



Don't Forget the Children 2026 - Final Draft

The HIV status of all children, of adults living with HIV, including adult children, should be known and confirmed as a matter of clinical urgency.

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Confirm the HIV status of every child, including adult children

Confirm the HIV status of every child of parents living with HIV. **If in doubt, test.**

See the proof

Verbal reassurance is insufficient. Misunderstandings can occur regarding whether an HIV test has been done, so documentation should be reviewed. **If in doubt, test.**



Testing should be undertaken irrespective of age

People with perinatally acquired HIV are being diagnosed into their late twenties. **If in doubt, test.**



Review testing annually

Children and young people may join a family later or move to the UK after the parent's diagnosis. An annual review should include checking that you have an accurate list of a person's children. **If in doubt, test.**



A message from the Chiva Youth Committee, who are young people growing up with HIV

Every child deserves to grow up healthily. Early testing can help identify when someone has been born with HIV or acquired HIV in early life. This early detection means each person can receive the right medication and benefit from a long-term healthcare plan.

Overall, this helps protect children and young people from serious long-term illnesses linked to HIV. The benefit of this is that the child will have a happy, long, and healthy life. No child should be forgotten!

If in doubt, test!

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People First Language

This document is written in line with The People First Charter language guide, recognising that people are people, and not defined by a medical diagnosis. For more information, visit peoplefirstcharter.org.

Abbreviations

ART	Antiretroviral therapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
CHARS	Children's HIV and AIDS Reporting System
DHSC	Department of Health and Social Care
GMC	General Medical Council
GP	General practitioner
HIV	Human immunodeficiency virus
MDT	Multidisciplinary team
NHIVNA	National HIV Nurses Association
NHS	National Health Service
PN	Partner notification
PVC	Perinatal Virtual Clinic
PR	Parental responsibility
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Foreword

Seventeen years ago, Don't Forget the Children set out a clear and necessary standard: Every child of a parent living with HIV should have their HIV status known.

It was a call grounded in evidence, compassion, and a commitment to prevention.

Today, this updated report reminds us that while progress has been made, our work is not yet complete.

Recent data shows that too many opportunities to test children, including adult children, are still being missed. Behind every missed test is a person whose diagnosis may be delayed, and whose health may be compromised unnecessarily. This is not a failure of science or capability, it is a failure of systems, processes, and sometimes confidence to act.

The message of this report is therefore both simple and urgent:

No child should be left without knowing their HIV status.

What makes this document particularly powerful is its combination of clinical evidence, legal clarity, and practical guidance. It recognises that testing children is not always straightforward; families face stigma, fear, and complex personal circumstances. Clinicians navigate confidentiality, safeguarding, and trust.

But the document also shows that these challenges are not insurmountable when we work together.

I want to extend my sincere thanks to the authors, contributors, clinicians and, critically, the young people and parents whose voices have shaped this work. Their insight ensures that this is not just a technical document, but a human one.

This report is also timely. It aligns directly with the ambitions of the HIV Action Plan for England to end new transmissions by 2030. Achieving that goal demands that we close every gap in prevention, and this is one of the most important.

The responsibility now sits with all of us, across the NHS, local government, community organisations, and beyond. Implementation will require leadership, accountability, and partnership at every level.

We know what needs to be done. We have the tools to do it. And we have a shared responsibility to act.

Let us ensure that, this time, we truly do not forget the children.

Professor Kevin Fenton CBE FFPH PhD
Regional Director of Public Health, London.

DRAFT

Executive Summary

In 2009, the Don't Forget the Children report was published jointly by BHIVA, Chiva, and BASHH. It set out clear standards of care to ensure that all children of adults accessing HIV care in the UK, had an HIV test.

Don't Forget the Children was driven by the death of a 10-year-old child who had undiagnosed HIV despite both parents being in HIV care, highlighting missed opportunities for testing and medical care.

Findings from the BHIVA National Audit (2025) show that 17 years later, significant gaps remain; one in five services do not provide testing or have pathways in place for the testing of children of people with HIV, and, for 10% of children identified, there was no documented evidence of testing (BHIVA, 2025). Many services still lack the robust policies and procedures needed to reliably identify and test children of adults living with HIV, indicating that earlier recommendations have not been fully embedded into practice.

