



nhivna

NATIONAL HIV NURSES ASSOCIATION
support | research | education

21st Annual Conference *of the* National HIV Nurses Association (NHIVNA)

27–28 June 2019 · Manchester Conference Centre

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Supporting Young People

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Health Lead – CHIVA

Senior Lecturer in Children's Nursing – UCLan

Clinical Nurse Specialist

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Declaration of interests relating to this presentation

No conflicts of interest

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Plan

- Review the cohort of young people in HIV care
- Highlight the challenges young people experience
- Consider the support required
- Question how we can do better



Audio One – Jane

**“My dad didn’t accept me
so tell me why I should
accept me?”**

Emptiness

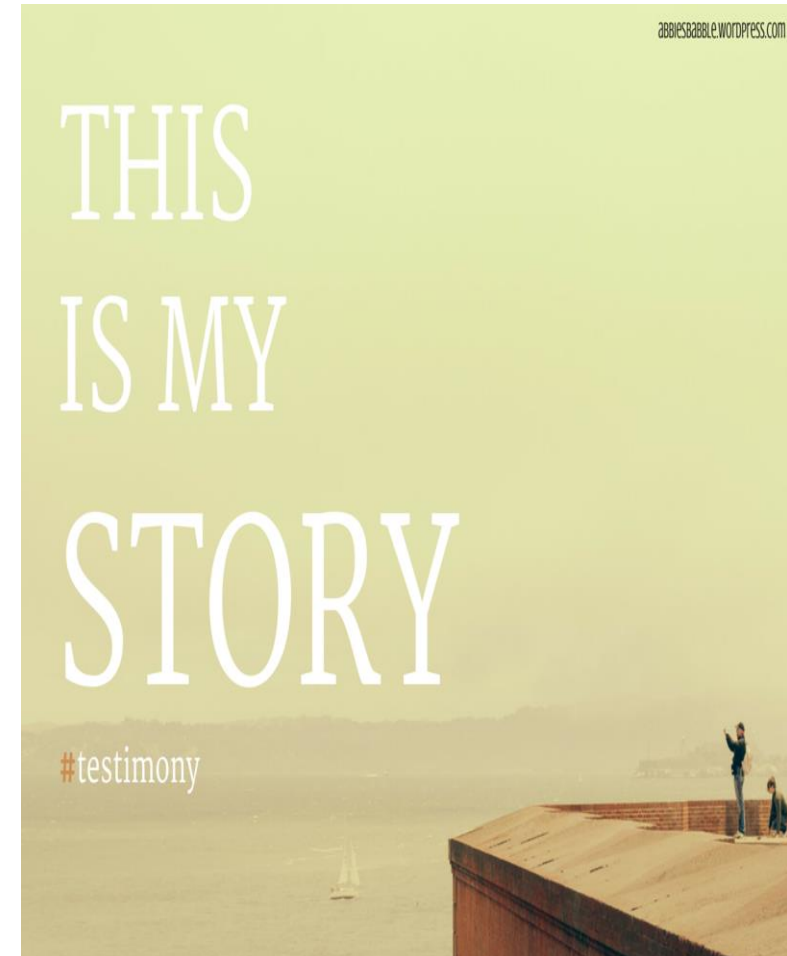
Unwanted

Controlled

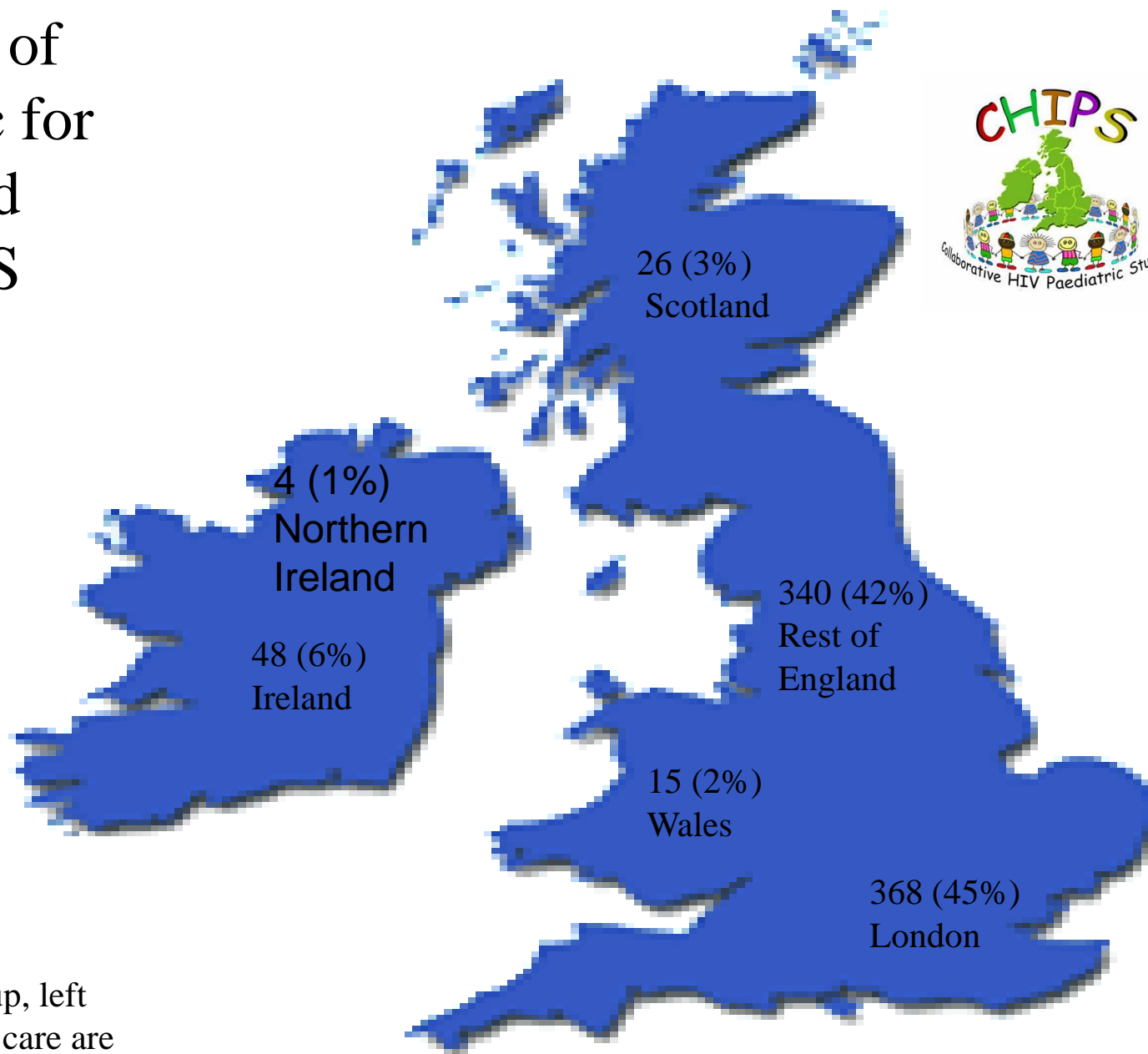
Anxiety

Defeated

Pain



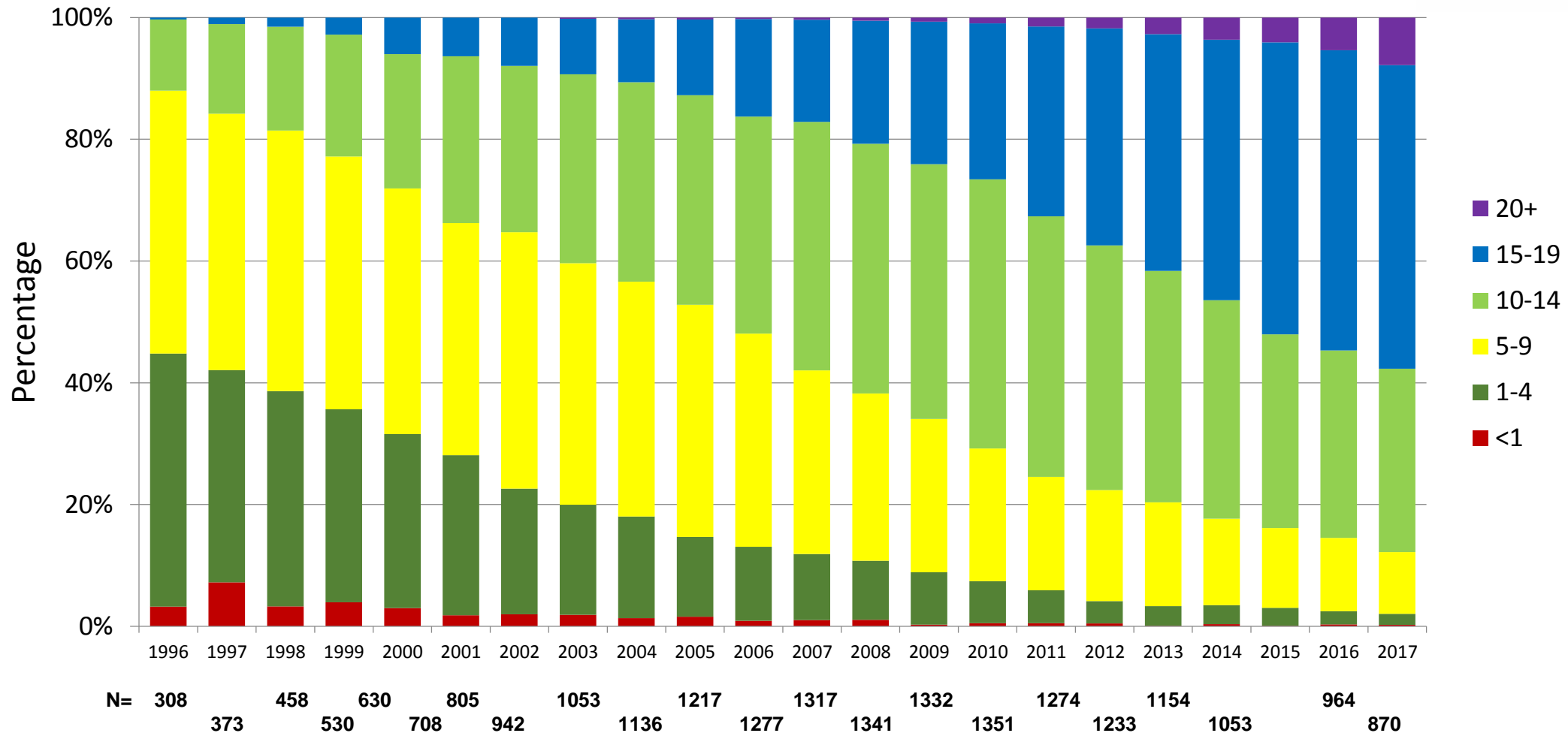
Regional distribution of main follow-up clinic for 801 children alive and followed up in CHIPS (2018 data)



Children who have died, lost to follow-up, left the UK & Ireland or transferred to adult care are excluded

Children and Young People in Paediatric Care in the UK

National Study of HIV in
NSHPC
Pregnancy and Childhood



Growing up

- World Health Organisation definition:
Young people =10-24 years
- United Nations definition:
Youth = 15-24 years
- Different needs:
 - Medically
 - Socially
 - Physically
 - Emotionally
- More support than any other group?



Moving to Adult Services

- “Transition is the purposeful, planned movement of adolescents & young adult with chronic, physical, medical conditions from child centred to adult orientated health care systems” (Blum et al 1993).
- “Transition of care from paediatric to adult setting is not specific to HIV.....However, there are important differences for young people living with HIV which may make this process more difficult” (Lyall 2007).



