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# Children and young people living with perinatal HIV in Europe: numbers and clinical outcomes in adult care

Ali Judd

[a.judd@ucl.ac.uk](mailto:a.judd@ucl.ac.uk)

## Background

- Few data on long-term outcomes of children with HIV, especially during/ after transition to adult care
  - HIV-related: ART adherence, CD4, hospital admission
  - Wider outcomes: mental health, growth, stigma, fertility
- Many children with HIV are in long-term follow-up studies (cohorts) across Europe, which have described their health
- ....but are the studies able to track them as they become adults, to provide longer-term outcomes?

## Objectives

1. Which European *countries* have HIV+ children in cohort (long-term follow-up) studies?
2. How many children are there & where are they?
3. Are the cohorts able to follow children into adulthood?
4. What do we know about HIV outcomes in adult care and adulthood?

## Methods

- EuroCoord cohort collaboration survey
  - Includes most of the major cohorts in Europe
  - Number of children with HIV in follow-up
  - Whether follow-up extends to adult care to continue to be able to report on outcomes
- Outcomes in adult care in the UK
  - Linking the UK paediatric cohort to an adult cohort

## CASCADE

- Amsterdam NEM
- Amsterdam NEI
- GEMES-haemo
- German ClinSurv HIV Project
- Italian Seroconversion
- Lyon Primary Infection
- Oslo & Ulleval
- UK Register

## EuroSIDA

## COHERE

- AMACS
- ANRS CO2 SEROCO
- ANRS CO3 AQUITAINE
- ANRS CO4 FHDH
- ANRS CO6 PRIMO

## COHERE

- ANRS CO8 COPILOTE
- ANRS CO13 HEPAVIH
- Athena
- Austrian
- CHIC
- Cologne Bonn
- Co-RIS
- Danish HIV Cohort
- Frankfurt
- ICONA
- KOMPNET
- Master
- Modena
- NENEXP
- PISCIS
- San Raffaele
- St Pierre
- Swiss
- VACH

