

Children Of the Cohort (CHOC) study : The unseen population behind people with HIV

C. Merlin¹, J. Damas MD¹, O. Nawej Tshikung MD², N. Wagner³, A. Hachfeld MD⁴, A. Duppenhaler⁵, M. Stoeckle⁶, M. Kohns⁷, I. A. Abela⁸, P. Paioni⁹, L. Elzi¹⁰, L. Kottanattu¹¹, P. Schmid¹², C. R. Kahlert¹³, K. Kusejko PhD¹⁴, P.A. Crisinel¹⁵, P. Pellegrino¹⁶, M. Cavassini MD¹, K.E.A. Darling MD PhD¹ and the *Swiss HIV Cohort Study*

¹Infectious Diseases Service, University Hospital Lausanne, University of Lausanne, Lausanne, Switzerland ²Division of Infectious Diseases, University Hospital Geneva, University of Geneva, Geneva, Switzerland ³Hôpital des Enfants, University Hospital Geneva, University of Geneva ⁴Department of Infectious Diseases, Bern University Hospital, University of Bern, Bern, Switzerland ⁵Department of Pediatrics, Unit of Pediatric Infectious Diseases, Bern University Hospital, University of Bern, Bern, Switzerland ⁶Department of Infectious Diseases, University Hospital Basel, University of Basel, Basel, Switzerland ⁷University Childrens Hospital, University of Basel, Basel, Switzerland ⁸Department of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, University of Zurich, Zurich, Switzerland ⁹Institute of Medical Virology, University of Zurich, Zurich, Switzerland ¹⁰Division of Infectious Diseases and Hospital Epidemiology, University Children's Hospital, Zurich, Switzerland ¹¹Division of Infectious Diseases, Regional Hospital Lugano, Lugano, Switzerland ¹²Institute of Pediatrics of Southern Switzerland, EOC, Bellinzona, Switzerland ¹³Division of Infectious Diseases, Infection Prevention and Travel Medicine, Cantonal Hospital St. Gallen, Switzerland ¹⁴Infectious Diseases and Hospital Epidemiology, Children's Hospital of Eastern Switzerland, St. Gallen, Switzerland ¹⁵University Hospital Zurich, Division of Infectious Diseases and Hospital Epidemiology, Zurich, Switzerland ¹⁶Unit of Pediatric infectious Diseases and Vaccinology, Service of Pediatrics, Department Woman-Mother-Child, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland ¹⁶Author, "Papa Gay", Editions Favre 2009

