

Working together



The HIV Outcomes UK programme is funded by Gilead Sciences, ViiV Healthcare and MSD as co-sponsors. Editorial control sits with National AIDS Trust

Towards improving the experience of people living with HIV in primary and secondary care:

A discussion paper on potential role of collaborative care frameworks

How could HIV care be better experienced as a long-term condition

Advances in HIV treatment and care have led to improved health outcomes, meaning that people living with HIV can now live long and healthy lives. HIV is now a manageable long-term condition, but in many ways our health system is often playing catch-up in how it recognises and delivers HIV care and treatment.

While people living with HIV in the UK highly rate the quality and experience of care they receive at their HIV clinics, satisfaction with general practice was substantially lower.¹ In addition, the management and lived experience of HIV is now much more comparable to that of a recognised long-term condition (LTC) than previously, so the current approach to coordination between HIV care, primary care and other secondary care may require a different approach.

HIV is increasingly understood as a condition characterised by ageing, multimorbidity, polypharmacy and complex social needs.² In this context, a predominantly specialist model where all aspects of care are treated by HIV clinicians throughout the patient's life — while other care is the responsibility of primary or other secondary care — may result in fragmentation, and poorer access and availability to care and treatment that could be more accessible, more convenient, and closer to home for individuals.

'Long-term condition' is a specific term in the NHS. Recognised LTCs are chronic health issues that cannot be cured but are managed through medication or therapy, typically lasting over a year. Current examples include diabetes, asthma, COPD, cardiovascular diseases (like heart failure), epilepsy, dementia, arthritis, and multiple sclerosis (MS). Long-term conditions often involve management, screening and secondary prevention of co-existing conditions as well as polypharmacy. The patient with an LTC may be under specialist care or require the input of more than one healthcare service beyond their GP. LTCs are a specific area where NHS England targets improvements in care.^{3 4}

HIV is not currently formally recognised as an LTC within the NHS, meaning that people living with HIV may not be receiving the best options and opportunities of care available to people living with other LTCs.⁵ This is particularly the case in relation to the experience and care that people living with HIV get within primary care services, and what they access through non-HIV specialist care. HIV not being a formal LTC also makes it less straightforward for GPs to deliver the best coordinated care for their patients as formal pathways are not in place.

1. UK Health Security Agency (2024) Positive Voices 2022: survey report. Available at: <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report> [Accessed September 2026]
2. Whole Person Care Partnership (2022) Fifty over fifty. Available at: <https://www.hivwholepersoncare.co.uk/wp-content/uploads/sites/511/2024/10/Fifty-Over-50-E-Book.pdf> [Accessed September 2026]
3. NHS England, Long term conditions. Available at: <https://www.england.nhs.uk/ourwork/clinical-policy/ltc/> [Accessed September 2026]
4. UK Government (2025) 10 Year Health Plan. Available at: <https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future/fit-for-the-future-10-year-health-plan-for-england-executive-summary> [Accessed September 2026]
5. LTCs that qualify for medical exemption certificates are listed at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/medical-exemption-certificates> [Accessed September 2026]

At a time when NHS England is going through fundamental changes in its organisational arrangements, and alongside the publication of the Government's 10 Year Health Plan⁶ which outlines three significant shifts in future healthcare (sickness to prevention, hospital to community, analogue to digital), it is the right time to consider whether and how some people living with HIV could benefit from primary care interventions that support the management of LTCs. This does not presume direct HIV-related care is transferred to primary care — the role of the specialist remains fundamental.

As part of the journey towards HIV being recognised as a long-term condition to realise the benefits of greater integration into primary care (as recommended in the evaluation of the London HIV GP Champions Pilot Project Service Evaluation⁷) this paper puts forward the case for enhanced care collaboration between primary and secondary care. It also responds to clinical and international consensus that the long-term management of HIV requires greater involvement from primary care^{8,9}, as well as the targets of the UK Government's HIV Action Plan for England 2025–2030, which highlights that strong links between primary and specialist care are key to ensuring people are linked and retained to care.¹⁰ It also recognises the House of Care framework that provides for a coordinated service model that enables patients with long-term conditions and clinicians to work together to determine and shape the support needed to enable them to live well with their condition.¹¹

While some people living with HIV are increasingly receiving enhanced, HIV-informed care from their GP in certain practices, both access to this in England and the framework used remain inconsistent. This variation may reflect differences in local primary and specialist care relationships, levels of HIV knowledge and confidence within primary care, available resources and training, and the absence of a nationally agreed framework for collaborative care. This proposal seeks to build on existing good practice by establishing a formal collaborative care framework between primary and specialist services, creating a co-created consistent model that can be adopted and scaled across England.

