

MAKING HIV UNDERSTANDABLE

TALKING TO CHILDREN & YOUNG PEOPLE ABOUT THEIR HIV

MAGDA CONWAY

WHAT I WILL COVER

- Consider why we have a process of disclosing to children
- International and national practice on naming HIV
- General communication with children and young people
- Talking to children born with HIV about their diagnosis
- Talking to young people who acquired HIV in adolescents about their diagnosis

QUESTION ONE

Socially due to stigma and
discrimination

IS HIV 'DIFFERENT' FROM OTHER HEALTH CONDITIONS?

In medical terms, HIV is a
chronic health condition

WHY DO WE HAVE A 'DISCLOSURE PROCESS' FOR CHILDREN BORN WITH HIV?

HISTORICAL?

STIGMA?

Telling Your Child About Cancer: Age-Appropriate Advice

Your child's age will play a key role in how much she understands about your illness — and how she might react to the news.

It will be helpful for you to think about your child's age when considering things like:

- How much your child can understand about cancer
- How your child might react to the news
- What you can do or say to help your child

Keep in mind that every child will react in her own way — that's true at every age.

▼ Expand All Sections

▶ Collapse All Sections

▶  Babies and Toddlers (Ages 0 to 2 Years)

▶  Preschool and Kindergarten (Ages 3 to 5 Years)

▶  Elementary and Middle School (Ages 6 to 12 Years)

▶  Teenagers (Ages 13 to 18 Years)

▼ Expand All Sections

▶ Collapse All Sections

UN CONVENTION ON THE RIGHTS OF A CHILD (UNCRC): ARTICLE 12

The right to express your views and be heard

States Parties shall assure to the child who is capable of forming his or her own views **the right to express those views freely in all matters affecting the child**, the views of the child being given due weight in accordance with the age and maturity of the child.

INTERNATIONAL GUIDANCE: NAMING HIV

In 2011, after 3 years of extensive research, World Health Organisation produced guidelines which recommend:

Children being told that they have HIV by the time they are school age (and this is defined as 6 encompassing all children under the age of 12).

The guideline also points to research which indicates that concealing the child's HIV status may lead to or exacerbate:

Depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life, including parenting ability and the child's social and academic life

http://www.who.int/hiv/pub/hiv_disclosure/en/

CURRENT PRACTICE IN THE UK

- ✧ In 2008 Children's HIV Association (CHIVA) research indicated that most children were being told their HIV status at the age of 12.
- ✧ **Quality Standard: "Open and Honest Practice when working with children"**
Ely, A (CHIVA, 2012) stated that most children should know before they are 9, with consideration to tell a child beginning at 6.
- ✧ CHIVA Audit (2017) to see what age children are now being told their HIV diagnosis .

THE SWEDISH APPROACH

Karolinska University Hospital in Stockholm

- ✧ Since 2009, HIV has been spoken about openly with all new patients, regardless of the child's age.
- ✧ The child and parent/carer are spoken to about HIV openly at each clinic appointment.

The key aims of the model are to reduce anxiety and give hope to children growing up with HIV.

- ✧ All questions asked by children are given honest answers.
- ✧ Attention is given to not using stigmatising language.

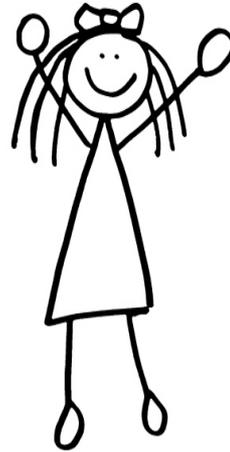
Children are not told they cannot tell other people they have HIV. They are asked who they would want to tell. This is then explored, and the children take part in the decision made as to whether telling would be a good thing to do at that time.

GENERAL PRINCIPLES FOR CHILD-CENTRED COMMUNICATION

Age and cognitive ability

Give the same information in different ways

Clear, simple, factual



REFLECTIVE LISTENING

Non-judgemental and child-led

They are developing, at different points they will retain different things.....

YOUNGER CHILDREN BORN WITH HIV

Naming HIV to a child is just the start of their journey. Conversations should be on-going and the word 'HIV' used often.