This updated 2026 document is informed by current national guidance, including the BHIVA Standards of Care (BHIVA, 2018), BHIVA HIV Testing Guidelines (BHIVA, 2020), Chiva Standards of Care (Chiva, 2025), and the recent BHIVA audit findings (BHIVA, 2025). Together, these sources inform an updated framework for improving consistency, accountability, and safeguarding across services. This guidance reaffirms the responsibilities of all adult HIV services to ensure the HIV status of children of adults living with HIV, including adult children, is confirmed and documented.

This document highlights the legal requirements that support children and parents, reminding professionals that the needs of the child are paramount.

To achieve the recommendations, practical guidance on age-related considerations and the management of potential barriers is provided and workable solutions are included.

Don't Forget the Children (2026) recognises differences in services and highlights that effective implementation relies on collaboration between health and social care teams and community organisations to embed coordinated pathways.

The recommendations offer a practical framework that should be used alongside current professional guidance and national policy to ensure the HIV status of all children of adults living with HIV, including adult children, should be known and confirmed as a matter of clinical urgency.

The following recommendations provide a clear strategy to ensure this happens:

- All professionals in HIV services engage in safeguarding training and should be aware of the potential for vertical transmission of HIV.
- All services have written protocols aligned with this document that include referral pathways and clear MDT escalation plans.
- Annual clinical reviews for adults living with HIV include exploration of whether they have any children and the outcome of testing.
- All services conduct audits every two years, to ensure the recommendations are being followed.

Specialist expertise and support is available from local Paediatric and Adult HIV services, Paediatric HIV Lead Centres across the UK and directly from Chiva.

Note: The issue of testing children applies to children of people with HIV who are now adults and therefore the term 'adult children' will be utilised throughout this document.

Introduction

Seventeen years after the publication of the original Don't Forget the Children document, recent case reports (Curto, 2025) and findings from the 2025 national BHIVA audit (BHIVA, 2025) show that significant gaps remain in ensuring that all children of adults living with HIV in the UK are tested for HIV. In addition to children whose parents are already engaged in care, consideration must also be given to children born outside the UK and for those whose parents are not currently accessing care. While this document is informed by current legal frameworks, it does not replace the need for legal advice, which when required, should be obtained locally.

The 2025 BHIVA national audit (BHIVA, 2025) showed that, despite the national recommendations around testing children, gaps still exist in the pathways and procedures to ensure that this is completed and documented. One in five services do not provide or have pathways in place for the testing of children of adults living with HIV. One in ten children had no documented evidence of testing or referral for testing. Most centres are not routinely auditing child testing or reviewing whether children have joined their parents in the UK. Only a minority of services involve paediatric healthcare providers in multidisciplinary (MDT) meetings.

HIV testing has become a standard of care in some clinical areas, with routine testing for HIV in tuberculosis (TB) clinics for adults and children, routine HIV testing (along with screening for viral hepatitis, syphilis and sexually transmitted infections) for children and young people who are seeking asylum and refugees in the UK (Royal College of Paediatrics and Child Health, 2026), and the introduction of opt-out testing for those aged 16 or over who have blood tests in emergency departments (ED) in areas of high and extremely high HIV prevalence in England (NHS England, 2024).

NHS guidance on migrant health (Office for Health Improvement and Disparities and UK Health Security Agency, 2026). supports primary care testing and can assist GPs in managing HIV testing for families relocating to the UK, serving as an important pathway for testing children without necessitating sharing of a parent's HIV diagnosis. All the listed testing opportunities support the HIV Action Plan for England (Department of Health and Social Care, 2025) to rapidly connect those diagnosed to HIV care and to end HIV transmission by 2030.

The UK Government's HIV Action Plan, published in 2025, includes reference to improving HIV testing for children of parents living with HIV in addition to improving partner notification (Department of Health and Social Care, 2025).

HIV-associated stigma remains a significant barrier and parents' fears about their HIV diagnosis being shared can understandably result in a reluctance to bring children for testing. Stigma experienced by parents can result in a cycle of intergenerational stigma affecting children of parents living with HIV (Warburton et al, 2025).