This paper has been developed as part of HIV Outcomes UK's work to improve health-related quality of life for people living with HIV. It has been brought together through desk research and engagement with multi-sectoral stakeholders including clinicians (HIV clinicians and GPs) and communities living with HIV. While this paper focuses on the NHS in England, the principles of collaborative care described here may also be relevant to the devolved nations, and we encourage consideration of how similar approaches could be adapted and implemented within their respective health systems.

6. UK Government (2025) 10 Year Health Plan. Available at: <https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future/fit-for-the-future-10-year-health-plan-for-england-executive-summary> [Accessed September 2026]
7. King's Business School (2025) London HIV GP Champions Pilot Project Evaluation. Available at: https://fasttrackcities.london/wp-content/uploads/2025/09/London-HIV-GP-Champions-Pilot-Project-Service-Evaluation_Sept2025.pdf [Accessed September 2026]
8. British HIV Association (2018) Standards of Care for people living with HIV. Available at: <https://bhiva.org/standards-of-care-2018/> [Accessed September 2026]
9. UNAIDS (2026) Global AIDS Strategy for 2026–2031. Available at: <https://www.unaids.org/sites/default/files/2026-04/2026%E2%80%932031-GLOBAL-AIDS-Strategy.pdf> [Accessed September 2026]
10. UK Government (2025) HIV Action Plan for England. Available at: <https://www.gov.uk/government/publications/hiv-action-plan-for-england-2025-to-2030/hiv-action-plan-for-england-2025-to-2030> [Accessed September 2026]
11. Coulter, A et al (2016) Building the House of Care for people with long-term conditions: the foundation of the House of Care framework. Available at: <https://bjgp.org/content/66/645/e288> [Accessed September 2026]

Delivering collaborative care at scale will require coordinated action across the health system and co-creation with people living with HIV. The following recommendations set out the key actions that different stakeholders can take to support the development, implementation and adoption of collaborative care frameworks:

Primary and secondary care providers, commissioners, patient representatives and HIV voluntary sector

- Establish a multi-stakeholder implementation group to co-produce the template collaborative care framework and implementation programme.
- When established, DHSC, Integrated Care Boards and Primary Care Networks should promote the adoption of collaborative care frameworks and encourage GP practices to proactively offer it to eligible people living with HIV.

GPs and primary care teams

- Consider adopting collaborative care frameworks for people living with HIV and offer participation where it aligns with the patient's needs and preferences.
- Build confidence and capability in HIV care through strengthening partnerships with specialist HIV services and participating in training, including the HIV Confident charter e-learning programme¹², and endorse the One Voice Network's HIV Patient Charter¹³ to support person-centred, inclusive, stigma-free care.

Specialist HIV services and secondary care providers

- Consider collaborative care frameworks for people living with HIV and encourage eligible patients to consider discussing establishing a collaborative care arrangement with their GP.
- Strengthen partnerships with GPs and primary care teams by establishing clear communication channels, providing timely clinical information, and offering access to specialist advice and support.

People living with HIV

- Consider whether a collaborative care framework could help meet your wider health and wellbeing needs, and discuss this with your HIV clinic and GP.
- Play an active role in shaping and evaluating collaborative care models by sharing experiences and preferences with healthcare providers, commissioners and the voluntary sector.

12. HIV Confident. Available at: <https://www.hivconfident.org.uk/> [Accessed September 2026]

13. One Voice Network (2026) Voices like mine: HIV Patient Charter. Available at: <https://www.onevoicenet.org/voiceslikeminehivpatientcharter> [Accessed September 2026]

2. How might collaborative care deliver better outcomes for people living with HIV

‘Shared care’ is a formal local agreement involving the patient, and with their agreement, that enables General Practitioners (GPs) to accept responsibility for the prescribing and monitoring of specialist medicines. Sharing care through a collaborative care framework is not a transfer of risk; it is a structured partnership between primary and secondary care that clarifies who does what, what information is shared, and when escalation and referrals should take place.