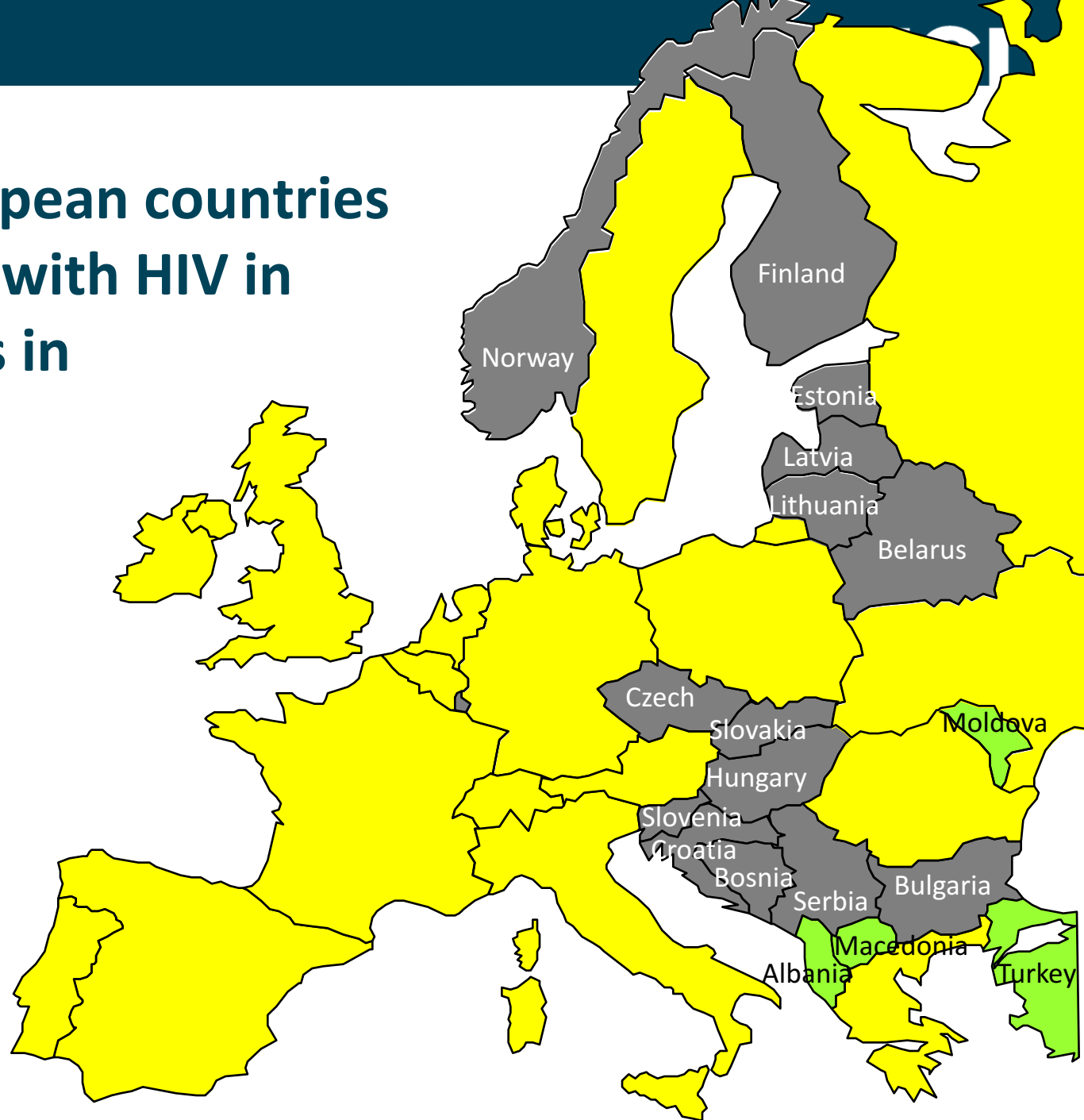
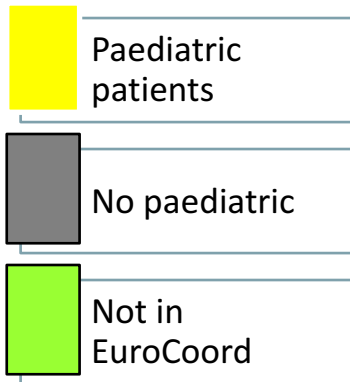
## PENTA-EPPICC

- ANRS EPF
- CHIPS
- CoRISPE-cat
- ECS
- Italian Register
- KOMPNET children
- Madrid HIV children
- NSHPC
- St Pierre paediatric
- Swiss mother/child
- Ukraine
- Victor Babes

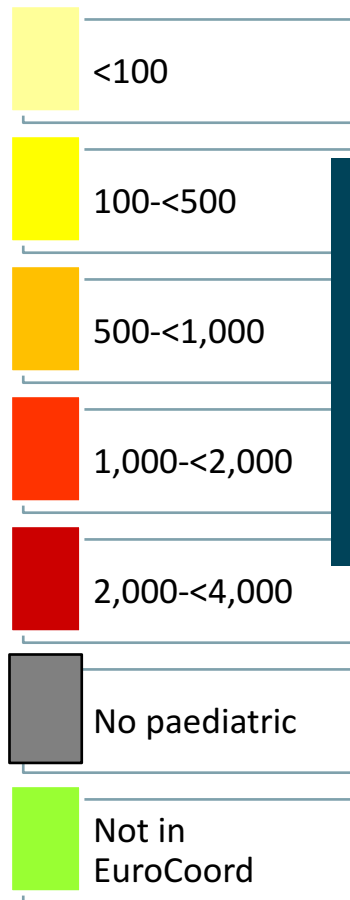
## Additional paediatric:

- Portugal
- Russia
- Sweden

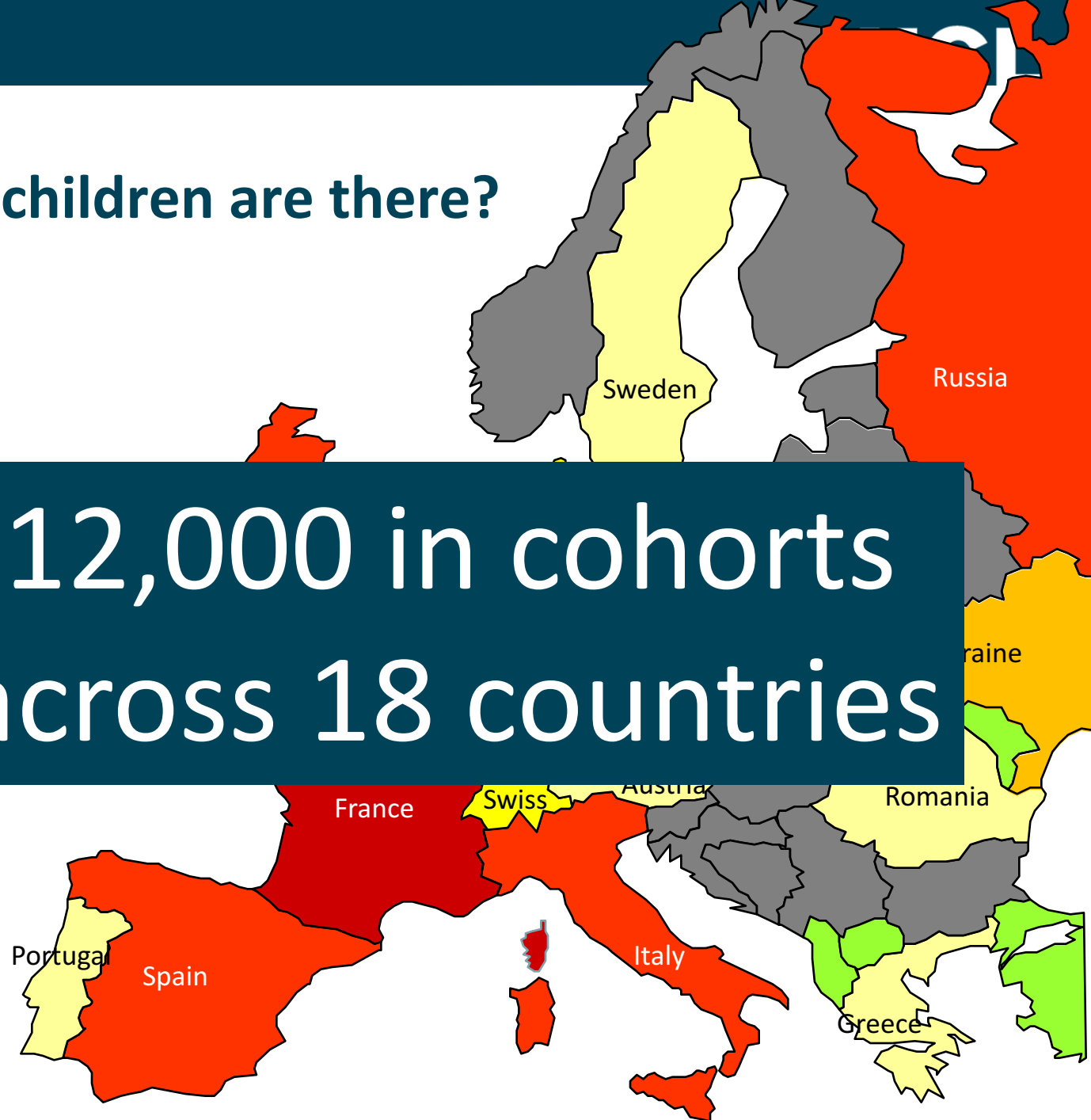
# 1. Which European countries have children with HIV in cohort studies in EuroCoord?