Perinatally-acquired HIV

The global picture

UNAIDS estimates that 40.8 million people, including 1.4 million children, were living with HIV globally in 2024 (UNAIDS, 2025a). Around half of the population living with HIV are female (World Health Organization, 2025) with a significant number being of reproductive age (Gilleece & Kankowska, 2021).

Whilst mechanisms to prevent vertical transmission of HIV are highly effective, prevention relies on access to antiretroviral therapy (ART). In 2024, 16% of pregnant women living with HIV had no access to ART and there are significant uncertainties over current and future treatment access linked to changes in global funding of treatment and services (UNAIDS, 2025b).

There are further concerns that this data does not report on continued engagement in care or access to treatment for the duration of pregnancy (World Health Organization, 2025). This highlights that, globally, children will continue to acquire HIV vertically.

Adults with perinatally-acquired HIV

The issue of testing children also applies to children of people with HIV who are now adults. Ensuring that adults whose parents are living with diagnosed HIV have appropriate testing can be challenging. Key barriers include parents not wishing to share their diagnosis, and parents and clinicians underestimating the duration that undiagnosed perinatal HIV can be asymptomatic.

Late diagnosis significantly affects morbidity and mortality

Worldwide, 75,000 children per year die from HIV related causes (UNAIDS, 2025a) and in a large prospective study, a late HIV diagnosis significantly increased deaths in children living with HIV (Oko et al, 2017). Curto et al (2025) report that 69% of children (31/45) referred to the UK Perinatal Virtual Clinic with newly diagnosed HIV met the criteria for late HIV diagnosis. This is reflected in national data in England which affirms that the majority of children and young people born abroad and diagnosed after arrival were diagnosed one to five years after arriving in England, and 24% had advanced immunosuppression meeting the criteria for late diagnosis (David et al, 2026). Those entering adult care with advanced disease in earlier childhood have higher incidence of morbidity and mortality following transition (Asad et al, 2021).

The data is clear - late diagnosis increases morbidity and mortality in children and young people living with HIV.

The oldest survivors born with perinatal HIV are now entering their fifth decade of life (Malik et al, 2025). They were born in the pre-ART era and survived childhood without therapy, with slowly progressive disease and likely favourable host genetics and immune responses (Vieira et al, 2023). Similar to elite controllers and slow progressors who have acquired HIV in adult life, a very small minority of individuals born with HIV will survive into adulthood without major clinical disease progression (Gasca-Capote and Ruiz-Mateos, 2025; Jackson et al, 2025; Vieira et al, 2022).

It is impossible to exclude perinatal HIV purely on age or clinical status alone. HIV screening should be offered to every child of parents living with HIV, including adult children. Parents should be informed of the potential for asymptomatic HIV in adult children and the need for testing. Where there are barriers to testing adult children, pathways similar to partner notification should be considered, including primary care and provider referral (BHIVA, BASHH, and BIA, 2020). Attempts should be made to check whether routine testing has already been done.

Legal and policy framework

This section highlights the legal framework relevant to testing children of adults living with HIV

In UK law, the child's welfare is given paramount consideration, as established by Section One of the Children Act (1989). All agencies working with children in the UK have a shared statutory duty to safeguard and promote their welfare, ensuring that the child's wellbeing remains the paramount consideration in all decisions and actions. This responsibility is underpinned by Section 11 of the Children Act (2004), which places a duty on key organisations, including local authorities, health services, and education providers, to safeguard and promote children's welfare. This duty is reinforced by statutory guidance, Working Together to Safeguard Children (Department for Education, 2023), which emphasises inter-agency cooperation to protect children and promote their best interests.

Furthermore, the General Medical Council emphasises that protecting children and young people is the responsibility of every doctor (General Medical Council, 2024). Children have a fundamental right to healthcare. This right is established in UK law and reinforced by international frameworks including Article 6 and 24 of the UN Convention on the Rights of the Child (United Nations, 1989), which pledges the right to life and access to the highest attainable standard of healthcare without discrimination.

