DATA ON NAMING

| Age (years) | Number of children<br>(n) | Aware of diagnosis<br>(%) | Not aware of<br>diagnosis (%) |
|-------------|---------------------------|---------------------------|-------------------------------|
| 0–5         | 11                        | 0                         | 100                           |
| 6–10        | 52                        | 61                        | 39                            |
| 11–16       | 121                       | 86                        | 14                            |
| 17–18       | 98                        | 97                        | 3                             |

(Rowson, 2017)

# INTERNATIONAL PERSPECTIVE ON NAMING

BJN

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## Talking to children about their HIV diagnosis: a discussion rooted in different global perspectives

Katie Warburton, Lars Navér, Juliet Houghton and Kamila Fatikhova

# RATIONALE

## Barriers

Parental guilt, fear, stigma



## Advantages

Improved adherence, increase in self esteem, trust, reduced self-stigma, confidence in onward sharing, reduced parental depression





# THE SKETCH STUDY

- **S**taories we need to **K**now about the **E**xperiences of **T**elling **C**hildren about their **H**IV diagnosis Study
- An arts-based narrative inquiry into the stories of young people and parents who have experienced the process of being told or of telling a child their HIV diagnosis
- Participants invited to make a creative piece of their choice that tells their story
- Qualitative approach conducted in four focus groups. Benefits of social interaction and communication (Pope & May, 2006)
- Data has been analysed with a reflexive thematic analysis approach (Braun & Clarke, 2023)



