No one left behind: Re-engaging the 12,000 people not in HIV care

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Background

The UK Government has the opportunity to make England the first country to stop the onward transmission of HIV, and end AIDS-related deaths, by 2030. This would be a remarkable achievement and would be the first time that an epidemic had been stopped without a vaccine or a cure.

While, understandably, there has been much focus on finding the estimated 4,700 people in England living with undiagnosed HIV, there could be over double that amount of people - 12,000 - who have been diagnosed with HIV but are not currently in care for their HIV. This is equivalent to 1 in 10 people living with HIV in England. Unless those people are found, re-engaged into care, and supported to live well with their HIV, the 2030 goal will not be achieved.

This is far from being an unsolvable problem: the names of these people are known. They have been diagnosed, and they have accessed care in the past. We have the evidence that shows what programmes and interventions work to re-engage people back into care. What is now needed is political will, funding, and a strategic approach.

The definition for the purpose of this report of a person not in care is someone who hasn't attended their HIV clinic for over 15 months. This is very often because of complexities, needs and challenges that they experience in their daily lives (for example poverty, insecure housing, poor mental health, drug and alcohol addiction) as well as negative and stigmatising experiences they have had in healthcare. Viral rebound can begin as early as 3 to 6 days after stopping HIV treatment, increasing the risk of onward HIV transmission and weakening the immune system, which can lead to serious illnesses.[1]

Re-engaging people to care must be a key priority in the Government's next HIV Action Plan. The numbers and scale of people not in HIV care now demands a national strategic approach supported with appropriate funding. To have got to the point where 1 in 10 people living with HIV are not in care is a huge concern and requires us to think differently - it now looks like more of a feature of our system, rather than a bug - and the solutions must meet the scale of the problem.

> **Unless there is a targeted, strategic approach to bring people back into care, England will fail to meet its 2030 HIV targets. Next steps must be:**

- **A national HIV Retention and Re-engagement programme.** Building on successful work by HIV clinics and voluntary organisations across the country which demonstrated how people can be re-engaged in care,the Department of Health and Social Care (DHSC) should work with NHS England to commission a national programme for retention and re-engagement.
- **NHS England ensuring that HIV services in every Integrated Care Board (ICB) provide high quality, person-centred HIV care and psychological support.** The national service specifications for adult specialised services for people living with HIV[2] (including HIV services having 'protocols for those who are lost to follow up') and BHIVA Standards of Care for Living with HIV must be met in every ICB to ensure wherever someone living with HIV lives, they can access high-quality, person-centred care.
- **Guaranteed access to psychosocial support including peer support.** DHSC, in partnership with ICBs and local authorities, should provide a national guarantee for psychosocial support services including HIV peer support. This should incorporate in-community, in clinic and online methods to ensure that people living with HIV have access to peer support as part of their care pathway and can access it whenever they need. HIV advice, support and information services should be considered as part of the 'support' offer, and peer support should not be delivered in isolation.
- **DHSC and NHS England ensuring training and awareness-raising programmes are in place in all healthcare settings** so that staff have the right knowledge on HIV and no one living with HIV experiences discrimination.

This report has been informed by a parliamentary roundtable that the National AIDS Trust convened with the All-Party Parliamentary Group on HIV & Sexual Health in April 2025. This meeting brought together multi-stakeholders leaders in the UK's HIV response - voluntary sector and community leaders, clinicians, civil servants, researchers, and parliamentarians. It featured presentations from the UK Health Security Agency, clinicians in South East London and the Terrence Higgins Trust.

Disengagement: A costly risk for health and the NHS

Numbers of people disengaged from HIV care

As of December 2023,

4,960

adults with HIV in England had not been seen in care for at least 15 months.[3]

However, when the scope is widened to include those not seen since 2017, the number rises significantly to

12,065

- about 10% of all people living with HIV in England.[4]

England has exceeded UNAIDS' 95-95-95 targets for the HIV response which aim for 95% of people living with HIV to know their status, 95% of those diagnosed to be on antiretroviral therapy, and 95% of those on ART to achieve viral suppression. However, when people disengaged from care are included, England's figures fall short of UNAIDS' 2025 goals.[5]

UKHSA has highlighted that marked inequalities exist for people out of care, with higher rates of disengagement among Black African women, people born abroad, and young people.