Children in the UK have a right to participate in decisions affecting their lives, including those relating to their healthcare, in accordance with their age and understanding. This is reflected in the Children Act 1989, which requires courts to consider the child's wishes and feelings. This is reinforced by Article 12 of the UN Convention on the Rights of the Child (United Nations, 1989; United Nations Committee on the Rights of the Child, 2009), which the UK has ratified, affirming children's right to express their views in all matters affecting them.

In healthcare, this principle is further supported by the concept of Gillick competence where children under the age of 16 can consent to their own treatment if they're believed to have enough understanding to fully appreciate what is involved (NHS, 2022).

Practitioners should work collaboratively with parents to reach agreement, preserve family relationships, and uphold the child's rights. Where a parent persistently declines testing or treatment that is necessary to protect a child from significant harm, and that is in their best interests, legal advice should be sought. Local authorities have duties under Sections 17 and 47 of the Children Act 1989 to safeguard children in need or at risk. In exceptional circumstances, the courts may authorise testing or treatment. Court intervention is always a last resort.

Under UK law, individuals, including children, have a right to confidentiality in respect to their health information, meaning that personal medical details should not be shared without consent, unless there is a lawful or overriding public interest justification. This right is protected under the Data Protection Act 2018. Health data is “special category data” and requires a higher level of protection. However, information may be shared without consent where necessary to safeguard the child or others, in line with guidance including Working Together to Safeguard Children (Department for Education, 2023).

The General Medical Council stipulates that if practicable, personal information should not be shared, however, the patient confidentiality guidance details that sharing personal health information without consent may be justified in the public interest, if failure to do so may expose others to risk of death or serious harm (GMC, 2017a, 2017b).

When considering HIV testing of adults (over 18 years) for whom there is an identified potential risk, access to HIV testing is grounded in a combination of public health legislation, clinical best practice guidance, equalities and human rights principles.

The European Convention on Human Rights, incorporated into UK law through the Human Rights Act 1998, protects the right to life in Article 2. This supports timely access to testing where a known risk exists in order to enable access to lifesaving treatment.

NHS organisations have statutory duties to reduce health inequalities. Through frameworks such as Core20PLUS5 (NHS England, 2021), the NHS is required to prioritise prevention and early diagnosis among underserved populations. It is widely recognised that HIV disproportionately affects populations already disadvantaged by health and social inequalities.

Ending HIV transmission is a national priority, set out in the Government’s HIV Action Plan (Department of Health and Social Care, 2025). The plan includes a commitment to scaling up HIV testing to rapidly connect those who are diagnosed with HIV to treatment and care.

These frameworks collectively ensure that children and adults in the UK, with an identified risk of undiagnosed perinatally-acquired HIV are identified and offered HIV testing to protect their right to access healthcare and treatment.

Service Recommendations

The following service recommendations support the essential goal of ensuring HIV testing is completed for all children of parents living with HIV, including adult children.

Awareness of vertical transmission: Staff in adult HIV services are aware of national guidance on the need to test children of all ages whose parents are living with HIV and should be aware of the potential for vertical transmission of HIV.

Written protocols: Every adult HIV service must have policies and pathways in place to identify and test all children of parents living with HIV, including adult children. These policies and pathways acknowledge and act upon the urgency of testing key groups (BHIVA, 2025, BHIVA, 2018, Chiva, 2025). There must be documented evidence of discussions and results.

Annual reviews: As part of routine adult clinical care, the number of children (including non-resident children), and their HIV status, should be reviewed annually. This should be part of clinical annual reviews.

Safeguarding training: All staff working within HIV services, including adult clinicians, must have training in child safeguarding.

Referral pathways: Establish links with a regional paediatric HIV centre and implement formal pathways. Paediatric HIV Lead Centres can be contacted directly for advice on testing and care.

MDT escalation: Where parents do not engage with the recommendation of testing, or there are safeguarding concerns, escalate to a multidisciplinary team (MDT) and include paediatric representation within the MDT. This may include a regional paediatric HIV service, GP, and adult HIV services to ensure sensitive case management.

Audit: All services conduct audits every two years to ensure the recommendations are being followed and to ensure that no children, including adult children, are missed.

Practical advice

The following practical advice supports the essential goal of ensuring HIV testing is completed for all children of parents living with HIV, including adult children.

