

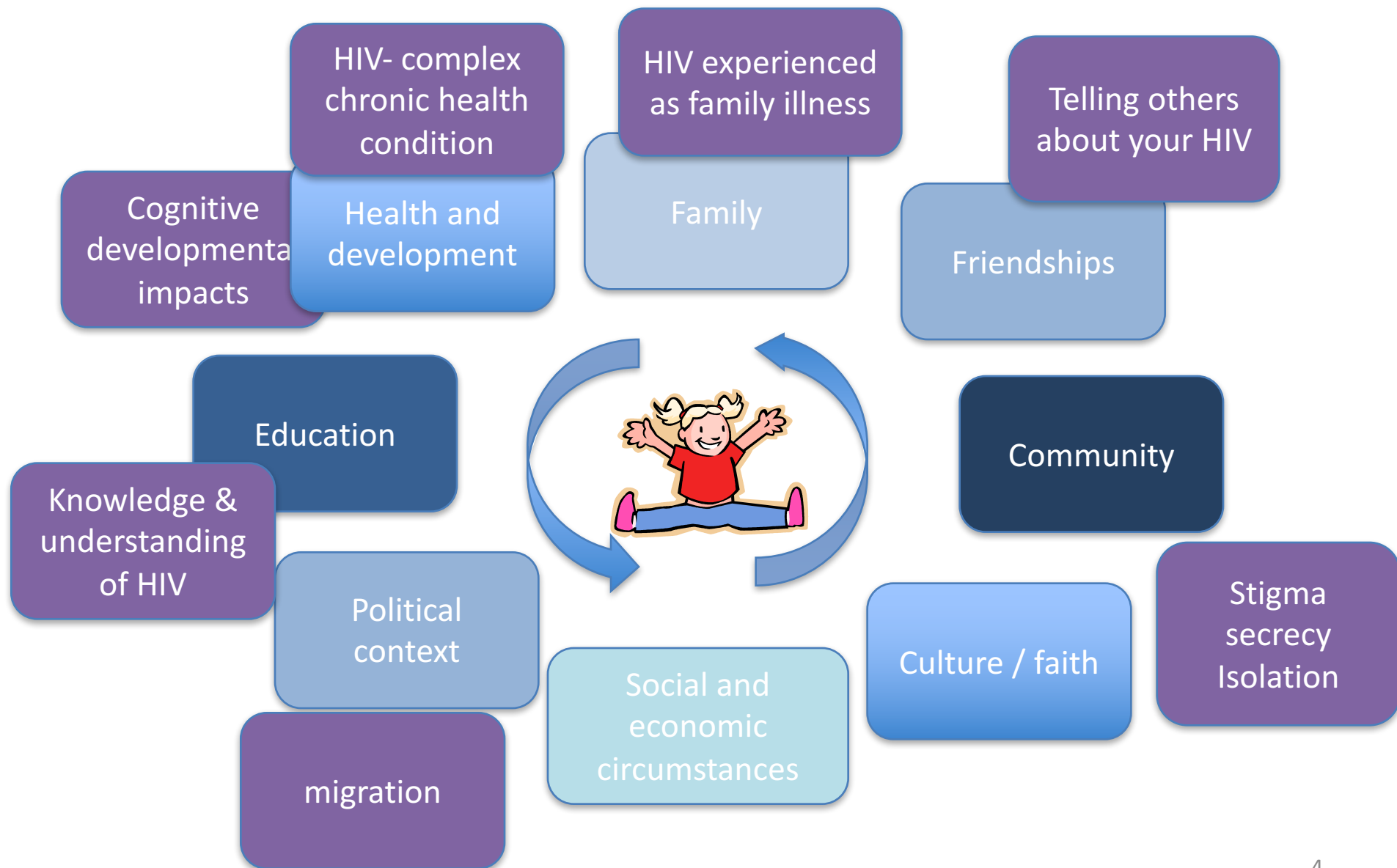
Transition is defined as “*a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult orientated health care systems*”
(UK Department of Health 2004)

- CHIVA Guidance on transition say should begin around the age of 11
- Process not event
- Can feel like a ‘loss’, but also a ‘new opportunity’