# RECRUITMENT

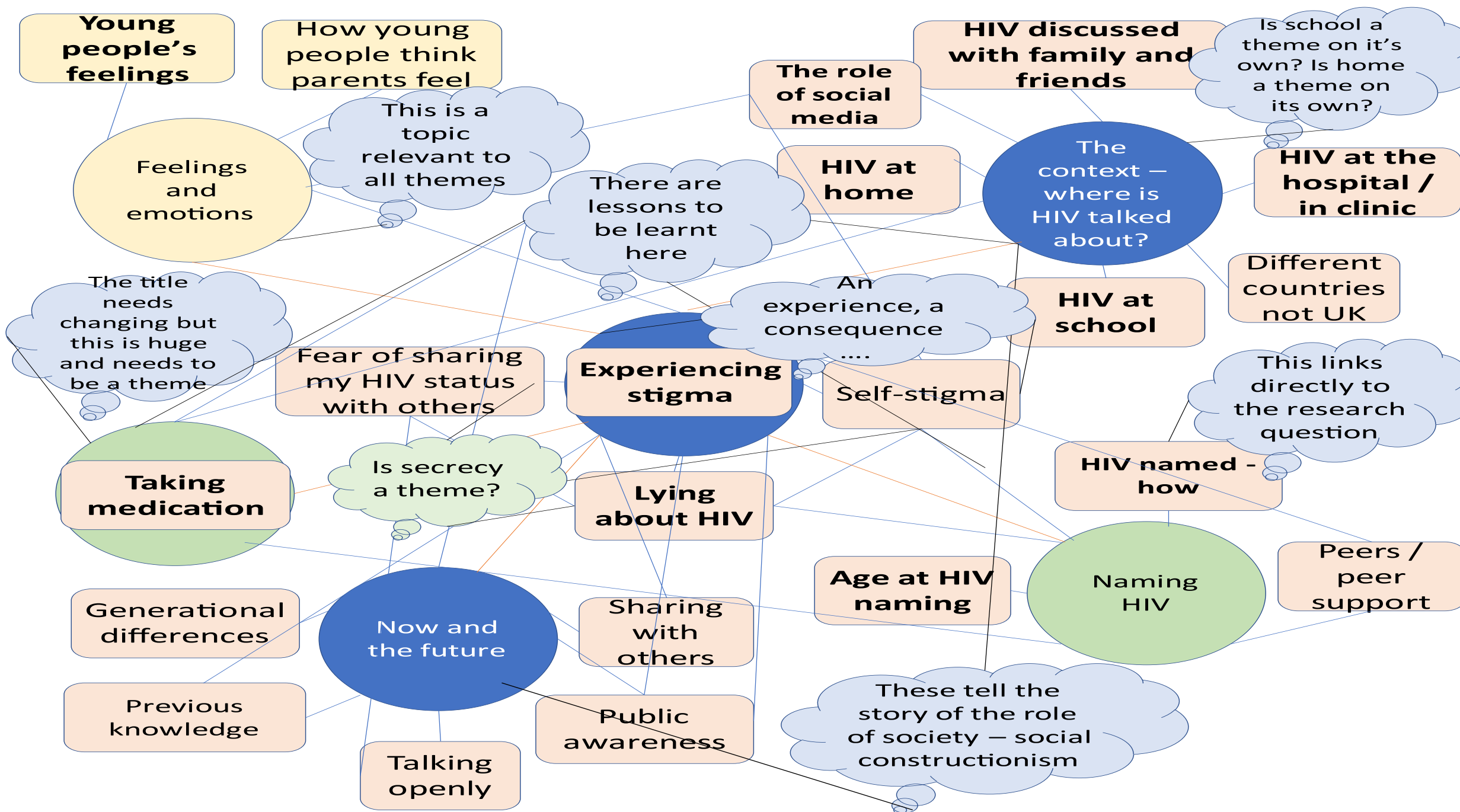
## Young People

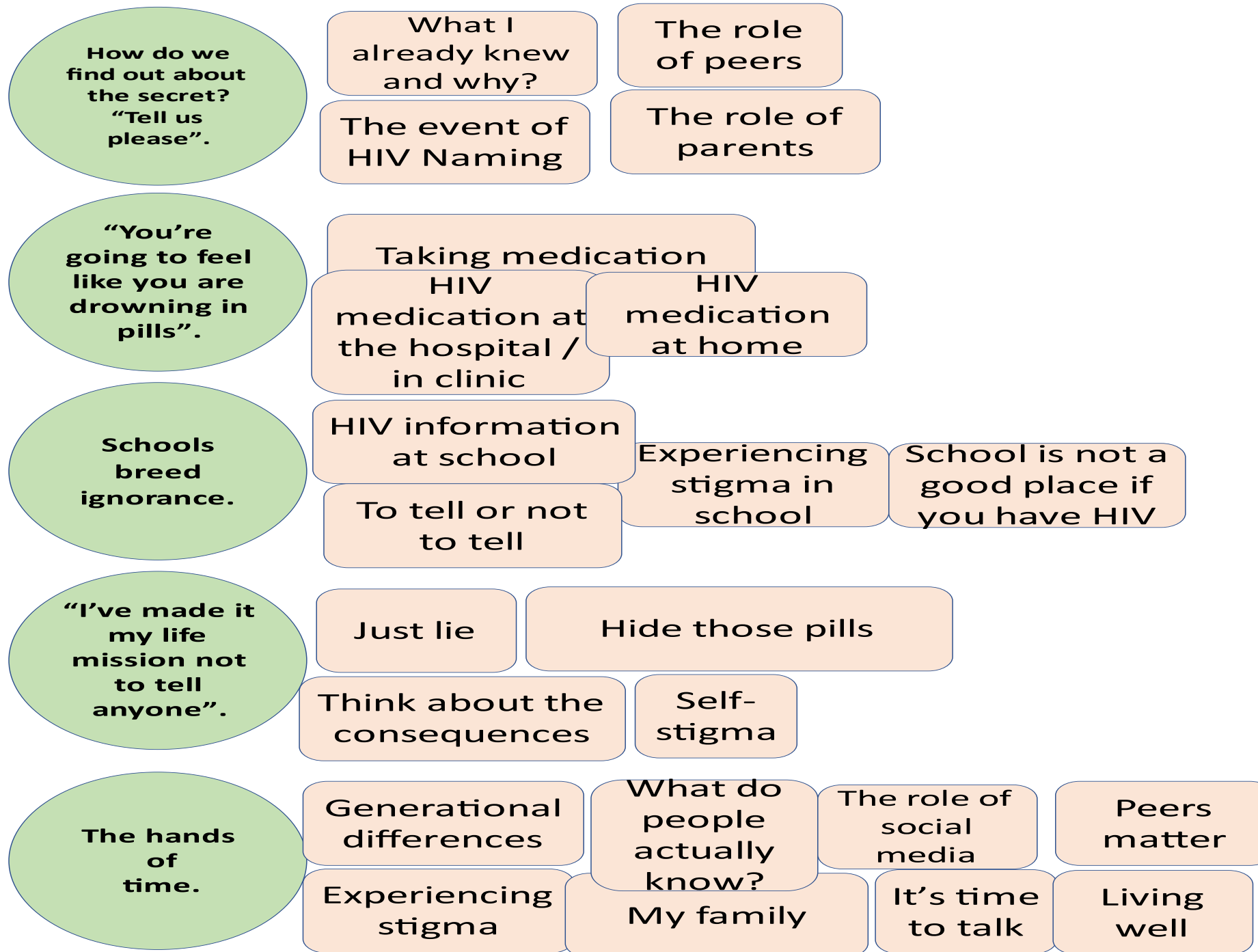
- Sixteen young people living with perinatally acquired HIV
- Age 15 – 21 years
- 11 young people born in the UK (69%)
- Young people from Scotland, Ireland, England (North-West, North-East, Midlands, South-West, South-East, London)
- HIV named: 8-13 years of age

