

Research and Implementation Presentations

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Presentation 1: James Cole

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ASK A QUESTION HERE



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

Potential role of collaborative care frameworks

James Cole, Senior Policy Manager, National AIDS Trust



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Securing rights
Stopping HIV



The case for collaborative care in HIV response

- HIV care is increasingly characterised by: ageing populations, multiple long-term conditions, polypharmacy, social and wellbeing needs. Health system is often playing catch-up in how it recognises and delivers HIV care
- While people living with HIV are increasingly receiving enhanced, HIV-informed care from their GP, both access to this and the framework used remain inconsistent
- HIV is currently not recognised as a 'long term condition' (LTC) within the NHS - people may not be receiving the best options and opportunities of care
- NHS's shift for care in the community provides opportunity to consider whether and how people living with HIV could benefit from enhanced primary care interventions that support the management of LTCs



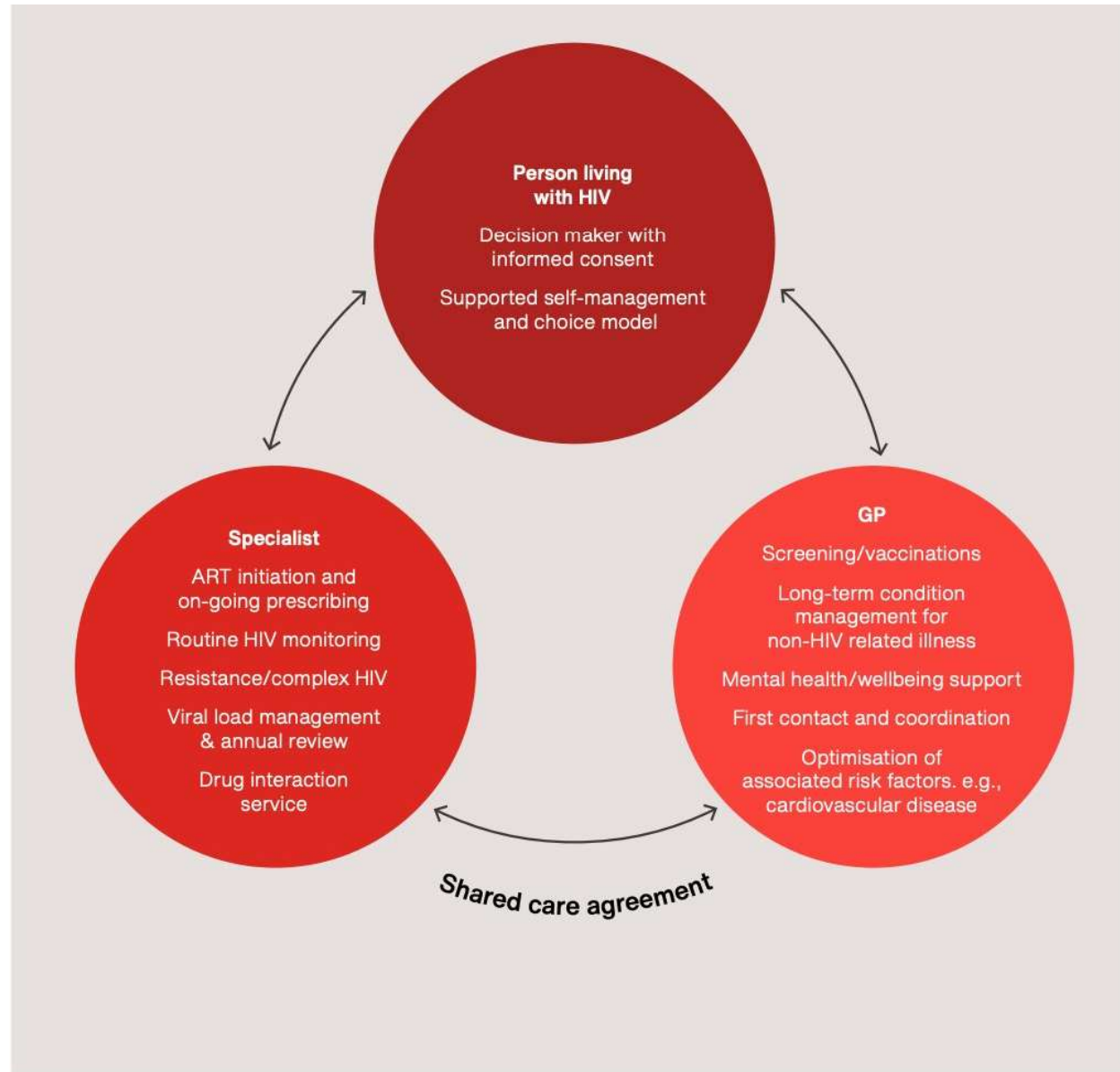
Collaborate care framework for HIV

- ‘Shared care’ is a formal local agreement involving the patient, primary care and secondary
- Not a transfer of risk - structured partnership between primary and secondary care that clarifies who does what, what information is shared, and when escalation and referrals should take place
- Not proposing direct HIV related care (including ARV prescribing) is transferred to primary care and the role of the specialist remains fundamental



What collaborative care framework 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
- Where a framework is in place and agreed to by the GP and patient, specialist HIV services and primary care would jointly support the person living with HIV
- Collaborative Care Framework would give 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