This could mean that for people living with HIV, the GP would be able to manage and monitor comorbidities in primary care including, but not limited to cardiovascular disease, high blood pressure, diabetes, and osteoporosis. While it is possible that GPs could in theory cover all of these areas, some will need HIV specialist input, so it may be beneficial to start with conditions that are more common and that GPs are well-placed to respond to — for example, hypertension and diabetes. As the population of people living with HIV ages, the prevalence of comorbidities and potential role for management by GPs increases.

Collaborative care does not, however, intend to be for prescribing Antiretroviral Therapy (ART) — this would remain the responsibility and role for specialist HIV services.

It is important to note that the proposal that is set out here is aligned with what is considered the general approach and normal standard of care in NHS General Practice. It is not setting out an expectation that GPs take on extra workload that they would not already do to optimise outcomes for any of their patients, but adds in a standardised approach to enable them to offer people living with HIV the same enhanced level of care from their GPs as those living with other LTCs.

2.1 What collaborative care for HIV could look like

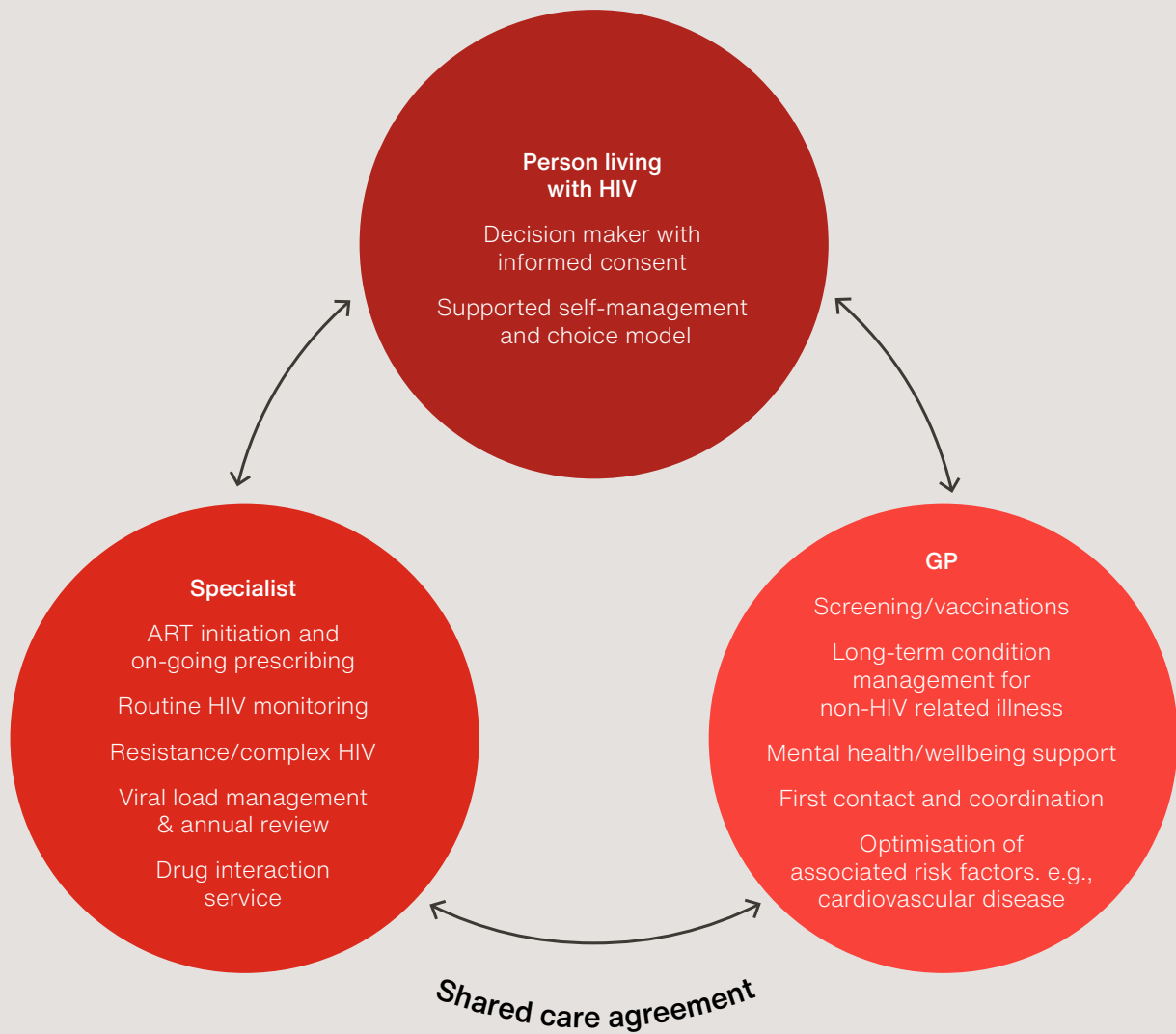
Agreement on how care is delivered between primary and secondary care can be set out in the form of a collaborative care framework. The person living with HIV is the decision-maker with informed consent on whether they want to establish, and remain in, a collaborative care framework. This is a written agreement, discussed and agreed to by the patient, that puts in place a basis for collaboration between primary and secondary care. It clarifies the roles of GPs and secondary care providers, so that everyone — the patient, the GP, and the specialist — has a clear idea of who is responsible for what, and gives reassurance to the patient about who is managing what in relation to their healthcare.