Utilise network support: Advice and testing support can be accessed via the GP, local paediatric teams, or the regional HIV paediatric and adult MDT.

Verification: Never rely on verbal reports that children have been tested. HIV status must be confirmed by reviewing the laboratory result or a relevant clinical letter that details the laboratory result.

Final antibody test: A child is not confirmed HIV-negative until they have an HIV antibody test at 24 months or beyond, and if relevant, at least eight weeks after cessation of breastfeeding (even if they had negative PCR tests as an infant). Children on follow-up pathways for prevention of vertical transmission should have a final antibody test before discharge. MDT discussion is warranted if there are challenges completing this.

Tracking non-resident children: For children living outside the UK, review their country of residency at least annually and have a testing plan for if, and when, they enter the UK.

Prioritise urgent cases:

- Infants (<1 year): Test as a matter of urgency to allow for immediate initiation of ART and prophylaxis against opportunistic infections.
- Symptomatic children: Test immediately if any HIV-indicator conditions are present.
- Adolescents: Prioritise those who may be sexually active.

Collaborative follow-up: If a child misses a testing appointment, the paediatric and adult HIV teams must work together to re-engage the parent and agree a clear plan.

Consent and deadlines: For asymptomatic children over one year of age, parents may be given time (up to six months) to agree to testing, but must engage with the clinical team during this period.

If testing is not completed within six months, a discussion with the regional paediatric HIV team or MDT is necessary so that a safeguarding referral to local authority children's social care can be initiated. The same timeline should be used by adult teams for adult children.

A Practical Approach to Testing

Testing children, including adult children, whose parent(s) are living with HIV is a priority. There may be barriers that make testing challenging. Whilst recognising that local solutions may differ, this document provides some service recommendations and experience-based guidance. Knowledge and confidence in the necessity to test is important for all professionals. Additionally, peer support must be recognised as beneficial and can be invaluable in supporting testing.

Testing considerations by age

0-11 years

Infants and young children are not competent to consent to testing or treatment themselves and therefore consent is needed from someone with parental responsibility (PR), as for other tests or procedures. This can be either the mother or father, or the local authority where they hold PR. In infancy, there is a high risk of rapid HIV progression and death if HIV is untreated.

Infants under a year, and symptomatic children of any age, need immediate testing so that if the test is positive, they can start treatment. Older children should be tested as soon as possible and always within six months of recognising the need to test.

12-15 years

Adolescents aged 12-15 years should be involved in decisions around their healthcare. They should be aware of what tests they are undergoing and be able to give their assent. Children under the age of 16 can consent to their own treatment if they're believed to have enough understanding to fully appreciate what is involved. This is known as being Gillick competent. However, many parents are understandably reluctant to share their HIV status with their adolescent children. Parents have a right to confidentiality and adolescents have the right to information about tests they undergo.

A practical compromise, usually acceptable to both parents and adolescents is to explain that, as part of a health check they will have a blood test for common health problems including infections such as hepatitis B, hepatitis C, HIV, and, where appropriate, TB (for people relocating to the UK from countries of medium/high TB incidence), and haemoglobin electrophoresis (from regions with sickle cell/other). Should a positive result occur for any of the above conditions, the young person is aware that they have had the tests, and this allows a follow-up conversation so that confirmatory testing can be arranged. If the adolescent is confirmed to be living with HIV, subsequent conversations by a specialist team can explain routes of transmission and allow a wider family conversation.

Over 16

Testing young people and adults whose parents are living with HIV involves checking records for existing HIV test results. Approaches to testing may include asking GPs or relevant teams to use migrant health guidance, conducting testing as part of a routine health check or sexual health partner notification (PN) methods.

If asking a GP to test, this will likely require a phone call for detailed discussion, because the GP may not have encountered a similar request before. Suggesting use of migrant health guidance or a routine health check with other bloods, as well as checking for any indicator conditions that should prompt testing, are all options and allow testing without breaching parents' confidentiality.

Practical Steps to Manage Potential Barriers

This table identifies some potential barriers to testing and provides guidance on practical steps to take. Recent case studies, found in appendix one, highlight the necessity to follow these recommendations and ensure testing occurs.