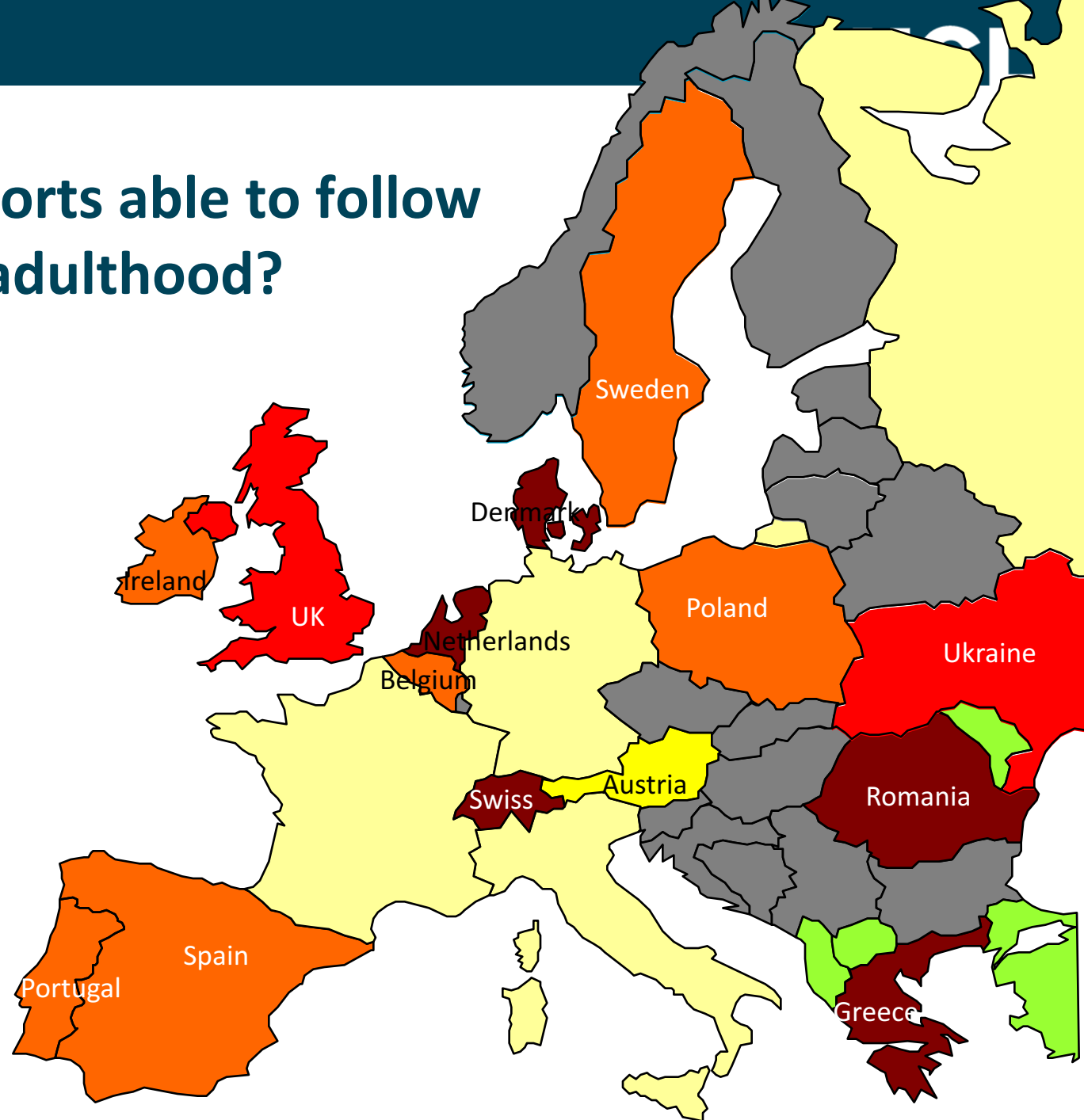
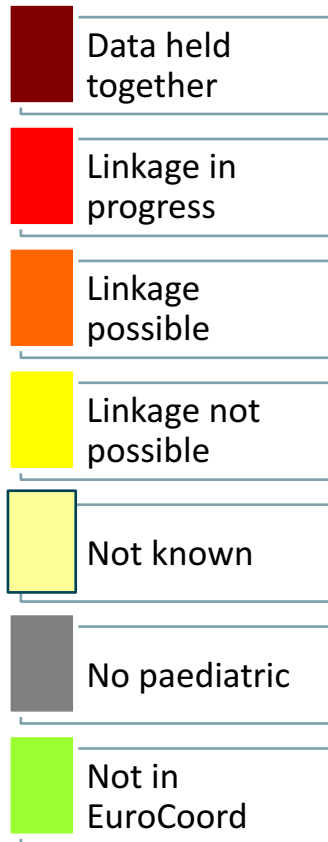
## 2. How many children are there?