Where a collaborative care framework is in place and agreed to by the GP, specialist service and patient, specialist HIV services and primary care would jointly support the person living with HIV. Specialist teams would retain overall responsibility for HIV treatment, monitoring, resistance and complexity; primary care provides holistic healthcare, long-term condition management, integration with co-morbidities and coordinates wider support.

Alongside the collaborative care framework, it would also be important to consider who the nominated ‘care coordinator’ is for people with higher levels of health and care need.

People with higher levels of clinical and social need may benefit even more from enhanced collaboration between primary and specialist services. For these individuals, the collaborative care framework would require more intensive coordination and robust pathways. Greater involvement of primary care can help ensure that people remain connected to healthcare services, reduce the risk of disengagement from HIV care, and provide additional opportunities to identify concerns early and coordinate support across services.

Collaborative care diagram



Key:

Specialist HIV services remain the clinical anchor for HIV-specific care; primary care coordinates holistic healthcare and prevention, with rapid escalation back to specialists when needed.

2.2 What is needed to make collaborative care work

- Named specialist contact and rapid advice routes for GPs.
- Clear eligibility and review criteria (including reversion to specialist-led care when needed).
- Timely, high-quality communication (clinic letters, medication lists, interaction warnings) and the technology to assist this.
- Funded training and stigma reduction support in primary care.
- Co-production with people living with HIV and community organisations.
- Named care coordinator for people with higher levels of health and care need, and personalised care plan (although it is noted that the key issue of who funds this needs to be determined).
- Primary care provided with information on HIV specific wellbeing/mental health resources available locally.
- Equity should be a core implementation principle, recognising that people living with HIV do not experience primary care equally. Collaborative care frameworks should be designed and evaluated to address barriers related to stigma, discrimination and wider social determinants of health.

3. What could be the benefits of collaborative care?

3.1 Better outcomes through prevention and long-term condition management

Primary care is, and should be, the main source of prevention and long-term condition management. Enhancing GP involvement in the management of HIV would enable systematic screening, risk reduction and earlier intervention, particularly for cardiovascular risk, metabolic disease, renal function, bone health and mental wellbeing.

3.2 Better experience: continuity, access and whole-person care

The collaborative care concept can support a shift from disease-specific care to person-centred care. For many patients, the GP is the most accessible clinician and the coordinator of care across health conditions, as well as social and welfare needs when they affect health outcomes.