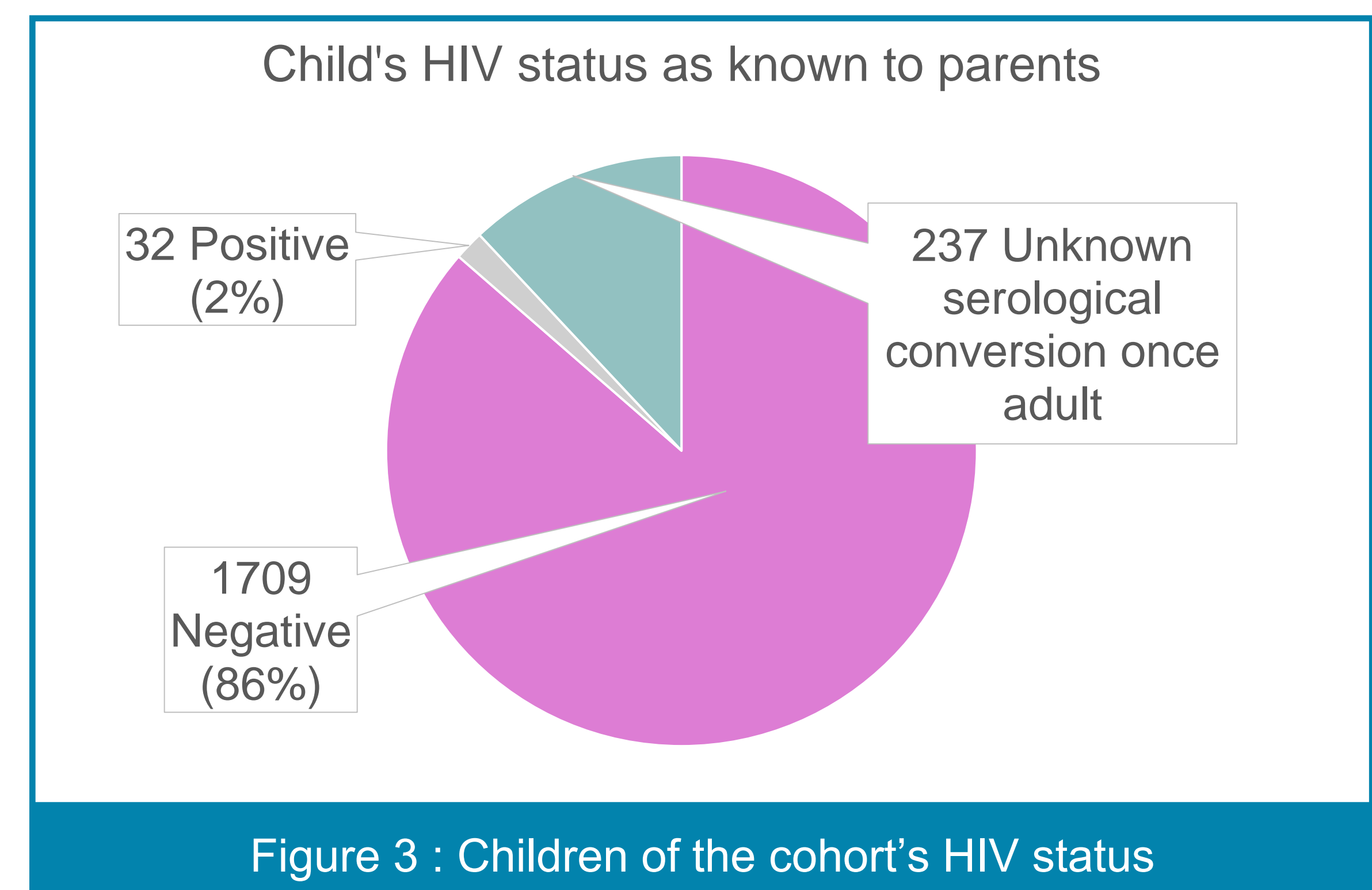
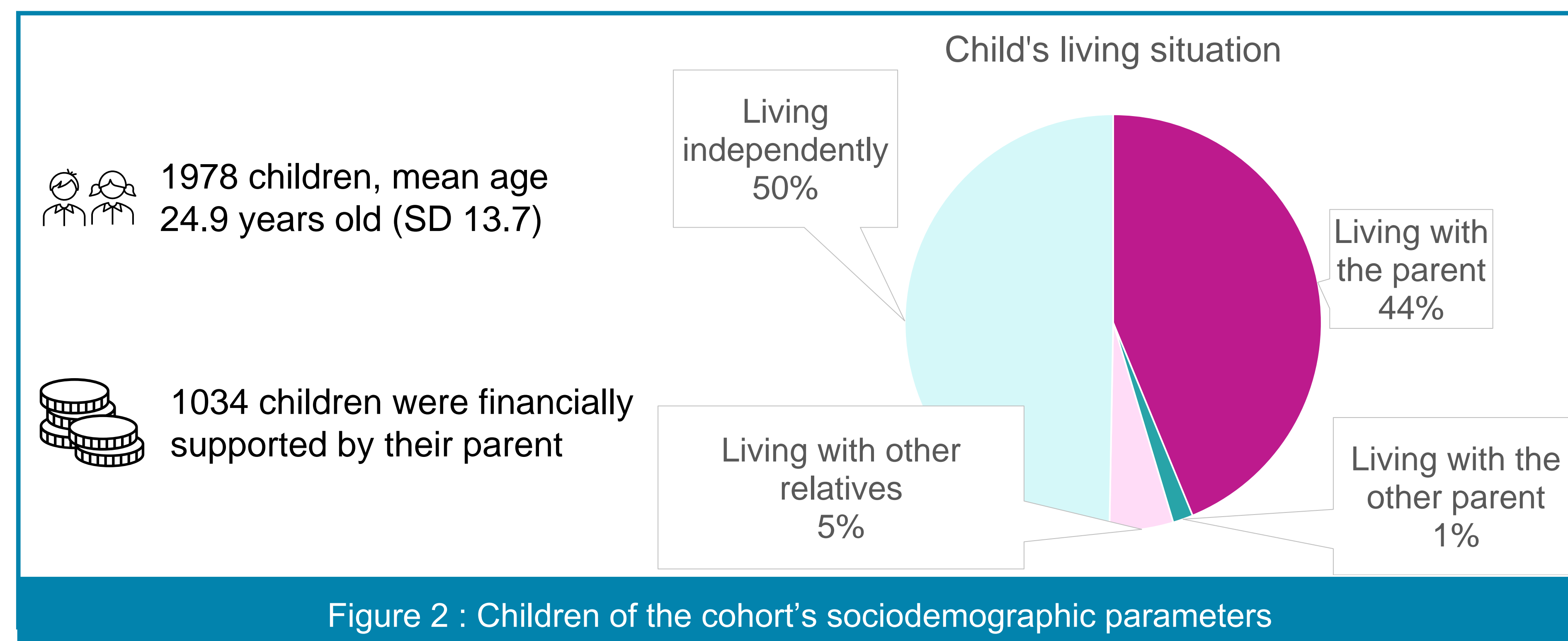
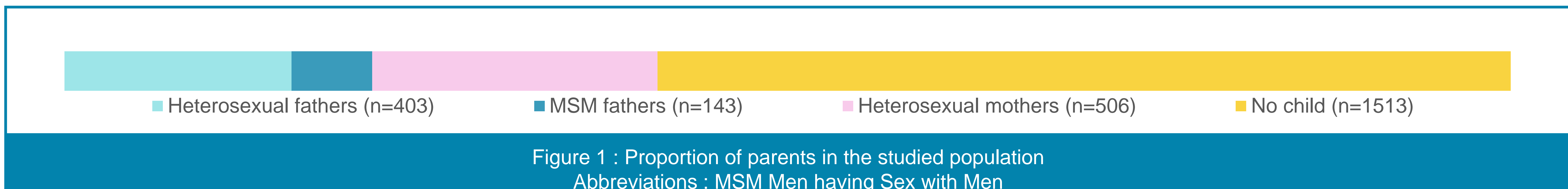
Introduction