What if..?	Recommendations
The parent(s) feel very strongly that they cannot discuss HIV with their child or are concerned about naming HIV to their child. See case study one.	Acknowledge and explore concerns or fears. Offer and arrange peer support for the parent(s). Sensitively explain to the parent(s) that under UK law you are obliged to facilitate testing and acknowledge this may differ from their country of origin.

	Agree to inform the child they are having a health check that includes testing for several infections, including HIV, but without sharing the parent's diagnosis. Encourage the parent(s) to facilitate this approach by bringing the child for the testing appointment. Inform parent(s) that if the test result is positive, discussions can be held later to explain transmission.
The child is at an age where they will ask questions or decline testing	Children and adults should have their questions answered truthfully, without breaching the parent's confidentiality. Children over the age of 16, and younger children who are Gillick competent, have the right to make an informed decision about consenting to a blood test.
The child does not live with the parent accessing HIV care, and lives with a former partner, whose HIV status is not known. See case study two.	If the birthing parent tests negative and there are no ongoing risks for transmission, then the child may not require testing Explore whether partner notification and screening is appropriate. Explain the necessity to test the child if the birthing parent is, may be, or may have been, living with HIV Agree plan to arrange HIV testing, which can be part of a routine health check. Consider involving the child's GP to facilitate this, particularly if out of area.
The child does not live in UK. See case study four.	Recommend and encourage testing in the country of residence. The child's current country of residence must be revisited in clinic appointments at least annually. Advise parents that testing will be needed when the child moves to the UK and agree how this will be facilitated.

	If a child has moved to the UK, appropriate support and a timeline must be agreed with parents.
The parent(s) struggle with stigma, guilt, and fear of a positive test. See case study one.	Acknowledge the challenges of stigma and the emotions identified. Offer and arrange peer support. Provide reassurance that children living with HIV in the UK are clear that they do not want parents to feel like this. Offer psychological intervention and referral.
The parent(s) are concerned about having to bring children to hospital for testing.	Explore reasons for this concern. Explore and arrange GP or community testing using telephone calls to the GP to ensure thorough discussion and confirmed plan. Highlight NHS Migrant Health guidance to GP and parent to support reasoning for testing without sharing the parent's diagnosis. Offer school holiday hospital or GP attendance if preferred. Offer testing at home if this is available.
Parent(s) say that the child has already been tested elsewhere, or are unsure if they have been tested. See case study one.	Acknowledge the information provided and explain that the HIV team must either see documented evidence of the child's HIV status or repeat the test. Check the child's record first, including contacting laboratories if another UK service was involved, or emergency department testing may have occurred, to obtain copies of any previous HIV tests. Explore any fears or concerns with the parent and offer peer support where helpful.

	Work with the parent to confirm a testing timeline and ensure evidence is obtained or testing is completed within six months.
The parent(s) are concerned about others knowing about their HIV and onward sharing.	Acknowledge concerns and challenges of stigma. Provide reassurance of confidentiality within services. Provide reassurance that children can also be supported to manage appropriate sharing; noting that this is explored with children receiving HIV care.
The parent(s) continue to decline to bring a child (over 18) for testing or to facilitate testing. See case study three.	Ensure peer support has been offered and arranged. Explore associated emotions and feelings. Offer psychological support and referral. Provide a sensitive but clear explanation to parents that their adult child will be contacted via contact tracing. Contact tracing, following the same process as partner notification following an adult diagnosis, may be appropriate and specialist service guidance should be sought.
The parent(s) continue to decline to bring a child (under 18) for testing or declines to facilitate testing.	Ensure peer support has been offered and arranged. Explore associated emotions and feelings. Offer psychological support and referral. Explain that it isn't necessary to share a parent's HIV diagnosis, but the child will be informed which tests are being carried out. If persistent decline passes an agreed timeline, contact your paediatric HIV service or a Lead Centre for MDT discussion and advice. The child's needs are paramount.