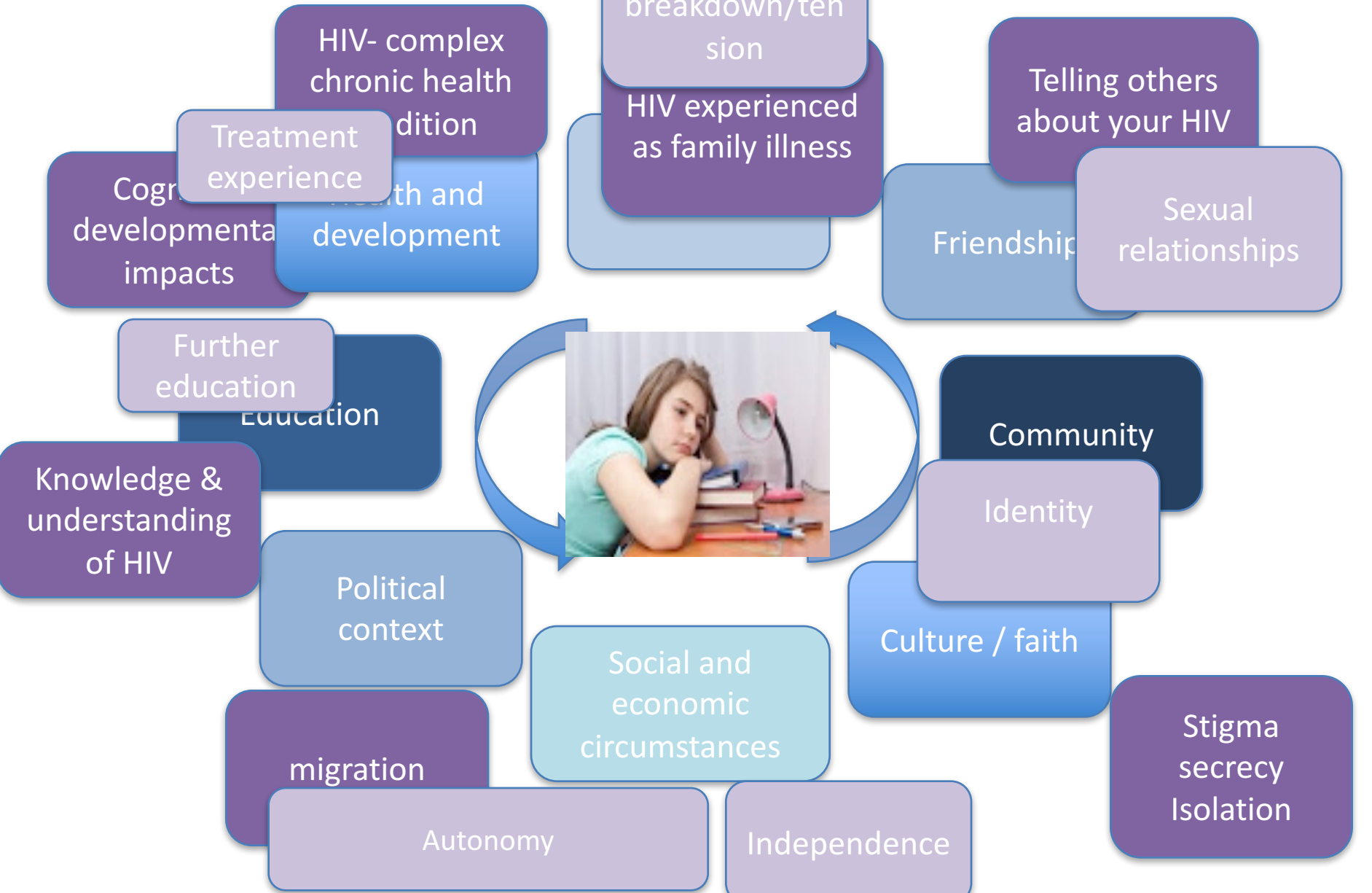
Transfer is the physical event of the young person moving from paediatric to adult services and if unsupported by the **process of transition** has been associated with increased morbidity and mortality in other chronic diseases of childhood”

(Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol* 2000; 14(6): 469-72.)

Child-centred practice



So what's happening in adolescence?" We are no longer children, but are we an adult right?"