## Parents

- Ten parents living with HIV whose child is HIV positive and aware were recruited
- 2 born in the UK (80%)
- Parents recruited from across England and Scotland

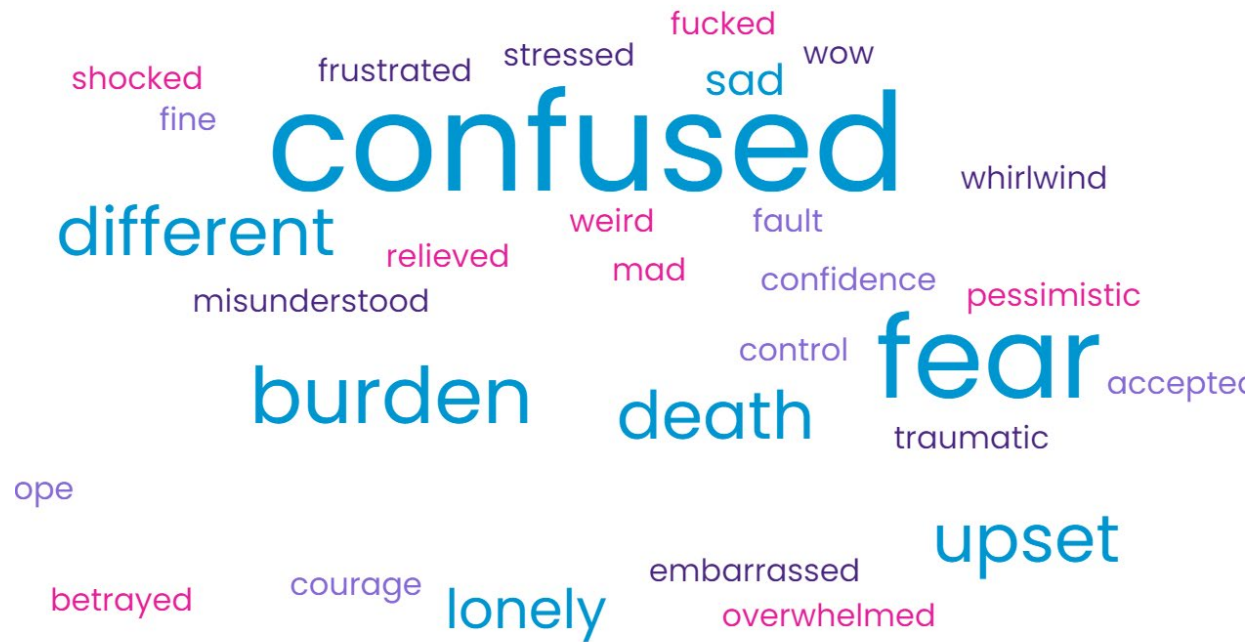
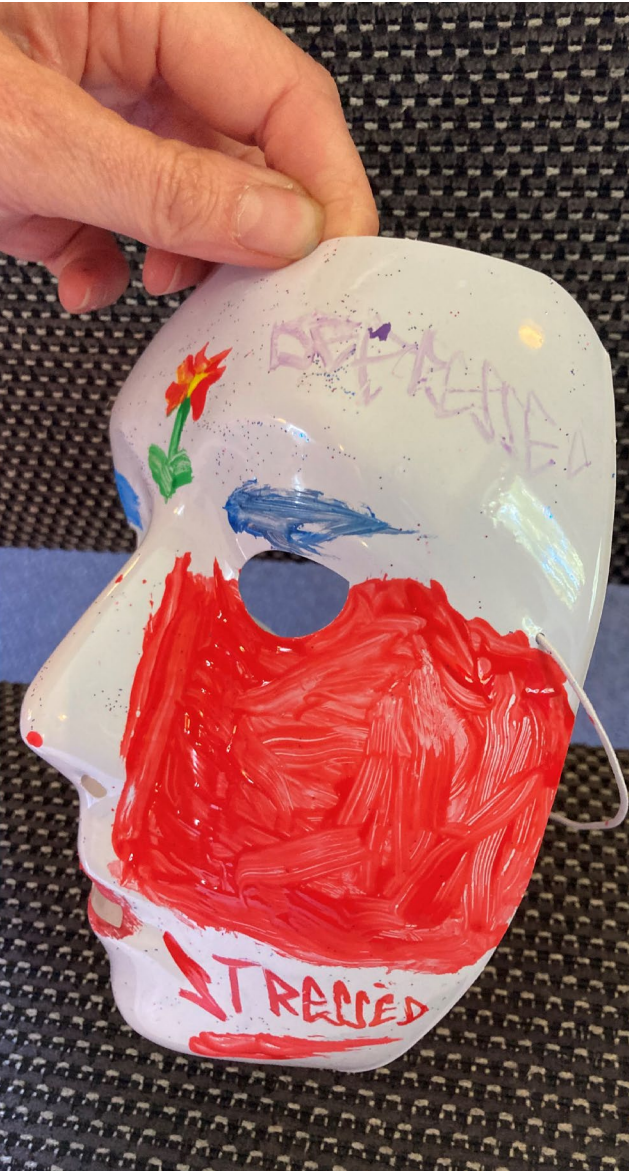