Potential benefits of collaborative care

Better outcomes through 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

Better experience: continuity, access and whole-person care

- Supports shift from disease-specific care to person-centred care
- Could enhance the experience that people living with HIV have at both primary and specialist settings

Equity and consistency

- A national template for collaborative care would go towards reducing postcode variation and provide commissioners a common, safe framework
- 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



How national approach to collaborative care could be introduced

Initial implementation programme

- Co-produce framework with stakeholders including people living with HIV
- Ensure appropriate training material is available
- Implement information-sharing standards, templates and resources
- Develop evaluation systems

Evaluation

- High patient confidence and experience measures
- Improved uptake of key preventative measures
- High levels of viral suppression
- Clear reduction in duplicated tests and appointments
- 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

Recommendations



- Real potential for greater collaboration between primary and secondary care, done with full involvement and agreement by the person living with HIV
- 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 SCP, there should be formal classification within the NHS of HIV as a long term condition

If you would like to share your reflections on the discussion paper and explore opportunities to work with us, please contact HIV.Outcomes@nat.org.uk

Stigma, exclusion and views of palliative care among people living with HIV:

Findings from a co-produced UK study

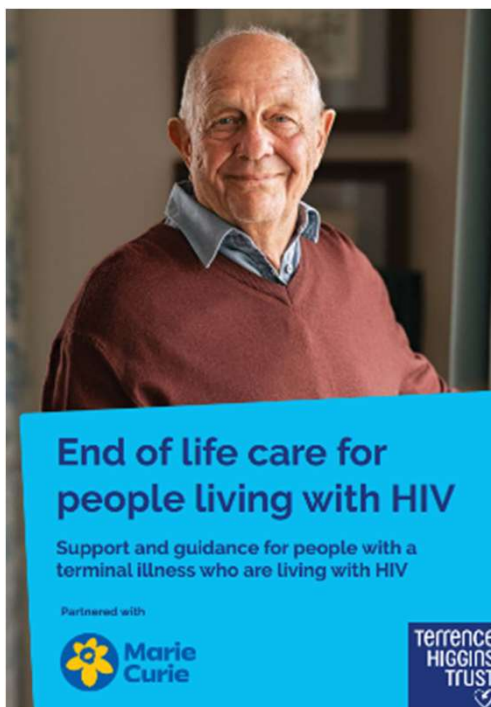


Marc Tweed, Jodie Crooks, Louisa Dreja, Lynne Hughes, Michael Brimacombe, Richard Jeneway, Robert Macrowan, Esther Garibay & Dr Briony Hudson

Terrence Higgins Trust | Marie Curie | UCL



Why focus on people living with HIV?