	Provide a sensitive but clear explanation to parents that a referral to local authority children's social care is required and will be done. Refer and liaise with local authority children's social care.
The parent(s) believe that their child has or can be cured by prayer.	Facilitate a non-judgemental discussion. Ensure peer support has been offered and arranged. Explore associated emotions and feelings. Offer psychological support and referral. Explain that the hospital needs a recorded test result, encourage testing or retesting so the evidence of the result can be discussed together. Consider involvement of faith leaders previously involved in HIV care and related literature.
The parent(s) report that the child is well and believes that this is not consistent with having undiagnosed HIV. See case study five.	Acknowledge information provided by parent. Explain the evidence that reports that children can remain symptom free into adulthood. You may wish to refer to a parent's symptom-free timeline. Provide a sensitive explanation that late diagnosis increases morbidity and mortality. Ensure peer support has been offered and arranged. Explore associated emotions and feelings. Agree testing plan. If testing plan is not agreed see above practical advice.

Discussion and support are available locally with adult or paediatric HIV services or with lead specialist centres.

For further signposting, support and advice contact:

- Chiva: chiva.org.uk/contact
- Paediatric HIV UK Lead Centres: chiva.org.uk/clinic-networks

Further resources and support for parents can be found at: chiva.org.uk and 4mmm.org

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Appendix One: Recent Case Studies

Five case studies are presented below to illustrate different, recent anonymised scenarios of testing children, young people and young adults whose parents were accessing HIV care in the UK. The case studies acknowledge challenges to testing children whilst highlighting the necessity to ensure clear pathways for all services providing care for adults living with HIV.

Case one: Reported to have been tested elsewhere

A woman who had been diagnosed with HIV 12 years earlier moved to the UK for work and engaged with local HIV care. During routine discussions, clinicians identified that she lived with her 17-year-old daughter. The woman reported that her daughter had previously tested HIV-negative outside the UK. Clinicians explained that UK guidelines require retesting when original results cannot be verified. HIV testing for the daughter was revisited at the next two appointments, and consent was eventually obtained. The test confirmed that the daughter was living with HIV. The mother initially expressed shock but later shared that her daughter had, in fact, been diagnosed at the same time as she had been, 12 years earlier. She described long-standing feelings of fear and denial.

Key messages: It is important to make earlier appointments to resolve testing issues and prevent diagnostic delay, rather than wait for routine follow up appointments, to emphasise the importance of retesting, explain the obligation to repeat a HIV test if the original result is not available, and ensure testing opportunities are not missed.

Case two: Dads are important too

A male who engaged intermittently with HIV services explained that he lived with his own mother and his fifteen-year-old daughter. No history of the daughter's biological mother was documented, and no contact details were available. Testing of the adolescent was discussed and a further appointment made to explore this in more detail. The man sadly died before his daughter was tested. The adolescent was then identified through school health records, and the school was able to share details of the next of kin. The HIV service identified that the man's HIV diagnosis was on his death certificate that had been collected by the next of kin, which provided reassurance regarding confidentiality when discussing the need to arrange testing.

The adolescent was tested and was HIV-negative. At a testing appointment three other children were identified who were living with their mother, another previous partner. She was contacted and tested negative removing the need to test the other three children.

Key messages: it is important to pursue testing of partners and former partners of men, to identify children who need testing. It is important to pursue testing of children even though there may be delays in the process.

Case three: Missed opportunities and late diagnosis

A woman in her early 20s attended a sexual health clinic for a check-up and screening. The HIV test was positive. She was born outside the UK and moved to the UK as a young child and was noted to have spent a period of time in the care system. As an adolescent she had several hospital referrals and appointments due to chronic ear infections. She discovered that both parents were accessing HIV care, although they had both had periods of time not engaged in care. A lookback showed that parents had reported that she had tested negative, but no documentation of previous HIV tests had been provided.

Key messages: Several missed opportunities for testing were identified. It is essential that HIV clinicians ask about children and confirm reported test results to avoid any misunderstanding about past test results. This confirmation should be by viewing original test results or repeating testing.

Case four: Children move to join their parents

A man in his early 20s presented to hospital with fever after returning from travel. He was born in southern Africa and moved to the UK as an adolescent. His HIV test was positive, and CD4 count under 50. He was diagnosed with disseminated TB and required a prolonged hospital stay. TB contact testing quickly found that his mother was living with diagnosed HIV and on treatment. She was known to struggle a great deal with stigma. A lookback showed that the service providing care for the mother had not identified that her son had moved to the UK.