Disengagement from care costs the healthcare system at every stage: HIV clinics lose time on missed appointments, untreated HIV often leads to costly inpatient admissions; and new cases of HIV, resulting from onward transmission, create lifelong care costs.

For example, in 2019 at Guy's and St Thomas' hospital alone, the cost of inpatient care for people out of HIV care was over

£408,135

in a single year [6]

Supporting people to live well with HIV and maintain an undetectable viral load also means they cannot pass the virus on.

This not only prevents new HIV transmissions - and the potentially life-changing impact on people - but also avoids lifetime care costs estimated at

£220,000

per person

Why people disengage: Inequality, stigma and systemic barriers to care

The reasons people disengage from care are often complex and reflective of broader health inequalities, including stigma, mental ill health, poverty, substance use.

Data from South East London's re-engagement programme highlights that those who were re-engaged to care were experiencing a range of barriers to engagement, with high proportions of competing social and economic needs:

- Persistent stigma, both external and internalised, which create barriers to HIV care. This is seen by how one in seven people living with HIV in the UK report that they avoided accessing healthcare services because of their HIV status.[7]
- Poor mental health, often untreated, which can hinder health-seeking behaviours and retention in care.
- Many patients are migrants with insecure immigration status and limited awareness of their rights including access to HIV treatment.
- Economic deprivation, food insecurity, insecure housing and homelessness, and intimate partner violence which create direct barriers preventing people engaging with healthcare.
- Standard clinical systems (limited hours, strict appointment rules, lack of continuity) which can fail to meet people where they are including difficulties surrounding work commitments, child care and travel to clinics.

At the roundtable, a researcher who worked on the SHIELD Study on retention to care shared that their research found that there are patient, service and system level interactions that are harmful to engagement[8]:

- At the patient level; social and economic factors, treatment fatigue, competing priorities, stigma, and care triggering past trauma all negatively affect engagement.
- At the service level; accessibility, flexibility and personalised approaches were seen as central to building trust and patient-centred relationships.
- And at the system level; the lack of prioritisation of engagement, precarious funding for support services, and a lack of reliable data and data sharing across clinics were found to harm engagement.

Re-engagement in action: Learning the lessons from successful local projects

Getting to Zero re-engagement project

In partnership with The Food Chain, 4M Mentor Mothers Network and Africa Advocacy Foundation, Terrence Higgins Trust have established a care coordination service which is funded by Fast Track Cities London. The project supports people disengaged from care to identify barriers to care and supports them to overcome them. The Terrence Higgins Trust HIV Care Coordinator works across six HIV clinics in London, with limited access to patient data and an honorary contract.

One-to-one support with a care coordinator is used to discuss:

- **Concerns about care, treatment and the importance of adherence**
- **Psychological support to process diagnosis and address self-stigma and/or denial**
- **Access to food and nutrition support, financial, housing and immigration support and peer support**

Since the programme was established in 2024, 46 referrals have been made from 6 clinics across London.

Underscoring the barriers to care faced by migrants living with HIV, at the roundtable, Terrence Higgins Trust's Care Coordinator shared the experience of a woman living with HIV who was trafficked to the UK, who was then supported by their service.

The Care Coordinator explained that, due to her immigration status and housing issues, taking medication was the least of this woman's concerns. She was referred to Terrence Higgins Trust's re-engagement service and was then connected with African Advocacy Foundation for housing advice, 4MNet for one-to-one peer mentoring, and Food Chain for nutritional support. With help from these voluntary sector organisations, she resolved an error on her name with the Home Office, secured access to Universal Credit, and is now bidding for housing. With these wider needs addressed, she has re-engaged with her clinic and is adhering to her treatment.

70%

of people supported by the service are now better engaging with their clinic, attending appointments and taking their medication.

> **"I'm feeling on top of things now, mentally I'm in a good place and physically I'm getting much better and more mobile, more than I thought I was going to be. I'm now taking my medications every day"**
>
> - A service user of the care coordination service.

South East London re-engagement programme

In South East London, doctors observed that the majority of patients admitted with HIV related illness were known to have HIV and no longer in care rather than new diagnoses. A project involving three hospital trusts in South London sought to re-engage people living with HIV. It was initially funded by Elton John AIDS Foundation's Social Impact Bond and after its success, continued funding from the South East London ICB was secured.