An estimated **113,500** are living with HIV in the UK. The combination of **ageing + multimorbidity** means HIV care increasingly overlaps with PEOLC needs.

Complexity drives unmet need: +19% risk with one comorbidity; **+37%** with **3+** comorbidities. As PLHIV age, comorbidities are increasingly common: most have at least one long-term condition, and over **30%** live with three or more (Shah et al., 2025).

Experiences of **discrimination and stigma** can influence trust, service engagement and future care planning.

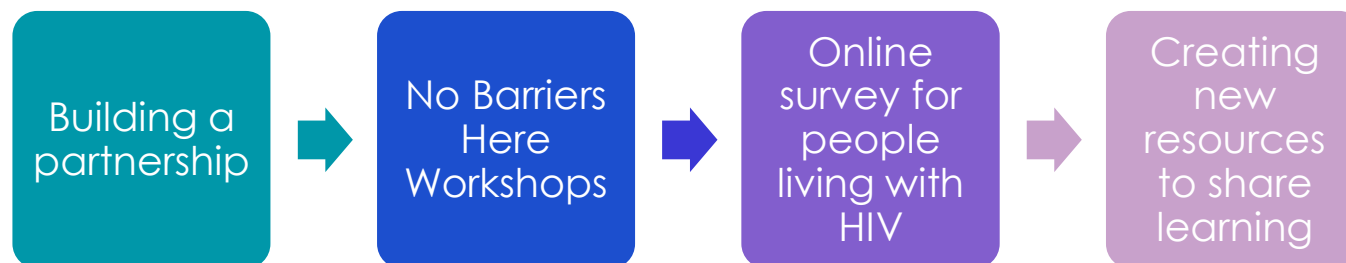
This project aimed to work alongside people living with HIV to explore **views about and barriers to advance care planning and palliative care**.



Shah A, Mackay N, Kitt H, et al. What matters to people living with HIV as they age? Findings from a large UK survey. Research Involvement and Engagement. 2025.



Engagement through trusted relationships



- Building a partnership
- Co-produced with people living with HIV.
- Workshops and survey explored experiences, priorities and barriers relating to PEO LC.
- Designed to ensure lived experience informed both findings and recommendations.



Image: members of the Steering Group that advised on the development and direction of the project, at least half of whom are living with HIV.



Participatory research

We adopted the **No Barriers Here© approach**, developed by Mary Stevens Hospice, to engage communities who are often underserved by health and care services.

Creative, arts-based methods enabled conversations that may not have emerged through traditional engagement approaches.

This helped us **understand people's experiences**, **identify barriers** to accessing palliative and end of life care, and **co-produce resources** for people living with HIV alongside **recommendations for more equitable service design** and commissioning.



Facing Discrimination.



27

people joined
creative workshops 6 hours
each (3 x 2-hour sessions)



90

Survey completions
(85 eligible responses)



Palliative and end of life care for people living with HIV: key themes identified in the project relating to Stigma



What did we learn? Lesson 1: Stigma shapes trust

Previous negative experiences in generalist care influence disclosure and expectations of future care.

They used to put the clipboards on the end of the bed with the temperature charts on it, and **they had written across it “homosexual, risk of AIDS” for all to see.** And I remember taking it off and ripping it up. *(Person living with HIV)*



There is still a lot of stigma despite tremendous medical advances. *(Person living with HIV)*