Key messages: It is essential that clinicians ask about children and have a clear plan for testing. When children live outside the UK, testing must remain on the agenda with annual review of residency of children at HIV care appointments.

Case Five: No upper age limit with adult children

A 27-year-old woman who had moved to the UK with her parents at the age of five was recently engaged to be married. Her parents told her that they had been diagnosed with HIV when their daughter was 10 years of age, following presentation with TB. She had not been screened for either TB or HIV at that time. Home HIV testing was positive, and this was later confirmed. Her CD4 count was 220 and HIV viral load over 100,000 copies/ml. She was asymptomatic at diagnosis but had had shingles three years previously. Her partner tested negative and clinicians concluded that this was very likely vertical / early childhood-acquired HIV infection.

Key messages: All children of adults living with HIV require testing regardless of age. Missed opportunities for testing in childhood were identified, in the HIV service and other services.

Appendix Two: Clinician Letter for Personal Delivery Only (NOT TO BE SENT BY POST)

This letter provides an example for clinicians to use when communicating with parents during clinic appointments. DO NOT send this letter by post, as this may result in breaches of confidentiality, potential legal ramifications, and unintended disengagement from services.

Dear [Parent/Carer],

I am writing to explain why we need to arrange an HIV test for your child. In the UK, health professionals are required by law and national guidance to make sure that all children of parents living with HIV have had an HIV test. This is to protect your child's health and wellbeing. We understand that because of the stigma around HIV, that this can be very difficult for parents and we are here to support to you.

Why is this test important?

HIV treatment is extremely effective. Children and adults who are diagnosed early and start treatment can stay healthy and live full lives. The biggest risk to a child is not knowing they have HIV. Some children with HIV can look and feel completely well into early adulthood without any signs of illness.

How do children get HIV?

Most children who have HIV acquired it during pregnancy, birth, or breastfeeding if the mother had HIV at the time. It cannot be passed on through normal family contact.

What about confidentiality?

We understand that you may not want your child to know about your diagnosis. We can discuss the best way to test your child while respecting your privacy and supporting you. If your child is younger, only your permission is needed. Older children who can consent for themselves will need to be told what the test is for, but not necessarily about a parent's HIV diagnosis.

Why can't we wait?

Sadly, there have been cases where children became seriously unwell because their HIV was not diagnosed in time. Testing now means we can keep your child healthy. We are here to support you through every step. Please speak to me, or one of the clinical team if you would like help or further information. You can also find reliable information and family support at: www.chiva.org.uk.

Thank you for helping us to keep your child safe and well.

(Clinician Details)

Appendix Three: Peer Support Letter for Personal Delivery Only (NOT TO BE SENT BY POST)

This is a letter written by a parent living with HIV and can be used as a template which can be adapted by a local peer supporter to ensure it offers available support.

Peer support letter from a parent with lived experience which can be used as a template by local peer support services.

Dear Friend,

I'm writing to you not as a professional, but as another parent living with HIV who truly understands how heavy this can feel. I know the mix of fear, love, worry and responsibility that comes with looking after our children's health. You are your

child's champion. I also know the weight of stigma and how it can sit on your shoulders and make things feel overwhelming. I want you to know that you do not have to face this alone.

If you need someone by your side, I'm here. I will hold your hand through every part of this. If you want company, I'll come on the bus with you. If you need a moment to breathe, I'll sit with you. If you want a second opinion on your lipstick before we go, I've got you there too.

Whatever you need whether it be practical support, a listening ear, or a quiet moment; we'll face it together.

Testing your child can feel daunting, but it is also an act of love and protection for your child. You are already doing the brave thing: reaching out, asking questions, and thinking about your child's future. I want to assure you that treatment for children living with HIV is free, accessible, and very effective. Children grow up and live well with HIV with the right support.

You are caring, thoughtful and doing your very best in a situation that is not easy. Take my hand. We will do this, step by step, together.

With warmth and understanding,

Another parent who has been where you are
(Your team can connect you to your local peer support group or the 4M Mentor Mother's Group)