With many people only seeing their HIV consultant once or twice a year, it is important that the quality of that time is as high and beneficial as possible. Patients could benefit from a better schedule of appropriate clinical appointments, which means they are seen at the right time by the right clinical expert. For example, there could be an annual consultant review and a further review six months later by a GP or Nurse Practitioner providing regular monitoring and helping to ensure that all health and care needs are met. This could result in people getting better care but with fewer appointments.

Snapshot case study: initiating statins in primary care for people living with HIV

A project was undertaken in Islington to support Practice based pharmacists in primary care to identify patients living with HIV who were eligible for statin initiation following the BHIVA rapid guidance and invited the patients for a consultation to discuss. The project started more than a third of eligible patients on a statin in primary care, helping to support the care being offered by their HIV clinics.

Statin initiation for primary prevention is business as usual in primary care for other conditions so it utilised the skills of the primary care workforce and allowed patients to access care closer to home with the opportunity for ongoing support and review in primary care.

A model collaborative care framework can standardise the provision of statins in primary care enhancing the accessibility and consistency of approach for people living with HIV who are eligible for statin initiation.

A collaborative care framework could help ensure specialist time is focused on complexity (e.g., detectable HIV, resistance, complex interactions, pregnancy, comorbid complications) while routine long-term condition care is delivered through primary care and community pathways, where dedicated specialist services (e.g. frailty, joint CV clinic, joint renal clinic, etc) are not available within an HIV clinic, or difficult to access.

3.3 Equity and consistency

A national template for collaborative care would go towards reducing postcode variation and provide commissioners with a common framework. It also supports consistent engagement with Integrated Care Board priorities on integrated care and health inequalities.

Stakeholder	Key benefits	Risk – and management
People living with HIV	Able to access routine care and monitoring more easily (close to home, easier to get an appointment) Means their GP can have a better holistic overview of the patient's needs and wellbeing Can more easily understand and access management of comorbidities and polypharmacy Potential for fewer clinical appointments when organised as alternating visits Current poor communications around blood test results not being shared with health care providers would be eliminated, requiring fewer blood tests	Must be done only with full informed agreement of the patient Need for reassurance on data privacy and confidentiality Issue of communications being problematic between primary and secondary care. This can be mitigated through the NHS requirement to move from analogue to digital including implementation of the Single Patient Record
General Practitioner	Able to better respond to full needs of their patient Can better coordinate care and referrals across the system (Screening, vaccinations, management of risk factors for associated conditions, optimising of general health and wellbeing in context of living with HIV)	Training and awareness of HIV and stigma Consistency across primary care
Specialist care	Confidence that the patient is able to receive more holistic care at their convenience Capacity in clinic improves	That any referrals and appropriate issues related to HIV care and medication are made as expected

4. How could a national approach to collaborative care for people living with HIV be introduced?

4.1 Initial implementation programme (12–18 months)

1. Co-produce the collaborative care framework with people living with HIV, specialist teams, primary care, and community organisations; agree minimum standards.
2. Ensure appropriate training material is available and routes to any advice services are defined.
3. Implement information-sharing standards, templates, and resources (structured clinic letters, medication lists, interaction alerts, coding guidance).
4. Evaluate: patient experience, safety incidents, screening/monitoring uptake, duplication, waiting times, and workforce impact.

4.2 Evaluation: what success looks like

- High patient confidence and experience measures (including trust, stigma reduction, and access).
- Improved uptake of key preventive measures (vaccinations, screening, cardiovascular risk assessment, mental health support) measured against auditable targets.
- High levels of viral suppression.
- Clear reduction in duplicated tests/appointments where clinically appropriate.
- Demonstrable management: rapid escalation works; medication interactions and prescribing errors are reduced.
- Clinician confidence: GPs report clarity and support; specialist clinics report improved capacity for complexity.

HIV Outcomes recommendation

The opportunity is clear: build on the UK's strong HIV outcomes by modernising the model of care for an ageing population living with multiple conditions.

We believe that there is real potential for greater collaboration between primary and secondary care, done with full involvement and agreement by the patient. A collaborative care framework can offer a practical way to deliver person-centred care, improve capacity, reduce existing frustrations in the experience for patients, and sustain services for the future.