The programme re-engaged

197

patients across a two year period, 96 in 2022/23 and 101 in 2023/24

These patients were systematically re-engaged using a range of methods, with

87%

of patients being re-engaged directly by the re-engagement team

Highlighting the risk to their health, a third had a CD4 of <200 at re-engagement and half had a CD4 of less than 350 cells/ml. CD4 cell counts give an indication of the health of someone's immune system. The lower the CD4 cell count, the greater the damage to the immune system and the greater the risk of life threatening illness. People living with HIV who have a CD4 count below 200 are at high risk of developing serious illnesses. 78% of patients were initiated on antiretroviral therapy upon re-engagement, with 70% achieving an undetectable viral load that means HIV can't be passed on through sex (U=U).

The programme found that the re-engaged cohort experience a range of barriers to engagement into care, with high proportions of competing social and economic needs. Key barriers to care include poor mental health, stigma, unemployment and drug and alcohol misuse. Women, individuals of Black ethnicity, and people in the most deprived areas were disproportionately affected.

These barriers are leading to devastating preventable morbidity and mortality. One example involved a 45-year-old man who had been out of care for several years and presented with a headache. His CD4 count was just 8, and he was diagnosed with cryptococcal meningitis. Despite appropriate treatment, he went blind and died after a three-month hospital admission.

The programme found that effective re-engagement requires a tailored, individualised approach. In their presentation, they highlighted best practices for supporting retention in care - including providing bus and food vouchers, referring to peer mentors, offering outreach clinics and community visits, ensuring a named, contactable person in clinic, and enabling two-way communication via smartphone.

The project costs South East London ICB £170,000 per year, with three trusts receiving £56,000 per year of the project. Their presentation noted that £56,000 per annum, per trust is cost-saving, considering the averted hospitalisations.

South East London HIV clinicians have highlighted that at a minimum, all clinics should have a loss to follow up contact, review UKHSA data on people not in care and revert back, ensure staff have a flexible understanding attitude and ensure that there is better communication between community organisations. However, to strengthen approaches to re-engagement, they recommend interventions including funded teams of case-workers doing outreach; strengthening secondary care's partnerships and pathways with other services, a dedication navigation phone line/website/email for those out of care, and functional networks of clinical and third sector organisations including commissioning of peer mentors.

George House Trust's Intensive Support Service

Funded through Greater Manchester's ICB, George House Trust's Intensive Support Service provides person-centred social and wellbeing support to people living with HIV who are experiencing significant challenges with engagement with their HIV care.

The one-to-one support follows a referral from the clinic for any patients with a detectable viral load. The support aims to address social problems in order to overcome barriers they face, recognising the impact of external factors on individuals that prevent the effective management of their HIV.

The programme works to support the individual in an accessible and straightforward way, with a single access point via the Intensive Support Worker that is embedded within the HIV clinical multidisciplinary teams. This enables a stronger understanding of the holistic needs of the individual, together with an understanding of their history and their barriers to engagement.

57%

of people supported through the programme had attained an undetectable viral load,

95%

had improved their engagement with clinical appointments and

78%

reported an improvement in their emotional health and

83%

an increase in their overall wellbeing

These impactful, cost-effective projects demonstrate that there is not a one-size fits all approach to re-engagement and retention in care, although there are patterns. Work to re-engage people in care requires a flexible and personalised approach and will vary depending on the demographics of an area and the needs of particular communities.

The case studies highlight the critical role of multidisciplinary partnerships and the key role of the HIV voluntary sector in overcoming the complex, intersecting barriers to care. Effective re-engagement work requires close collaboration between clinicians and voluntary sector organisations. The HIV voluntary sector offers unique reach, trusted relationships with communities, and high-quality person-centred care which makes them well-placed to partner with clinicians and lead re-engagement interventions. There is limited clinic and voluntary sector capacity to deliver re-engagement work without dedicated funding (as was secured in South East London) and it is time intensive. This means further investment is urgently needed to scale and sustain re-engagement efforts.

The delegation of specialised services to ICBs includes commissioning retention and re-engagement interventions and ensuring that HIV services within their ICB are sufficiently resourced to meet BHIVA Standards and the NHS service specification for specialised services for people living with HIV.