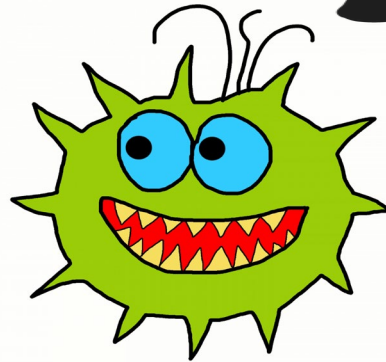




“I just feel alone .... I’m just alone”



# WORD CHOICE



## **“NOT AT HOME, NOT A CONVERSATION IN MY HOUSE”**

- “my mum was like close the door close the door make sure they’re all in their room lock the door I don’t want anyone else to hear this so I thought it was something bad .... it was that deep that no one could hear it”
- “sometimes I wouldn’t take my meds and um I also had denial because my father would not believe I had it”
- “she’d just rip it up, put it in its own bag then put it in the bin”
- “we used to hide them in my room and then like in a drawer and then lock it”







## SELF-STIGMA AND MEDS

- The need to hide HIV and HIV medicines adds to negativity and self-stigma
- “if I don’t take it I sometimes I used to think like **maybe I don’t have it lets just not take it**”
- “that’s when like sleepovers then became a thing and then it was harder for me at first cos it was like I have to take medicine and my mum would be like oh **you can’t go you can't go but I’d have to be like having to hide the fact that I take this medication which was kinda hard**”

going to feel like you are drowning  
in pills.