12,000 in cohorts  
across 18 countries

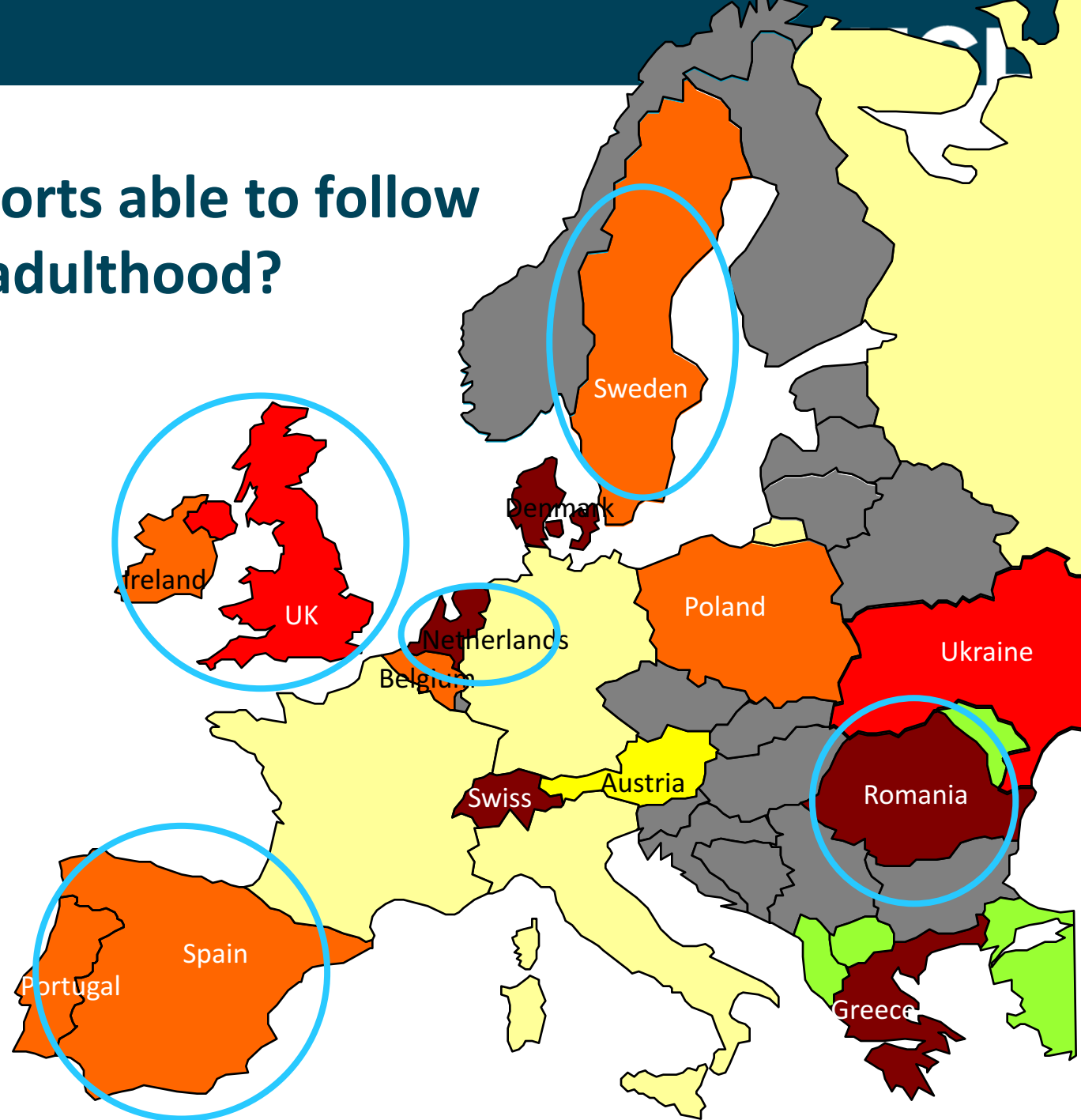
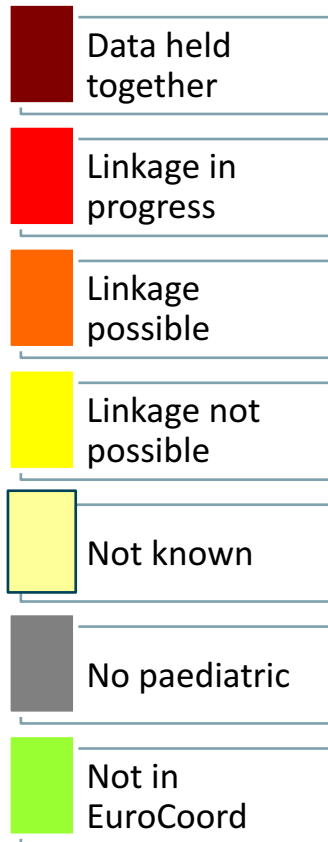