Antiretroviral therapy enables an excellent life expectancy for people with HIV (PWH) in Switzerland and has reduced to virtually zero the vertical and horizontal transmission rate, resulting in an increase in children with ≥1 parent living with HIV. While children born to women with HIV are followed up by HIV physicians during their first two years of life, children of men with HIV, children born prior to a parent's diagnosis, those aged >18 years old or not living with the parent may be undocumented. We aimed at quantifying and characterizing the children born to PWH in Switzerland as well as quantifying the extent of parental HIV diagnosis sharing.

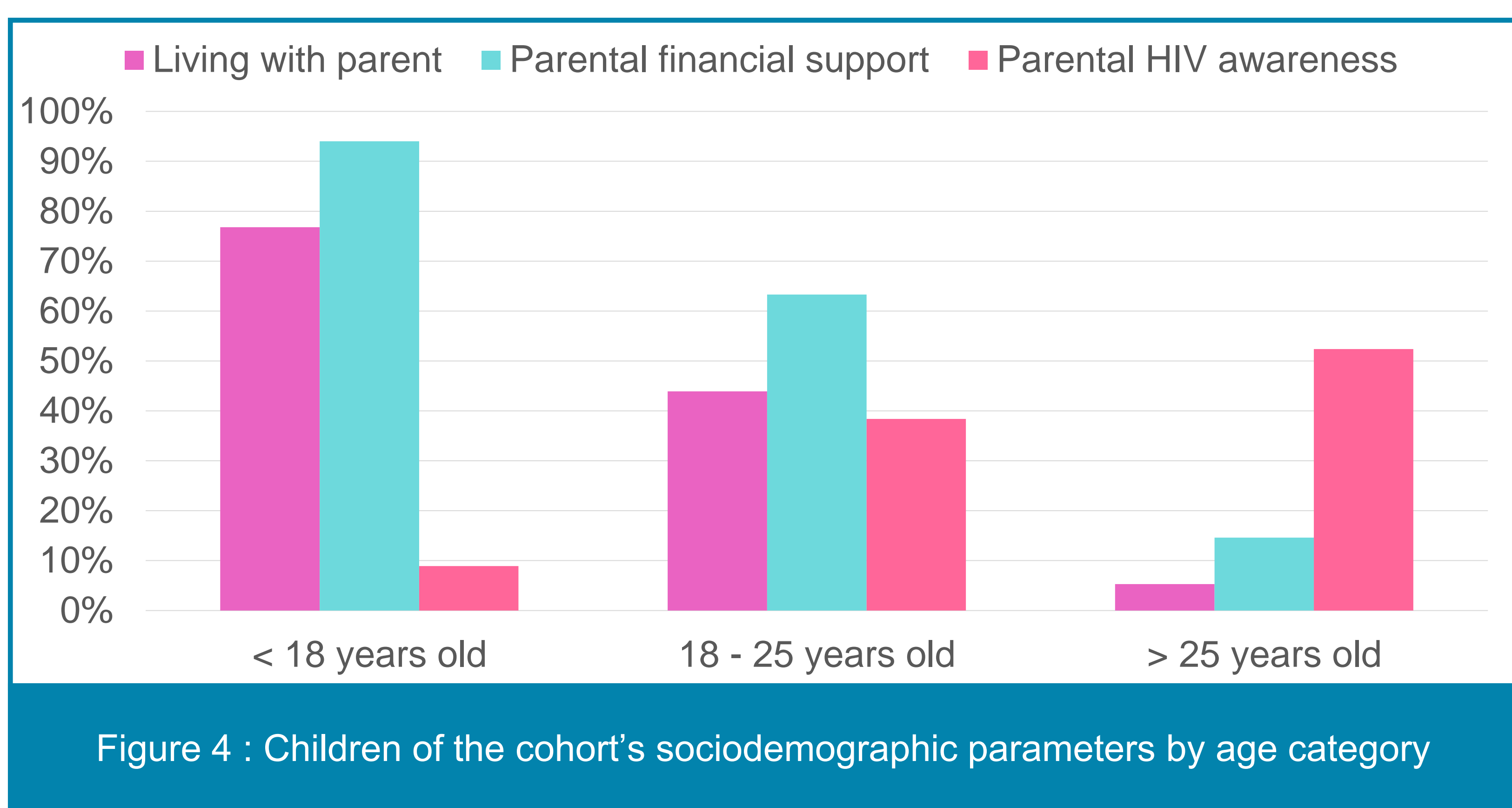
Methods

- The SHCS is a multicenter, prospective cohort study enrolling adult PWH in Switzerland within seven university centers.
- A structured questionnaire co-designed with patient and public involvement was embedded in one of the biannual follow-up visits from September 2022 to October 2023.
- There were no exclusion criteria
- Descriptive analyses are presented as mean (with standard deviation) for continuous variables and proportion for categorical values.

Results



- 1052/2565 participants were parents (41%), among them 546/1052 were men (51.9%). Men having sex with men (MSM) accounted for a quarter of the cohorted fathers (143/546) (Figure 1).
- 1978 children were registered, corresponding to a mean of 1.9 children per participant. Sociodemographic parameters are detailed in Figure 2.
- Although most of the children were reported as HIV-negative by their parent, 237 children's status were unknown to the parent after the child became an adult (Figure 3).
- Parental HIV status was shared with 35.2% of children, the proportion increasing as the children aged (Figure 4).
- Living with the parent and receiving financial support decreased as the child aged (Figure 4).



Conclusion

In this sample of PWH, 41% were parents, of whom 13.6% were MSM. Over half of parents still supported their children financially, even if the child lived elsewhere. In total, 35.2% of parents had shared their HIV diagnosis with their children. Questions on parenthood are not routinely asked at SHCS follow-up visits. Omitting this social parameter potentially underestimates financial and psychosocial responsibilities among PWH. Further, parents may benefit from healthcare professional support when considering sharing their HIV status with their children. Finally, 'unseen' children also means 'unseen' parents and reversing this could help to normalise HIV and counteract HIV-related stigma.