# MEDS SCARING DOESN'T WORK

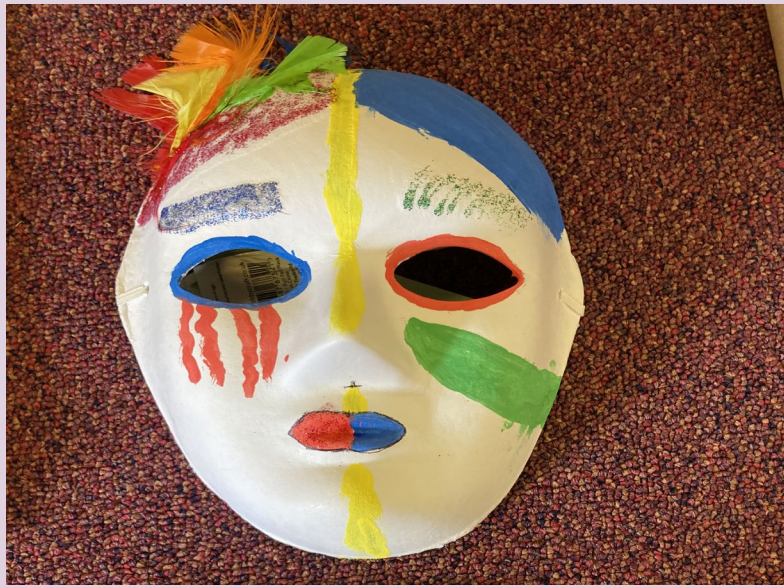
- “fear should not be linked to it anymore like you shouldn't want to take your medication cos you're scared of dying cos you should take it because you want to cos like you wanna be healthy because I feel like when someone tells someone they don't wanna take their medication the first thing they try to do is to scare them in to taking it and I think that makes it worse”
- “it's frustrating because I want them to understand and feel the same with how I feel that but I guess their never going to”
- “they basically said, if you don't take medication you're gonna die. That's just like, that's a lot for a ten year old, do ya know what I mean”
- **“it's just like death death death and it needs to stop”**
- “the pressure of like doctors being judgemental with you and I feel like cos at one point I stopped taking mine for like a year and I was getting problems a bit ill but like I wasn't seeing it myself and I was going to my appointments the doctors were like its very easy to take medication like its just one pill a day its not as easy as you think it is like doctors cant relate to what you feel and how your day to day life is with HIV”
- “re-educate people yeah to like there's no scaring people in to taking medicines it's not what we do”

“JUST LIE”

## SELF-STIGMA

- “it’s like a constant lie that even you have to believe kind a thing, its not, yeah **it’s a secret but like it’s a secret you never tell**”
- “**vain of my life literally, you can’t tell**”
- “I made it sort of like my subconscious **life mission to make sure nobody finds out**”
- “I don’t know just like different un not in a positive way it’s like a different to the fact that like **no one can understand me**”
- “its uh **deep dark secret that you must keep** and like not tell and it like it can kind a make you feel lonely in a way because me personally I hate telling like keeping secrets I’d rather be truthful to everyone”





worried

denial

guilty

shocked

ashamed scared

fear

hard

bad

worry

“if your feeling guilty  
that’s gonna make me feel  
like its something even  
worse than it actually is  
and I just want like you to  
just act like its normal cos  
it is normal and you’ve got  
good medication now”



My Dearest Sunshine,

From the first day I held you in my arms I knew you were a blessing and I loved you even before you were born.

Knowing about your diagnosis when you were just under 2 years broke my heart. I have grieved that and was full of worry of losing you when you had drug interaction.

You were told about the sleeping bug and why it is important to take your meds. Telling you about your diagnosis and using the words HIV with you when you were 10 was the best thing I did. I must admit though that the build up to that was one of the scariest moments of my life. Since then HIV never became a secret in our home.

well and good  
I love you so much and if I can turn back the hands of time, there is just a little that I would do differently.