HIV & Stigma

**Intended
Stigma
(Experienced)**

Unintended Stigma



**Intended Stigma
(perceived)**

CHIVA Guidance on transition for adolescents with HIV

(Foster, C 2010)

Family Clinic	Adolescent Clinic	Specialist services work together
Can offer opportunity for adult services to be integrated into the family service so adolescents begin to be seen on their own	Separate 'youth clinic' created tailor made specialist clinic only for adolescents with HIV. Transition to adult services needed at a future point	Without a family or adolescent clinic planning a careful and comprehensive transition still possible. Requires good collaboration and flexibility to meet individual needs of adolescents

Transition in practice: the simplest way

Done as a 'Team'

Step One: Talk about it, make a plan

Step Two: Visit the adult clinic, meet the staff

Step Three: Supported appointment (s) and shared care between paediatrician and adult doctor

Step Four: Support to get to clinic, appointment with adult doctor

Step Five: A call to see how the YP is managing at the adult clinic

‘Your Life’ transition project

National Children’s Bureau project:

- Looked at broader challenges in late adolescents
- Produced ‘Your Life’ leaflets 13-25 year olds covering growing up, work, careers, education, rights and talking to others.

<http://www.chiva.org.uk/resources/young-people-information/>



SHARING IN LIFE
2

So you are HIV positive and are thinking about telling a friend, sexual partner or family member that you have HIV?

WHAT MIGHT YOU NEED TO THINK ABOUT?

Why might I want to tell someone in my life that I have HIV and what things do I need to be prepared for?

Page 3

What about my family?

Page 4

How can I plan to tell someone and what might happen after I tell?

Page 5-6

I want to tell my sexual partner – when might I do it?

Page 9

What if the condom came off or broke, or we didn't use one?

page 10

What does the law say about sex for people with HIV?

page 11

This leaflet is a starting point to answering these questions, and will direct you to support and further information. Download other leaflets on life for young adults with HIV from NCB.org.uk/LifeLinks or get them from clinics or support services.

Want to hear from other young people with HIV? Look out for the yellow boxes.

NCB.org.uk/LifeLinks

INDEPENDENT LIFE

LEAVING HOME AND STANDING ON YOUR OWN TWO FEET:

A GUIDE FOR PEOPLE WITH HIV IN THEIR TEENS AND EARLY ADULthood

NCB.org.uk/LifeLinks

STUDENT LIFE

GOING TO UNIVERSITY OR COLLEGE:

A GUIDE FOR PEOPLE WITH HIV IN THEIR TEENS AND EARLY ADULthood

NCB.org.uk/LifeLinks

STARTING IN LIFE 2

So you're thinking about leaving home to live independently, or have already left, and you have HIV?

WHAT MIGHT YOU NEED TO KNOW?

Do I have to change my hospital or GP if I move to another area?	page 3
How can I find somewhere to live?	page 4
How can I cope with sharing accommodation and being independent?	page 5
How might HIV affect getting a job and working?	page 7
Where can I find work opportunities?	page 8
What kind of welfare benefits might I be able to get?	page 8
Who might I want to tell about my HIV, and how can I do this?	pages 5 + 7

This leaflet is a starting point to answering these questions, and will direct you to support and further information. Download other leaflets on life for young adults with HIV from NCB.org.uk/LifeLinks or get them from clinics or support services.

Want to hear from other young people with HIV? Look out for the yellow boxes.

STUDENT LIFE 2

So you're thinking of going to university or college and you have HIV? Great. Lots of young people with HIV have done this.

WHAT MIGHT YOU NEED TO KNOW?

Do I tell my uni or college I have HIV?	page 3
What will it feel like living away from home?	page 5
Do I have to change my hospital if I move to a different area?	page 7
How can I remember to take my meds?	page 8
What support and money can I get while I study?	page 9
Do I need to tell sexual partners I have HIV?	page 10
Does HIV affect what or where I can study?	page 11