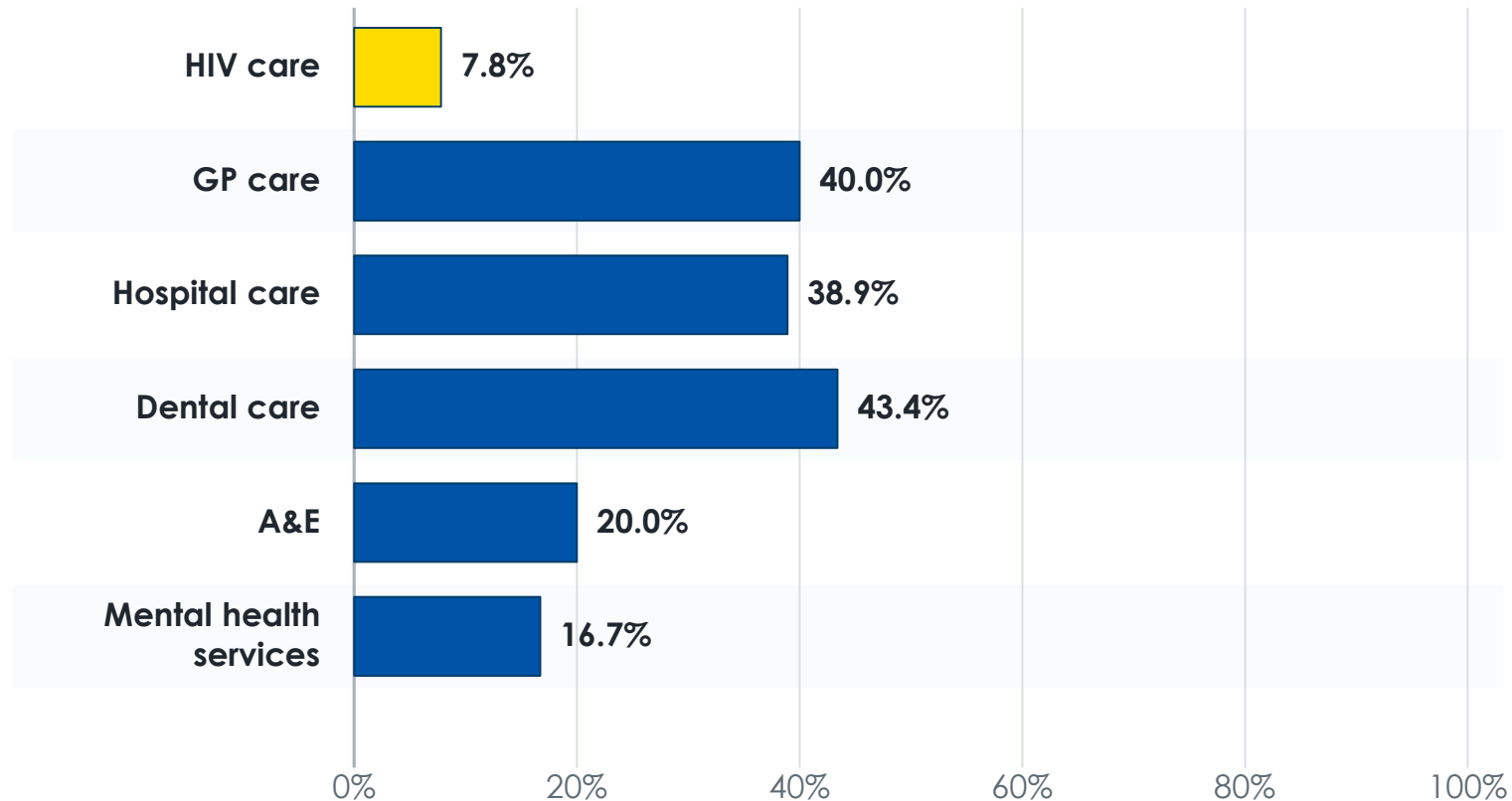
SURVEY

Experiences of stigma in health care settings were also evident among responses to the survey. **Just over a quarter of respondents (27.8%) reported that their HIV status “Sometimes” negatively affected their experiences of care**

There's certainly a sort of almost **paranoia about anything official in healthcare** and it's certainly why we had a problem looking after gay men in the hospice. *(Person living with HIV, with professional people experience)*

The contrast between specialist HIV care and general healthcare is striking

Survey Respondents who said their HIV status sometimes, often or always negatively affected their care



Context: 23.3% selected "not applicable" for A&E; 50.0% selected "not applicable" for mental health services.

Lesson 2: Trust has a location

Stigma created anticipatory fear, not only reported discrimination



Trust is strongly influenced by how HIV status is discussed, documented and shared across services.