When naming HIV to a child:

- ✧ Clear, simple statements
- ✧ Medical facts
- ✧ Visual props, drawings
- ✧ Check they understand
- ✧ Space for questions
- ✧ Honest answers
- ✧ 'Building blocks' of information



THREE

Ask what we talked about

Can they remember what HIV stands for? How their medicine works?
Explain a little more

Ask them to write all the people that are important to them. See who knows they have HIV and who

TWO

Ask what we talked about before

**No bugs,
no battles, no war.
Simple medical language, facts,
reflections and open
conversations about telling
others**

ONE

Simply explain immune system and different medical names for it (white blood cells, CD4 etc)

Explain how the immune system works to get rid of cough or cold

means.

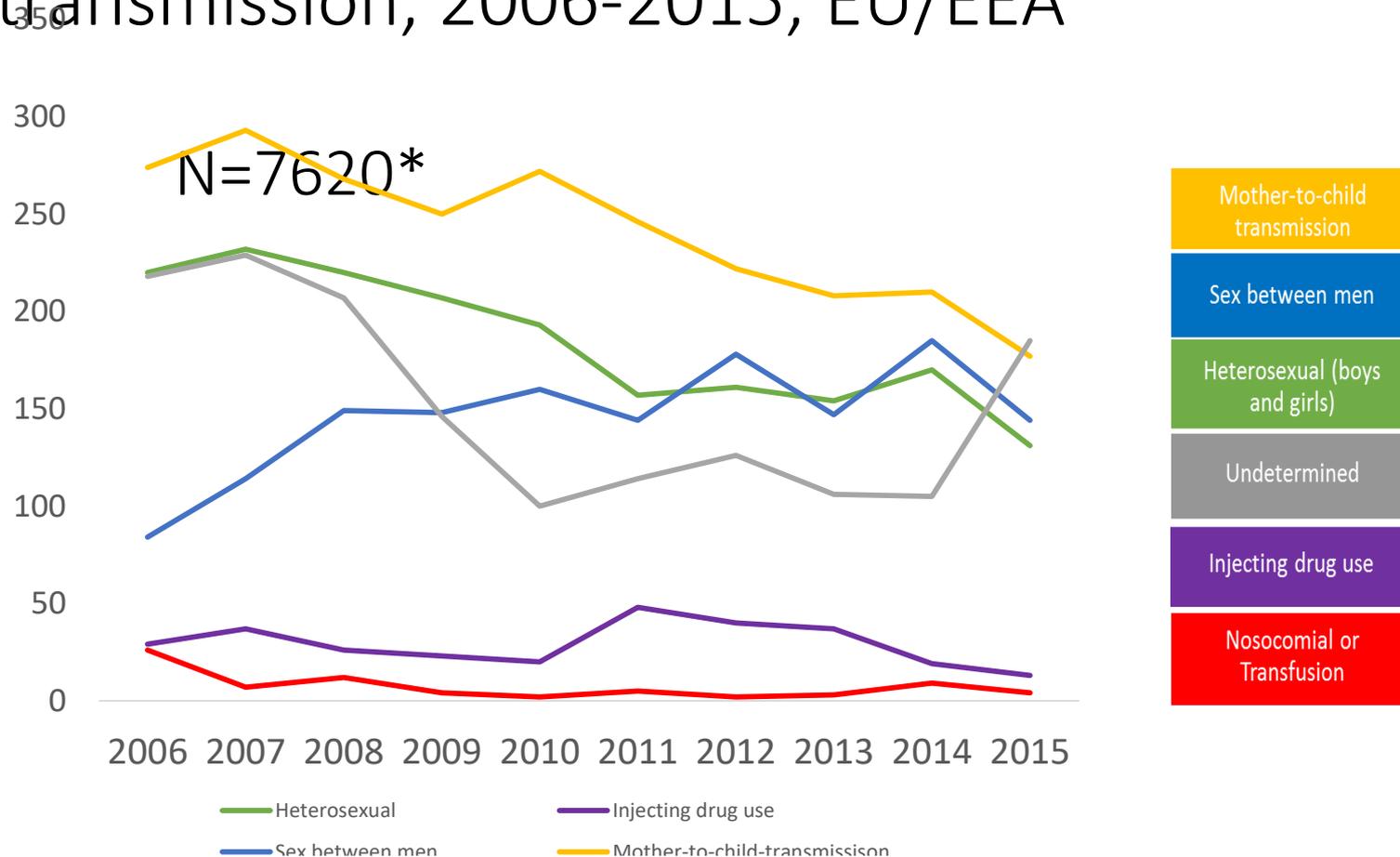
copies of itself.

go to sleep

and who you want to know

Talking to young people who acquired HIV in adolescents about their diagnosis

Trends of HIV diagnoses among children and adolescents (0-19 years), by mode of transmission, 2006-2015, EU/EEA