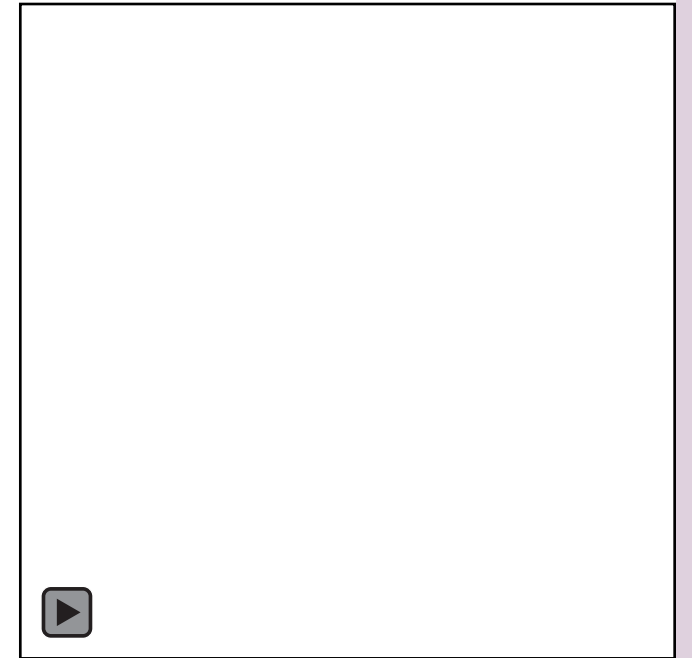
Love

Mum.

“WE CARRY  
AN  
UNBEARABLE  
LOAD UNTIL  
THEY KNOW”

# SO HERE WE ARE

- Health information is purposely withheld from children and young people living with HIV.
- Parents fear the process of telling their child or the child being told but feel relieved when they know.
- As health care professionals we need to take responsibility and accountability for this process and the effect it is having on people's lives.
- It is time to break the cycle.





# LESSONS LEARNT

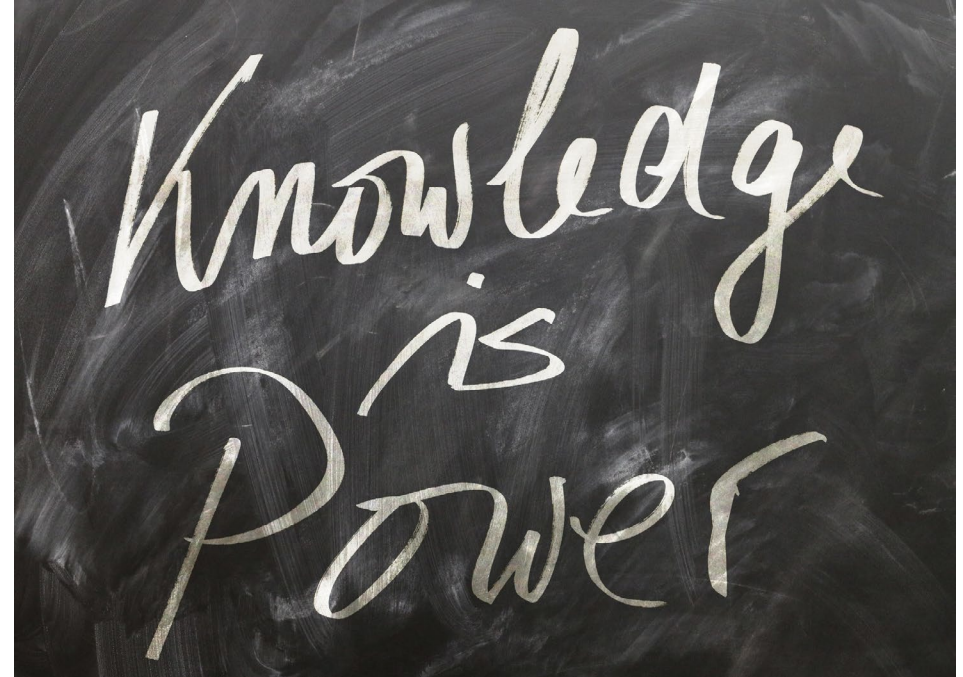
- Stigma is affecting daily life . The naming process creates social isolation and exacerbates self-stigma
- Think carefully about medicines discussions
- How adults are told about their HIV diagnosis affects talking to children and talking at home
- Young people want to know about their HIV diagnosis at a younger age. Most prefer to be told at home **“to be honest, to tell you the truth, I don’t, I don’t care who tells right”**



# NATIONAL POLICY

- Open communication
- Clear and consistent language / word choice
- Support for parents
- Resources for professionals, children and parents to enable confident discussions





STOP THE STIGMA





Thank you to all  
the children, young  
people and parents  
who participated  
and shared their  
experiences

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