Alongside the establishment of the collaborative care framework, there should be formal classification within the NHS of HIV as a long-term condition. This can go towards normalising HIV care, providing opportunities for better joined up care moving forward, and is the clear direction of travel for future management of HIV. It can also contribute to reducing stigma and ultimately improve health-related quality of life for people living with HIV.

If you would like to share your reflections on the discussion paper, highlight examples of good practice, or explore opportunities to work with us, please contact us at HIV.Outcomes@nat.org.uk

Annex 1:

Model collaborative care framework template for HIV

This template provides a starting point for local adaptation. It is designed to be consistent with NHS shared care principles for medicines and clinical responsibility, while reflecting HIV-specific needs (confidentiality, stigma reduction, drug–drug interactions, and rapid escalation).

A. Details

Field	Template entry
Protocol title	Collaborative care framework for people living with HIV
Geography/system	[ICS/ICB name]
Version/date	[v1.0/dd mmm yyyy]
Authors/governance	[names, roles, approvals]
Review date	[dd mmm yyyy]
Scope	Adults living with HIV in care; excludes complex pathways noted below

B. Eligibility and exclusion criteria

Eligibility (all should apply)

- Patient provides informed consent and understands care roles.
- GP practice agrees to participate and has access to training/advice routes.

Enhanced collaborative care pathways (examples)

- New diagnosis/initiation phase; detectable viral load or adherence concerns.
- Complex resistance, opportunistic infection or unstable HIV related condition, frequent regimen changes, or complex interaction management.
- Pregnancy and perinatal pathways; complex hepatitis co-infection requiring specialist management.
- Safeguarding complexity requiring specialist MDT oversight (with GP involvement as appropriate).

C. Roles and responsibilities

Specialist HIV service

- Initiate and modify ART; manage resistance and complex HIV-related issues.
- Undertake HIV monitoring (viral load/CD4 as per guidelines) and annual HIV-specific review.
- Provide clear medication lists and interaction warnings to primary care.
- Offer a named clinician contact and rapid advice route for GPs.
- Define and communicate escalation triggers and re-referral processes (guides of what needs monitoring and screening on a regular basis may need to be produced and provided).

Primary care/GP practice

- Manage non-HIV long-term conditions and prevention (CVD risk, diabetes, CKD, bone health).
- Provide vaccinations and reminders, screening per national guidance, ensuring accessibility and follow-up — specific guidance on which vaccinations are needed and national guidance on HIV will need to be provided.
- Support mental health and wellbeing, including referral/signposting, unless there is in-house HIV clinic psychological support that the consultant can refer to.
- Maintain accurate medication records; check interactions when starting new medicines and seek specialist advice as required.
- Scope for future development of the role to include administering injectable ARVs treatments, where clinically appropriate and supported by training and commissioning arrangements.
- Be the first point of contact for new or general symptoms and coordinate non-HIV referrals.

Patient (person living with HIV)

- Participate in shared decision-making and consent to information sharing including having access to digital patient records via the NHS app.
- Attend agreed appointments and recommended screening/vaccinations.
- Report new symptoms, medication issues, or concerns promptly — patients must know where to go when they have a problem or need assistance.
- Choose to remain in or exit the collaborative care at any time.

D. Communication and information sharing

- Specialist clinic letters to include: current ART, recent viral load status, key comorbidities, interaction cautions, and named contact details.
- Primary care records to code HIV diagnosis and record ART as hospital/specialist prescribed to reduce interaction risk.
- Agreed advice route (phone/email/e-consult) with response standards (e.g., same day/next working day).
- Clear approach to confidentiality and disclosure, with patient preferences recorded.

E. Prescribing and medicines safety

- ART prescribing remains with specialist HIV services (unless local policy explicitly and safely transfers with agreement).
- GPs to check interactions for new medicines and contact the HIV team when uncertain; avoid initiating interacting medicines without advice where possible.
- Medication reconciliation at every significant contact; review polypharmacy risks annually.

F. Escalation, safety-netting and re-referral

Immediate specialist contact/re-referral triggers

- Reported detectable viral load or suspected virological failure.
- Significant adverse effects or suspected ART toxicity.
- Potentially serious drug–drug interaction or need for interacting medication.
- New suspected opportunistic infection or unexplained systemic symptoms.
- Diagnostic uncertainty or clinician concern; patient request to return to specialist-led care.