However whilst there are pockets of good practice in certain ICBs, the vast majority have not prioritised their HIV response and do not have dedicated funding for either clinical or voluntary-sector led work focused on supporting re-engagement to care. This makes consistent, structured re-engagement initiatives difficult to initiate, sustain or scale. HIV voluntary sector representatives and clinicians have also highlighted significant challenges in engaging with ICBs - both in consultations on service development and strategies, and for the commissioning of needed services.[9]

Without national leadership and investment from DHSC and NHS England, retention and re-engagement in HIV care risks becoming patchy and uneven across England. Relying solely on the discretion of ICBs could result in some areas - such as London and Manchester - offering structured services to support people back into care, while people living with HIV elsewhere are left without support. This will deepen regional health inequalities and undermine the UK's ability to meet the 2030 targets. We are already seeing these disparities in action. In the North East of England - a region with limited NHS funding for HIV support services and re-engagement interventions - 1 in 8 people living with diagnosed HIV are disengaged from care.[10]

Tackling HIV stigma and discrimination

With HIV stigma being a key barrier to retention in care, everyone living with HIV must feel safe and confident in every healthcare setting that they go to.

At the roundtable, a representative from community organisation, 4M Mentor Mothers, shared that for a lot of people living with HIV 'they don't want to attend a clinic for fear of being seen by other people from their local community'. A representative from George House Trust, shared that a man living with HIV was recently referred to their organisation's 'Intensive Support Service' after he stopped engaging with his HIV care because he was frightened that his eye-clinic might find out that he's living with HIV. A London HIV clinician also shared that a woman disengaged from care after feeling stigmatised during childbirth. Because of this, she went on to buy her medication from abroad for ten years which led to drug resistance.

There is a need to address disengagement from care linked to alcohol and drug misuse. For example, at the roundtable, a representative from the Terrence Higgins Trust highlighted: "For gay men, a really particular issue... turning to chemsex... but the drugs involved are so addictive that people move from highly functioning to spiral addiction suddenly". Chemsex among people living with HIV often intersects with stigma and feelings of shame - with some seeking sex free from the weight of thinking about their HIV status. It was also noted that "traditional drug and alcohol services really don't cater for the cohort involved," creating additional barriers for people to access addiction support and pathways back into HIV care.

There are successful interventions which are tackling HIV stigma in the health service. For example, in the mandatory training in NHS Manchester Foundation Trust, an HIV stigma learning module has been completed by over 20,000 individuals, and HIV Confident[11] - a charter mark delivered by National AIDS Trust and Positively UK, is training thousands of clinical and non-clinical staff in healthcare settings that are part of the programme.

The need for this training is underscored by survey data from the pilot phase of the HIV Confident charter mark which showed that among NHS staff there are misconceptions about transmissions with 23% mistakenly believing that HIV could be passed on by spitting and 14% saying that they would feel at risk if they were looking after someone living with HIV.[12] Fears of transmission lead to discriminatory practices as indicated by 37% of NHS staff respondents who agreed that staff should take extra precautions when caring for a patient living with HIV.[13]

To ensure NHS staff have more confidence when caring for patients living with HIV, and to ensure people living with HIV have more confidence to engage with NHS services, the next HIV Action Plan should fund and champion training programmes that we know improve awareness and confidence in healthcare settings.

The case for a national HIV Retention and Re-engagement programme

Rapid access to treatment and retention in care was a key objective of the first HIV Action Plan - but the Plan failed to tackle the urgent challenge of re-engaging people living with HIV who are disengaged from care. The scale of this challenge is now far better understood and significantly greater than when the first Action Plan was published. Re-engagement in care must be a central priority of the next phase if we are serious about ending new HIV transmissions and tackling health inequalities.

To ensure a strategic approach and that we deliver at the needed scale, National AIDS Trust, Terrence Higgins Trust and the Elton John AIDS Foundation's 'Getting on track' report recommends that DHSC should work with NHS England to commission national HIV Retention and Re-engagement programme.[14]

The economic case for a national programme is clear. Preventable hospital admissions and onward HIV transmission carry significant costs.

The cost of a single inpatient stay for someone disengaged from HIV can be above

£100,000[15]

By contrast, the cost of re-engaging a patient - through outreach, peer support, and care navigation - is estimated at just £3,000–£5,000 per person.