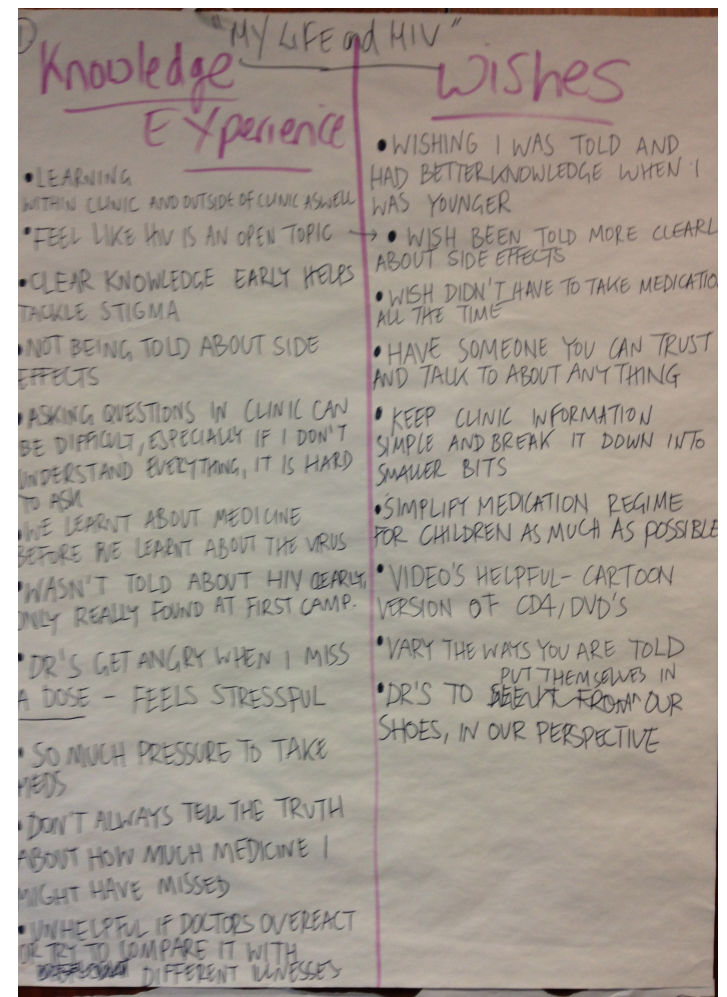
This leaflet is a starting point to answering these questions, and will direct you to support and further information. Download other leaflets on life for young adults with HIV from NCB.org.uk/LifeLinks or get them from clinics or support services.

Want to hear from a young person with HIV who is at uni? Look out for the yellow boxes.

Treat Me Like This

CHIVA Youth Guidelines Group Project 2015

- How they wanted to receive information on sexual health and how these conversations are held in clinic.
- Information and support on medication adherence, and transition



Personal and medical information needs to make sense to the YP- understanding it is very difficult. Needs repeating, given in small chunks and using different resources.

“It’s not just taking a pill” – empathy around adherence issues is critical

Avoid pressure, threats, and creating stress

Open conversations about HIV really matter, and when children are younger this is easier and helps to tackle stigma. The scientific information can come later.

To feel able to talk openly there needs to be trust established- changes in relationships with professionals is really difficult.

Top worries were “I will die young” “I will pass HIV onto my children,” and “Having to tell other people that I have HIV”



KEY THEMES

Guidance for Clinics on Transition

Amanda Ely: July 2015.

This guidance on transition was provided by young people living with HIV as part of the "Treat me like this" Youth Guidelines Group Project.

Young People described the positive aspects of their experience of attending paediatric clinics, which included:

- Being able to access clear information on medicine
- Friendly staff /seeing familiar faces each time
- Being rewarded for taking medicine
- Staff being protective over your health, feeling looked after
- Having extra time in appointments
- Working with you and your parents
- Booking your appointments for you
- Understanding your problems and being able to give advice
- Being in colourful and inviting environment

Those who had transferred to adult clinics described some key differences:

- You are expected to be more independent
- The clinic is less noisy and calmer
- It is less fun!
- There is no food!
- More people your age
- It can feel uncomfortable and awkward
- Doctors rely on you to look after yourself –the responsibility for your health changes
- You have less appointments, the advice is different, you can be seeing different doctors
- Rooms are not colourful
- It is more 'medical'

Young people have come up with some ideas on how clinics can support the transition of a young person from paediatric to adult clinic.

- People should be asked first if they feel they are ready to move on to adult clinic
- Try to ensure a parent or carer attends the first appointment with the young person in the adult clinic
- Try to keep support from the children's doctor going for a while
- Transferring to adult clinic with a friend, where possible, can be helpful. It may be possible to make a peer link who can attend appointments with the young person.

- Have a leaflet for the young person which is a guide to the changes which will take place when they move clinics

- Doctors need to be friendly to new people, have someone talk to people who have just transferred to adult clinic

- Offer young people a transition letter including a treatment chart which identifies the medicine they have taken, so they can take this to the adult clinic with them.

- Adult clinics should continue to offer topical anaesthetics before taking blood.