Participants preferred information from relationships and organisations already experienced as safe.



Lesson 3: People want to remain their whole self

Dignity, identity and relationships are central outcomes of good care. “Whole person” care includes identity, chosen family, confidentiality, hobbies, culture, spirituality and legacy.

“ To maintain identify

They were out being gay. They were very proud of that for many, many years. **Suddenly, by going into a hospice, all those things disappeared. And they weren't treated as that whole person with those identities.**”

“ Being remembered for who they are

I don't want other people to write my history for me...so many other people who I know who have died, their partners or the family have wiped them out. **They don't get to be remembered for who they were.**”

“ Even if people feel very comfortable with talking about their status, their sexuality or any lived circumstances. **Once they became end of life care, all of that disappeared.**”

Identity – openly being oneself

“ This why I put Africa in the middle of the hand. I love being African. There's nothing that people can say about Africa that embarrasses me. ”

SURVEY

97.8% reported that “being able to be my whole self” was important or very important to them at the end of life.



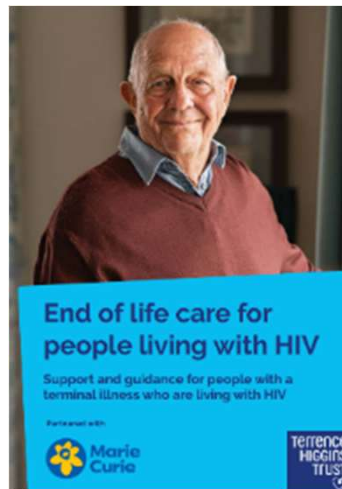
93.4% said not feeling judged because of HIV status was important or very important

76.7% said not feeling judged because of their ethnicity was important or very important.



Available resources

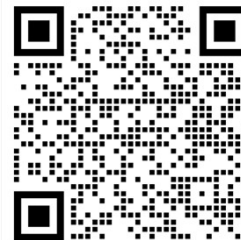
All of these were designed with input from PLHIV through the project steering group.



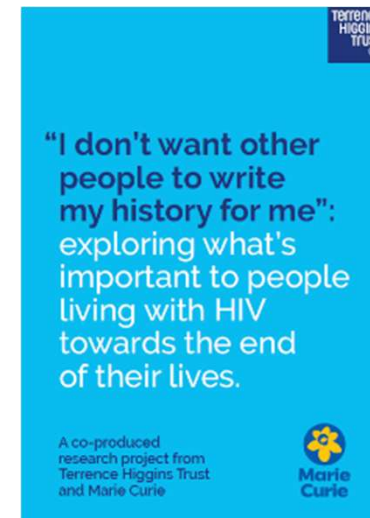
Booklets for the public & practitioners



MC and THT webpages relevant to the themes identified in the research



Plus: videos, 2x academic publications and conference posters, including at the PC Congress in Brighton



Project report



HIV and Stigma– Co produced resource



What can we learn from this project?

Services need to be designed around complexity

(multi-morbidity, polypharmacy, mental health, housing/finances, chosen family, trauma), so services must be designed for it.

Inclusion of PEoLC within HIV Action Plan

PEoLC providers are better equipped to meet the needs of people living with HIV, and HIV services have clear, trusted referral pathways for people approaching the end of life.

Stronger coordination and integration between HIV services and palliative and end of life care providers

(people can move between services more seamlessly and receive support that feels safe, trusted and appropriate)

Reduce stigma in PEoLC

Strengthen workforce capability and cultural competence. Build confidence in generalist care around stigma, medication, disclosure, trauma and chosen family



Inclusion of HIV communities in PEoLC service design and improvement.



Key messages

- Palliative care is understood through the lens of previous stigma and exclusion as much as through clinical need.
- Safe access requires trusted partnerships, HIV-informed generalist care, and pathways that protect identity, confidentiality and dignity.
- Palliative and end of life care should be considered as part of a whole-life-course for people living with HIV.



Marie
Curie



Thank you for listening