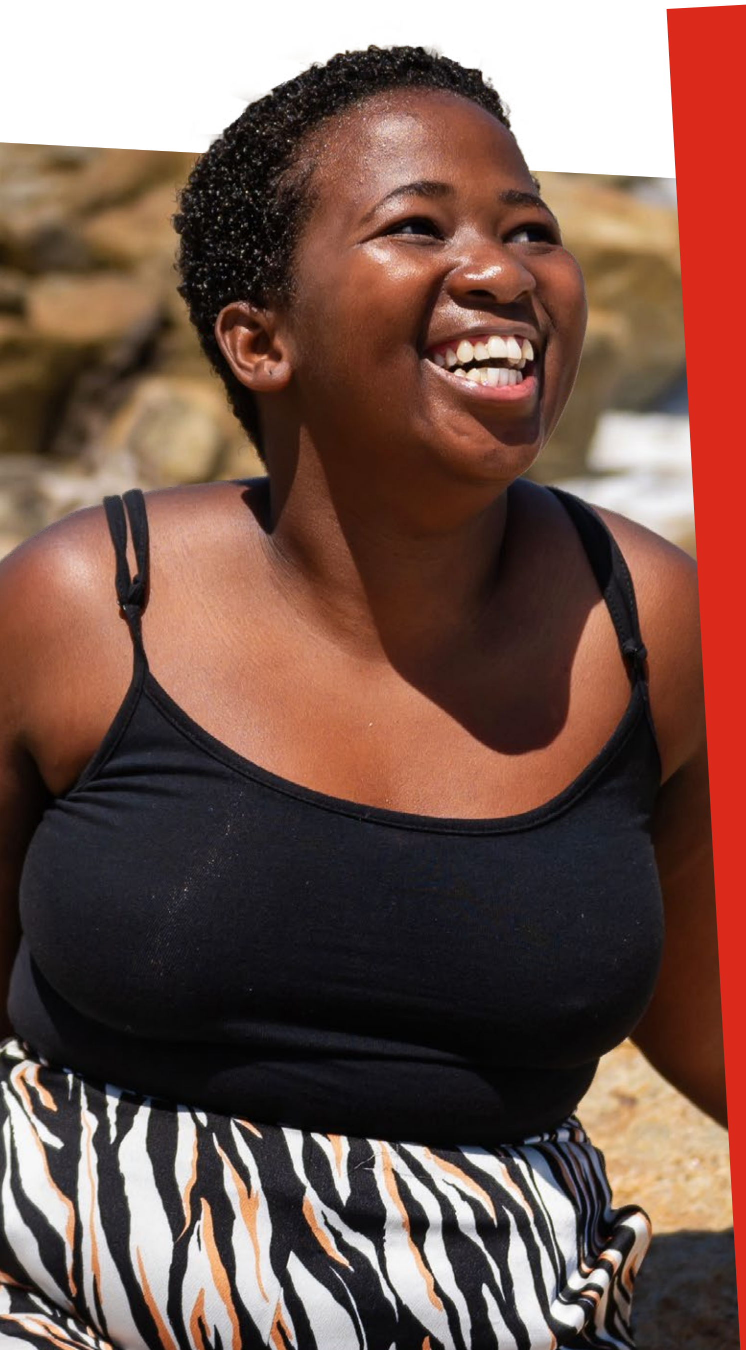
Key to a national programme should be harnessing multidisciplinary partnerships and the leadership of the HIV voluntary sector and communities living with HIV. The 10 Year Health Plan recognises that more integrated working between the NHS and the voluntary sector can deliver large efficiencies and the sector has 'all have the ideas, networks and drive to transform outcomes for patients'.[16] This opportunity is clear for the HIV response given that the HIV voluntary sector offers unique reach, trusted relationships with communities, and high-quality person-centred care.

As detailed in a previous Terrence Higgins Trust proposal to the Government for a national re-engagement programme, the commissioning of the voluntary sector to build a national team of dedicated support workers that are seconded to HIV clinics could be a key component. Voluntary sector employees could lead work to re-engage patients but be embedded in the HIV clinic and have access to NHS databases. In smaller HIV clinics or lower prevalence areas, the coordinator could work across a number of clinics and take learning from each clinic.

