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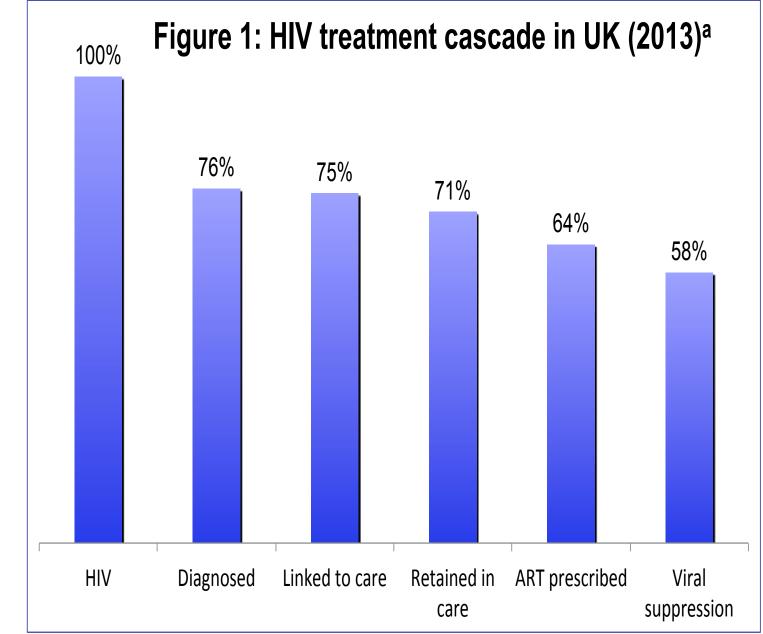
PATIENT PERSPECTIVES ON THE HIV TREATMENT CASCADE IN THE UK

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BACKGROUND

- In the UK over 95% of patients linked to care are retained (Fig 1).^a This is better than many other high income countries.
- The determinants of active engagement of patients are complex, including policy, community, health system, relationship and individual factors.^b
- Patient engagement has changed over the course of the HIV epidemic as both treatment and patient activism have evolved.



CONCLUSION

- The high standard of UK's HIV treatment cascade reflects strong relationships between patients and staff.
- Being sensitive to how patients experience different stages of decision-making and the wider influences on their behaviour is vital in sustaining high retention along the cascade.
- Proposed changes that may have an impact on patient engagement in care including a shift of routine management from hospital to community services, fewer specialist centres, further simplification of treatment regimens and monitoring, increased use of alternative providers for social aspects of care.

• As part of a broader study of patient journeys with HIV, we examined patient perspectives on the cascade among generations diagnosed at different points in the epidemic.

Continued good patient engagement will require providers to listen to patient perspectives and build strong relationships over time, which current reforms may undermine.

RESULTS: PATIENT STORIES

The waiting room "...these poor young doctors"

Alison* was diagnosed in the early 1990s and linked to care. But she dropped out for several years, describing the *"terrible situation"* of being at the clinic. She described young gay men, couples, where one would be fit and well and the other "in a wheelchair, a skeleton... In the waiting rooms people said 'don't take it, it will kill you', so I refused that (AZT)." She felt sorry for the doctors - "there were all these poor young doctors with nothing to offer and seeing these very ill people." She dropped out of care until the late 1990s, she became very ill and had to be admitted for 6 months when she started treatment.

Depression and adherence "...he taught me about myself"

Bella was diagnosed in the late 1990s and engaged with care from the start embracing complementary therapy which she felt delayed her need for ART. Once on treatment she remained in follow-up despite spending time in another

METHODS

- Interviews with 50 HIV-positive adults from two large SAMPLE HIV clinics in London. Age
- Participants were purposively selected from four 'HIV generations', based on ART development – diagnosed pre-1996 (n= 11), 1997-2005 (n=14), 2006-2012 (n=16), and since 2013 (n=9).
- Interviews were semi-structured around patient accounts of their "journey" with HIV. Participants were not asked explicitly about the treatment cascade or adherence.
- Framework was used to analyse the data.

RESULTS: ANALYSIS



• Patients from the early generations were diagnosed on the development of symptoms or following a partner's diagnosis. More recently late diagnoses were reported when patients underestimated their own risk or healthcare professionals did not spot indicator conditions.