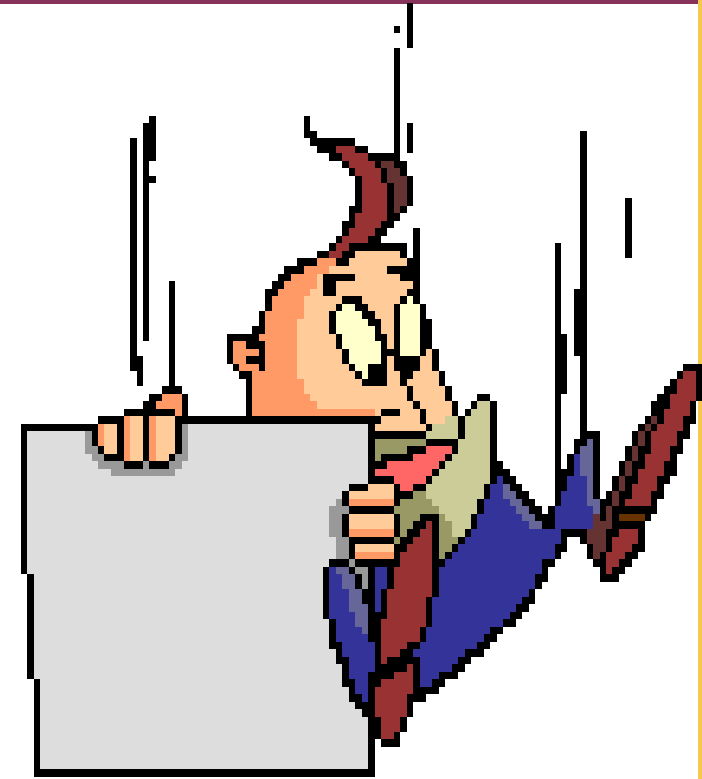
Along comes

- Complex drug resistance at 18 years of age
- Non-adherence
- Cognitive impairment
- Complex health needs
- Never said HIV
- Never told anyone about my HIV
- Never had sex
- DNA appts
- They don't know me so I could disappear
- Exams are more important



When it goes wrong

- Lost to follow up
- Increased morbidity
- Increased mortality
- Treatment failure
- Drug resistance



- Why – need more support, too much change, financial pressures, cognitive impairment, risk taking, want to be “normal”

What do young people tell us they want from clinic services (CHIVA Youth Committee):

- Know what you're talking about
- Talk to me, not my parent/carer
- Private conversations about me make me feel anxious, involve me
- Take the time to give me medicine choices and explain the side effects
- Treat me my age
- Don't make assumptions
- Show an interest in my life
- HIV doesn't define me; I'll always be me first
- HIV does not stop me achieving my ambitions
- Confidentiality is really important to me; my health isn't something to gossip about
- HIV affects my mental health as well as my physical health
- Stigma hurts

What if the Hoki-koki really is what it's all about?



Challenges

- HIV can be a small part of life but The issues highlighted are:
 - Stigma
 - Fear
 - Mental Health
 - Side Effects
 - Adherence
 - U=U
 - Relationships
 - Feeling secure
 - Rights
 - Friends
 - Acceptance
 - New family through peer support



Consultation with young people 2019

- Things that are good in my clinic:
 - I'm treated like an adult
 - I can make and change my own appointments
 - I see the same Doctor
 - Less reviews = less blood tests
 - When someone asks if there are any other issues
 - I can contact someone if I need to
 - Shorter clinic visits



Consultation with young people 2019

- Things that need to stop:

- People coming in and out of the room during my appointment
- Too many people in the room sometimes
- If I'm seen in GU medicine I can see a different Doctor every time and have to repeat the same information; they don't know me
- Lack of a rapport; remember what I do in my life outside of HIV
- Not being told my appointment had been cancelled
- Going to a sexual health clinic when I first transitioned was really hard, I'd never even had sex



Consultation with young people 2019

- Things that could make clinic better:
 - I would like better info and choices on medicines and side effects
 - More information around – leaflets in the clinic room, posters on the walls so I can look at them in the waiting room on topics like “my rights”
 - I don’t know what all the blood tests are for – more information needed
 - Show a general interest in my life and what else is happening, it’s bigger than HIV
 - It would be good to come to the same clinics (dates) as people I know so we can see each other
 - We need support groups



What now?

- Do you know that all young adults referred to your service from paediatric care are still in active follow up?
- Do you routinely ask about what else is going on in life?
- Can young adults see the same practitioner at appointments?
- Is the clinic environment youth friendly?
- Are there any tips from young people you can implement in your clinic?



Audio Two – Ben

I have to be me

It isn't easy

Scared

**Can I be
myself?**

I am worthy

**Would you
deal with
this with a
knife?**

**self care – a
nightmare**