**Italy and Spain not included due to changes in surveillance systems*

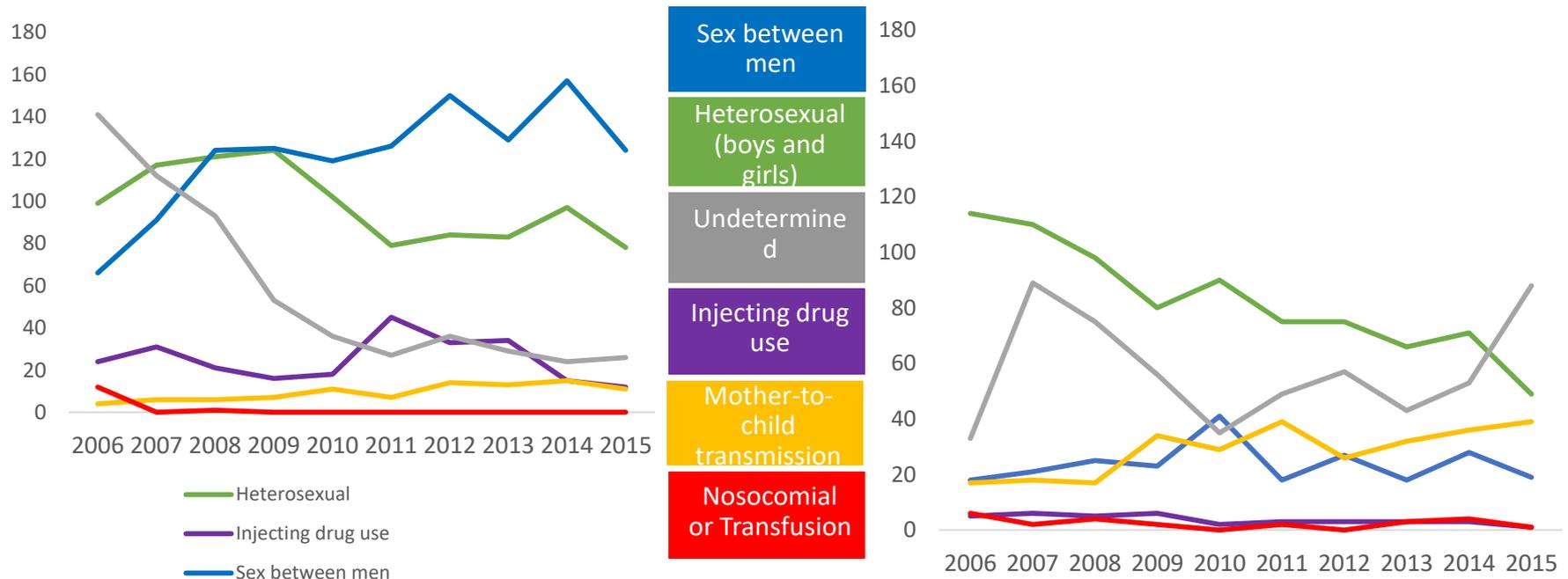
Source: The European Surveillance System, 30 EU/EEA reporting countries

Trends in adolescents?

Modes of transmission of HIV infection diagnosed among adolescents (15-19 years), by region or origin 2006-2015, EU/EEA, N=5120

Born in reporting country N=3128

Foreign-born N=1992



Note: Italy and Spain not included due to changes in surveillance systems

Source: The European Surveillance System, 30 EU/EEA reporting countries

GENERAL PRINCIPLES FOR ADOLESCENT-CENTRED COMMUNICATION

Age and cognitive ability

REFLECTIVE LISTENING

Give the same information in different ways



Non-judgmental and young person-led

Clear, simple, factual

They are developing, at different points they will retain different things.....

CONSIDER



- ✦ Where are they treated? Adult services? Paediatric?
- ✦ Language, including if English is their first language.
- ✦ Their perceptions of HIV and the context in which they grew up in.
- ✦ Positive messaging.
- ✦ How adherence can be both practically and emotionally complex – holistic approach to this.

TO CONCLUDE

- ✧ Telling a child they have HIV is just giving them a piece of information. The earlier it is done, the less impact it will have.
- ✧ Children and young people need clear, uncomplicated information. Use medical language, but then explain it and check they have understood.
- ✧ Always review and ask them to explain things back to you
- ✧ For all ages, use visual tools – pen and paper is enough!
- ✧ Starting a child's journey with HIV in a medically normal way will support acceptance and combat the development of self-stigma.

THANK YOU

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