

National Survey of Young People with Perinatal HIV, Looked after, adopted, or in care (LAAC)

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Background: By March 2022, approximately ~550 young people were accessing paediatric HIV clinical care in the UK, of whom, ~50% had been born abroad[1]. The vast majority transition into adult care in the UK, a proportion of whom are in Looked After or Adopted Care (LAAC). There is limited information on health service delivery, access, utilisation and outcome of LAAC support for young people living with perinatally acquired HIV (PHIV) in the UK

Aims: To conduct a national clinic based survey exploring the demographics and perspectives of health care staff managing young people living with PHIV who have LAAC needs.

Objectives: To capture variation in health and social care service delivery, identify unmet or additional support requirements, professional guidance and training needs in managing PHIV with LAAC needs.

Method: An electronic survey was circulated to all Collaborative HIV Paediatric Study (CHIPS) centres in the UK between October 2021 and February 2022. Information on

- their caseload of young people living with HIV that required foster care, kinship care, residential care or adoption,
- the proportion that transitioned into adult care, and
- perspectives on support required for young people with PHIV and LAAC needs, and
- Free text responses on support required for staff dealing with young people with PHIV and LAAC needs, was sought.

Results: 15 (44%) responses of 34 centres approached were received. Of these 12 completed the survey, 2 reported no PHIV with LAAC needs, and 1 had no resources to complete the survey. Services represented included Greater London (6), Manchester (1), Leeds (1), Liverpool and region (1), Newcastle (1), Bristol & South West (1), South Yorkshire and Humber (1), Hampshire (1), Northampton (1)

Services that responded provided information over a median of 10 years (10 units provided data over 10 years, 1 over 14 years and 1, 25 years) during which time they had provided support for a minimum of 870 young people living with PHIV, of whom at least 240 were currently in paediatric services, and 578 transitioned into adult services. They reported experience of LAAC in at least 15% (137/870) of young people living with PHIV: 35 adopted, 41 fostered, 55 receiving kinship care, and 6 in residential care. A the time of transitioning into adult services (n=578), 20 remained in foster care, 40 in kinship care, 15 adopted and 3 in residential care.

Only 5/12 reported that the support their team received around PHIV LAAC was adequate. Thematic analysis of free text responses identified deficiencies in provision of consistent support by social services for staff and families of LAAC young people with PHIV.

Perspectives in PHIV	Yes	No/ not sure
Do you feel that accessing, engaging, obtaining or sustaining social care support has been adequate for young people with LAAC needs in your care?	5	7
Do you think extra resources are required for adequately supporting young people with with LAAC needs in social care?	11	1
Are there separate issues that young people with PHIV in kinship care face?	8	4
Are there specific examples from your clinic where supporting a young person who is in LAAC has been difficult?	9	3

Figure 1: Perspectives on adequacy of PHIV LAAC social care support

'Yes we feel that LAAC families do not often receive the right support to look after children with HIV and their specific needs'

'Some positive experiences on the whole it can be a difficult process. Stigma /attitudes play a part but sometimes it is pressure and lack of resources'

'No we very rarely had any support from social services. We often had difficulties with Social Workers changing all the time and not communicating with us or not returning calls. There used to be a dedicated SW at the Trust who would take on the Social work issues leaving the medical staff to focus on the medical issues, but we no longer have this support. And safeguarding nurses are overwhelmed with other inpatient cases and do not have the time to support us'

Figure 2: Thematic examples: Free text extracts reported by PHIV services staff

Conclusion: Despite the limited response rate, the representation for this survey extended across the breadth of the country. There is a substantial need for support for families and staff engaged in LAAC support for young people with PHIV. Qualitative research exploring how better to promote effective support in this area is urgently required.