As part of a national programme, there would likely be a lead voluntary sector partner (the contract holder) but a network of regional or sub-London partners that take an area lead across a number of clinics. The voluntary sector would also be well placed to co-design with service users a concurrent national health promotion campaign to re-engage people in care and run a national helpline that would be a single contact point for people not in care. Building on learnings from Terrence Higgins Trust's HIV Reconnect Project (funded by ViiV Healthcare) that is entering the development phase, such a helpline would signpost people to local HIV and wider support services and support them to re-engage with care.

Any national HIV Retention and Re-engagement programme must be locally informed and delivered. Re-engagement interventions are most effective, and best value for money, when rooted in local systems and where trusted relationships and partnerships exist between clinics, voluntary sector organisations, commissioners and wider support services. In line with commitments from the 10 Year Health Plan, and building on the precedent of the roll-out of the national opt-out BBV testing programme in A&E's, Integrated Care Systems and local stakeholders should be empowered to co-design and lead re-engagement strategies tailored to the specific needs of their populations. It is also important to ensure that national investment complements - not displaces - any existing ICS-level investment for retention and re-engagement interventions that are already underway.

People who struggle to engage with HIV care can face complex and interrelated challenges - such as disability, poor mental health, insecure housing, substance use, or caring responsibilities - that may not be able to be addressed by clinical and HIV voluntary sector services alone. Strengthening partnerships and establishing formal referral pathways into adult social care would help ensure people receive coordinated, whole-person support that tackles the root causes of disengagement. As the population of people living with HIV ages and social needs increase, multidisciplinary working and investment in adult social care will be essential to delivering effective and sustainable re-engagement interventions.



There are many areas of strong alignment to the Government's 10 Year Health Plan that national HIV Retention and Re-engagement programme would bring:

- From sickness to prevention: Re-engaging people in HIV care is a clear act of prevention - reducing avoidable illness, stopping onward transmission of HIV, and preventing expensive hospital admissions.
- From hospital to community: A national programme would exemplify the move toward community-based care, proactively identifying people who have disengaged and supporting them through community and nurse-led outreach, voluntary sector partnerships and trusted local clinics. Re-engagement interventions and holistic support for people living with HIV could also be integrated into plans for the Neighbourhood Health Service.
- From analogue to digital: Harnessing digital tools such as plans for a single electronic patient record and national surveillance systems can help identify those out of care and at risk of disengagement, enabling services to better coordinate, design targeted interventions, and provide more personalised, predictive support. A national programme would also be a leading example of how digital transformation can strengthen care pathways and improve outcomes.

At the roundtable, it was also shared that HIV re-engagement interventions are a 'really transferable model of care and relevant for other important conditions'. To support the wider delivery of the 10 Year Health Plan, the Government and NHS could use a national HIV Retention and Re-engagement programme to build learnings to support retention and re-engagement across other long-term conditions.

The next HIV Action Plan must set out a clear, strategic approach to ensure that everyone living with HIV has the support they need to access care. With strong national leadership and targeted investment, this growing crisis can be addressed and thousands of people can receive the life-saving treatment they need, taking England closer to achieving the 2030 goal.

This strategic approach must include:

- **A national HIV Retention and Re-engagement programme.** Building on successful work by HIV clinics and voluntary organisations across the country which demonstrated how people can be re-engaged in care, DHSC should work with NHS England to commission a national programme for retention and re-engagement.
- **NHS England ensuring that HIV services in every ICB provide high quality, person-centred HIV care and psychological support.** The national service specifications for adult specialised services for people living with HIV[17] (including HIV services having 'protocols for those who are lost to follow up') and BHIVA Standards of Care for Living with HIV must be met in every ICB to ensure wherever someone living with HIV lives, they can access high-quality, person-centred care.
- **Guaranteed access to psychosocial support including peer support.** DHSC, in partnership with ICBs and local authorities, should provide a national guarantee for psychosocial support services including HIV peer support. This should incorporate in-community, in clinic and online methods to ensure that people living with HIV have access to peer support as part of their care pathway and can access it whenever they need. HIV advice, support and information services should be considered as part of the 'support' offer, and peer support should not be delivered in isolation.
- **DHSC and NHS England ensuring training and awareness-raising programmes are in place in all healthcare settings** so that staff have the right knowledge on HIV and no one living with HIV experiences discrimination.

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