### 3. Are the cohorts able to follow children into adulthood?





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## 4. What do we know about outcomes in adult care and adulthood? UK case study

Data linkage of two cohorts:

- CHIPS (Collaborative HIV Paediatric Study)
  - all children with diagnosed HIV in the UK and Ireland
- UK CHIC (UK Collaborative HIV Cohort Study)
  - Routinely collected data on HIV+ patients aged  $\geq 16$  years who have attended one of 21 collaborating clinics in the UK
- Linked using pseudo-identifiers
  - 271 patients who had transferred to adult care were found in both datasets



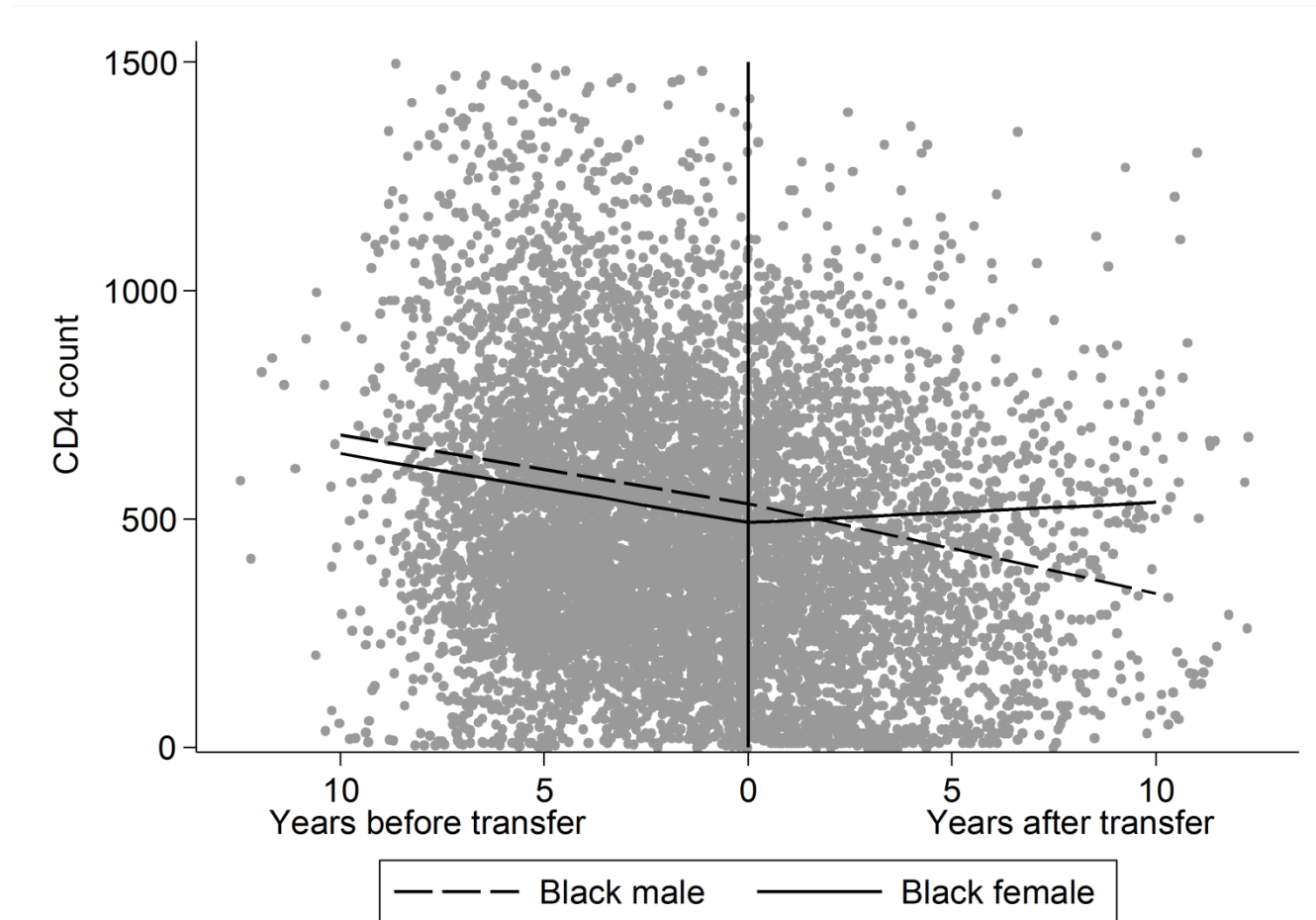
## Overall characteristics (n=271)