- - White European: 10
 - Black African: 6
- MSM: 29
- Heterosexual women: 12
- Heterosexual men: 4
- **Bisexual men: 5**

20-35: 8

Gender / sexual identity

• 36-50:27

• 51-59:9

• 60+: 6

- Ethnicity
 - White British: 27

 - Mixed: 3
- Asian: 2
- Other: 2



Link to care

Retention

in care

Prescribed

ART

• Earlier generations sometimes disengaged with care for a period following diagnosis, dismayed by limited treatment options. In contrast, those diagnosed since 2005 linked to care promptly and felt they received appropriate medical attention.

• Across the generations, once linked to care participants were committed to attending appointments and taking medications. Occasional lapses were explained by external issues such as drug misuse or household disruption, rather than their relationship with the clinic. Some reported concern at the recently reduced frequency of appointments, and the increasing role of primary care.

• Almost all the people we interviewed were on ART. Earlier generations described starting treatment at the point of a health crisis, or for prevention of mother to child transmission. Recent generations began treatment in line with protocols or, for some, at their own request based on reading of the evidence.

• Most participants on ART had undetectable viral load and good adherence. Actual or anticipated co-morbidities worried them more than HIV, however, wider discussions about NHS cost-cutting have raised patient anxiety about accessing the 'best' treatments.

country. A personal crisis and isolation as an unemployed single mother contributed to depression which led to her stopping her ART. She describes excellent response from her HIV consultant who noticed she had disengaged and called her personally to check, "...she booked me to see the psychologist... he taught me about myself", and she got back on treatment.

Fragmented support "...no back-up and stuff like that"

Callum was diagnosed in the early 2010s and started ART within a few weeks at his own request. He quickly went onto six monthly routine appointments, but ".. there is no support, no back-up and stuff like that". After diagnosis he started taking more drugs and risks "It was like a defence mechanism with me thinking I didn't care about anything". He then got HepC which was a wake up call. "I never, ever wanted hep C. .. HIV you can control, hep C is harder to control". Many back-up services are from alternative providers with clinics focusing on medical support, so people who are retained in care may still have problems.

Excellent support "I'm actually in the best hands"

Diego was diagnosed in the mid 2010s, diagnosed during an emergency admission for a respiratory infection. He considered himself a health-conscious gay man who had regular health checks but surprised to learn these hadn't included HIV. He felt ignorant, "I thought that I will die in four or five years", but the HIV team came to see him, "...really reassuring...(the doctor) told me, 'well you have to live with the tablets, but that's about it, you just need to wait until we find a cure". Diego remarked that the system had treated him well, including "the human approach that all of you have had."

Viral suppression

REFERENCES

a. Yin Z, Brown AE, Hughes G et al. HIV in the United Kingdom 2014 Report: data to end 2013. November 2014. Public Health England, London.

b. Mugavero MJ, Amico KR, Horn T, Thompson MA. The state of engagement in HIV care in the United States: from cascade to continuum to control. Clin Infect Dis 2013;57:1164-71

ACKNOWLEDGEMENTS

Thanks to participants for sharing their time and stories, to the staff of both clinics for facilitating the study. Thanks to Prof Sophie Day and the rest of the PERC team for advice and support.

DISCLOSURE OF INTERESTS

This study is funded by grants from the Imperial NIHR Biomedical Research Centre and the Imperial College Healthcare Charity and supported by the St Stephens AIDS Trust. No pharmaceutical grants were received in the development of this study.



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Therapeutic relationship "You build a relationship"

Evan was infected and quickly diagnosed in the 1980s. Working in biomedicine himself, he has been closely engaged in care since then. He expressed concern at proposals to base care with GPs rather than specialists. "You build a relationship, I think, with your doctor. Then, if you are having challenges or something, of course, you may not discuss with your GP." He described how HIV-specialist doctors offer something that GPs just don't have - the long association and understanding of the patient, the clinical expertise and up-to-date knowledge about HIV and the nonjudgemental approach to how patients' live their lives, "you want to feel that you can tell them the truth and not be judged".

* Pseudonyms