Transition:

http://chiva.org.uk/files/1014/5079/3341/Guidance_for_Clinics_on_Transition.pdf

Sexual health:

http://chiva.org.uk/files/7414/5207/6372/Guidance_for_Clinics_on_Conversations_about_Sexual_Health.pdf

What Young People say is *unhelpful* at clinic

- *When my doctor gets angry with me if I miss a dose – it is really stressful, telling me I am going to die.....*
- *I will lie a bit about how many doses I have missed. I have had to because I feel under pressure from my doctor.*
- *They need to put themselves in my shoes*
- *They don't really appreciate how difficult it is to take medicine every single day.*
- *When I take my tablets it's the only time I really think about HIV*
- *When my doctor asks me if I have any questions I always say “no” even though I have loads.*

UK YPLHIV

Check list for clinic consultations:

This checklist was suggested by young people who took part in the CHIVA Treat Me Like This patient engagement project. To be used in clinic consultations to ensure that patients are able to decide what happens in their consultation.

HIV Knowledge and Understanding:

What does viral load mean

What does CD4 count mean

How HIV is passed from one person to another

How do children like me get HIV

How HIV affects other people in my family

How does my immune system work

Yes	No

Medicine:

How do HIV medicines work

What does resistance to HIV medicine mean

Side effects from medicine

Changing the time I have to take my medicine

Tips to help me with taking my medicine

I'm finding taking medicine really difficult at the moment

Friendship and relationships:

How to tell a friend or partner about my HIV

Having safer sex

How to use condoms

Whether I have to tell someone I'm having sex with about my HIV

HIV transmission in different sexual activities

STI's

How to have a baby without passing on HIV to the baby

Having a sexual relationship with someone else who has HIV

Yes	No

Emotional and Social well being:

Feeling low and worried

Finding it difficult to be motivated

Feeling angry and upset about having HIV

Wanting to harm myself

Feeling worried about my future with HIV

How to meet other young people with HIV

Struggling with my school or college

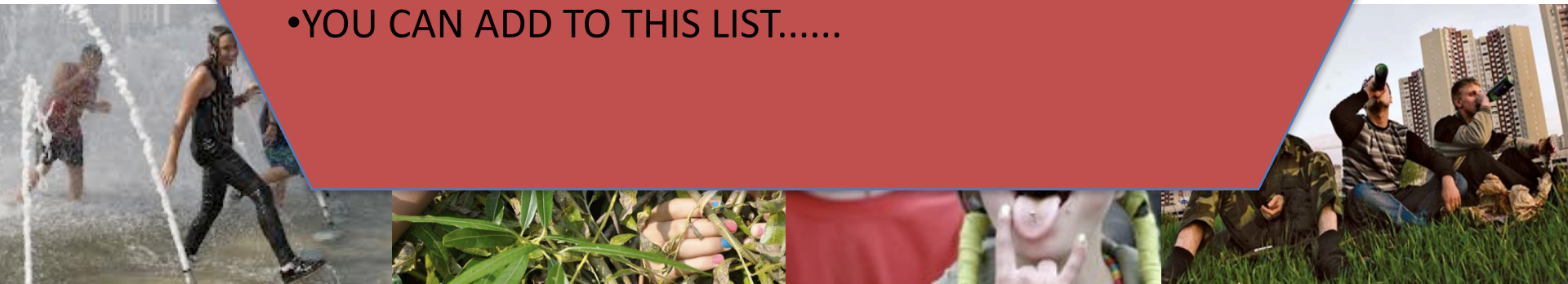
Unhappy at home

Not feeling safe

What

?

- **REALITY CHECK:**
What stops young people-centred healthcare provision where you come from?
 - Countries have varied ages in which a young person can consent to, or access, medical treatment without parental consent.
 - In small cohorts, rural setting, resource poor setting, it may not be possible to have adolescent clinics and one-stop shop services.
 - In some cultures, it may not be seen as acceptable for under 18 year olds to access care independently.
 - YOU CAN ADD TO THIS LIST.....



HOW CAN THIS CHANGE?

Produce a '**national charter for YPLHIV**' with simple, achievable, rights-based requests and ask key health care providers and politicians to endorse this

Produce simple outlines of **making a clinic YP friendly**.

Example: If there's no youth clinic, have one day a month which is mainly the youth clinic day. On that day, put up some 'youth' posters.

Transition: **gather experiences**, including those who moved to adult services and were lost to follow up, stopped ART. Written up, recorded. This is evidence and given to people who can influence changes in healthcare.

Lobby for law change on the age of **consent to treatment**. Work with key national children's organisations – this is not just an HIV issue, but a sexual health and human/children's rights issue.

CULTURES DO CHANGE





Thank you!

Amanda Ely

Amanda.ely@chiva.org.uk

www.chiva.org.uk