Characteristic	n (%) or median [IQR]
Female	146 (53%)
Black ethnicity	213 (80%)
Born abroad	163 (61%)
CDC Stage C (AIDS) diagnosis	86 (32%)
Age at transfer out of paediatric care	17 [16,18]
Age at last follow up in adult care	20 [19,23]
Duration of paediatric care follow up (years)	11.8 [6.6,15.5]
Duration of adult care follow up (years)	2.9 [1.5,5.9]

## Outcomes comparing paediatric and adult care

Outcome		Paediatric care n (%) / median [IQR]	Adult care n (%) / median [IQR]	p-value
1 <sup>†</sup>	On ART at last follow up	200 (74%)	228 (84%)	0.001
2 <sup>‡</sup>	Median CD4 count in last 12 months	456 [286,660]	450 [271,669]	0.37
3 <sup>†</sup>	CD4 <200 at least once in last 24 months	61 (31%)	76 (39%)	0.014
4	Two consecutive VL>400 in last 24 months	111 (56%)	113 (57%)	0.79

# Predictors of CD4 change over transition



**The association between sex and CD4 slopes over time for a hypothetical patient with the following characteristics: black ethnicity, born in the UK in 1991, nadir CD4 of 207, transferred to adult care at 17.5 years (sample means), no hospital change at transfer**

# Mortality rates by age and type of HIV care in young people with perinatal HIV, 2006-2011

Age group and type of care	No. of deaths	Person years	Rate/100 person years	Rate ratio (95% CI)
13-15 years, paediatric	3	1689	0.2 (0.1, 0.6)	1.0
16-20 years, paediatric	2	786	0.3 (0.1, 1.0)	1.4 (0.2, 8.6)
16-20 years, adult	4	825	0.5 (0.2, 1.3)	2.7 (0.6, 12.2)
≥21 years, adult	4	458	0.9 (0.3, 2.3)	4.9 (1.1, 22.0)

Fish R et al. Mortality in perinatally HIV-infected young people in England following transition to adult care: an HIV Young Persons Network (HYPNet) audit. *HIV Medicine* 2013,**15**:239-244.

## Conclusions

- Many children were followed-up in research studies in Europe
  - For most, outcomes in adult care are not available
- Lack of cohorts of HIV+ children in E. Europe
- In UK, adult care outcomes suggest some groups doing better and others doing worse
- Higher mortality following transfer to adult care is of great concern
  - Importance of adherence and mental health support as patients transition to adulthood
- Do outcomes improve after adolescence?

## References for European transition studies

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[a.judd@ucl.ac.uk](mailto:a.judd@ucl.ac.uk)