G. Training and support

- Minimum training offer for participating practices: HIV basics, stigma reduction, confidentiality, drug–drug interactions, and escalation.
- Ongoing access to specialist advice and periodic updates (e.g., annual webinar/PLT session).
- Optional: GP “HIV lead” or local network champion model to build confidence and peer learning.

Annex 2:

GP-facing summary (one-page handout)

Collaborative care for people living with HIV: what it means for general practice

The headline

Collaborative care does not make GPs responsible for overall management of HIV treatment. Specialist HIV teams remain responsible for ART, viral monitoring and complex HIV care. Collaborative care gives GPs the ability to strengthen primary care's role in holistic health, prevention and management of co-morbid long-term conditions, with rapid specialist back-up.

Who is it for?

- Patients who consent to collaborative care and prefer integrated, local support.
- Practices that have access to training and a clear specialist advice route.

What GPs do (core role)

- Manage non-HIV long-term conditions (e.g., hypertension, diabetes, CKD, COPD, mental health).
- Prevention and screening (CVD risk, smoking cessation, weight management, vaccinations, cancer screening support).
- Medication reconciliation and tolerability: check interactions for new medicines and seek specialist advice when uncertain.
- First point of contact for new/general symptoms; coordinate non-HIV referrals and follow-up.

What GPs do not do

- Do not initiate or change antiretroviral therapy (ART).
- Do not monitor viral loads or CD4 counts.
- Do not manage HIV resistance or virological failure.
- Do not take sole responsibility for HIV-specific complications.

When to contact the HIV team urgently

- If a detectable viral load is reported or suspected.
- If there are significant adverse effects or suspected ART toxicity.
- If an interacting medicine is needed and you are uncertain about safety profile.
- If there is diagnostic uncertainty, serious systemic illness, or patient preference to return to specialist-led care.

What support you should expect

- Named specialist contact and rapid advice route.
- Clear clinic letters including ART and interaction cautions.
- Training offer (including stigma reduction) and periodic updates.
- Clear escalation routes and shared governance.

References and key sources

Key sources used to inform this paper include:

BHIVA

Shared Care: Findings from the BHIVA Primary Care Project (BHIVA clinical standards/shared care resource).

National AIDS Trust

Providing coordinated care for people living with HIV (June 2024).

NHS England

Shared Care Protocols (medicines): principles for standardised shared care approaches.

BHIVA

HIV and Ageing: Health and Social Care (policy and evidence summary).

Howell et al. (2025) — Scoping review of services for long-term condition management for people with HIV in England (HIV Medicine/PMC).

Mapp et al. (2015) — Systematic review of shared HIV care models in high-income settings (Int J STD AIDS/PubMed).

Hutchinson et al. (2016) — Survey of shared primary and specialist HIV care models (Int J STD AIDS/PubMed).

Note: Local implementation should align with current clinical guidance and local governance arrangements. This paper is intended for policy and service design; it is not clinical guidance.

Working together



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About HIV Outcomes UK

An effective HIV response must be comprehensive, encompassing prevention, treatment, care, and support for people living with and vulnerable to acquiring HIV. In the UK, there is excellent access to HIV treatment and care. Yet many people living with HIV continue to face stigma, discrimination, and barriers to accessing and maintaining a good quality of life. This is exacerbated by persistent inequalities in access to and quality of HIV prevention and care, especially for structurally marginalised groups.

To address these challenges, HIV Outcomes UK was formed in 2023 as a cross-sector collaboration working through partnership to eliminate stigma in HIV care, enhance care engagement and coordination, support mental health needs, and improve data and confidentiality practices in the NHS. The HIV Outcomes UK programme is funded by Gilead Sciences, ViiV Healthcare and MSD as cosponsors. Editorial control sits with the HIV Outcomes Secretariat at the National AIDS Trust. The group is affiliated with HIV Outcomes at a European level.

Further information and partnership

For more information on HIV Outcomes UK, please visit: www.nat.org.uk/hiv-outcomes. If you have any questions or would like to arrange a meeting, please get in touch with us at HIV.Outcomes@nat.org.uk.

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