

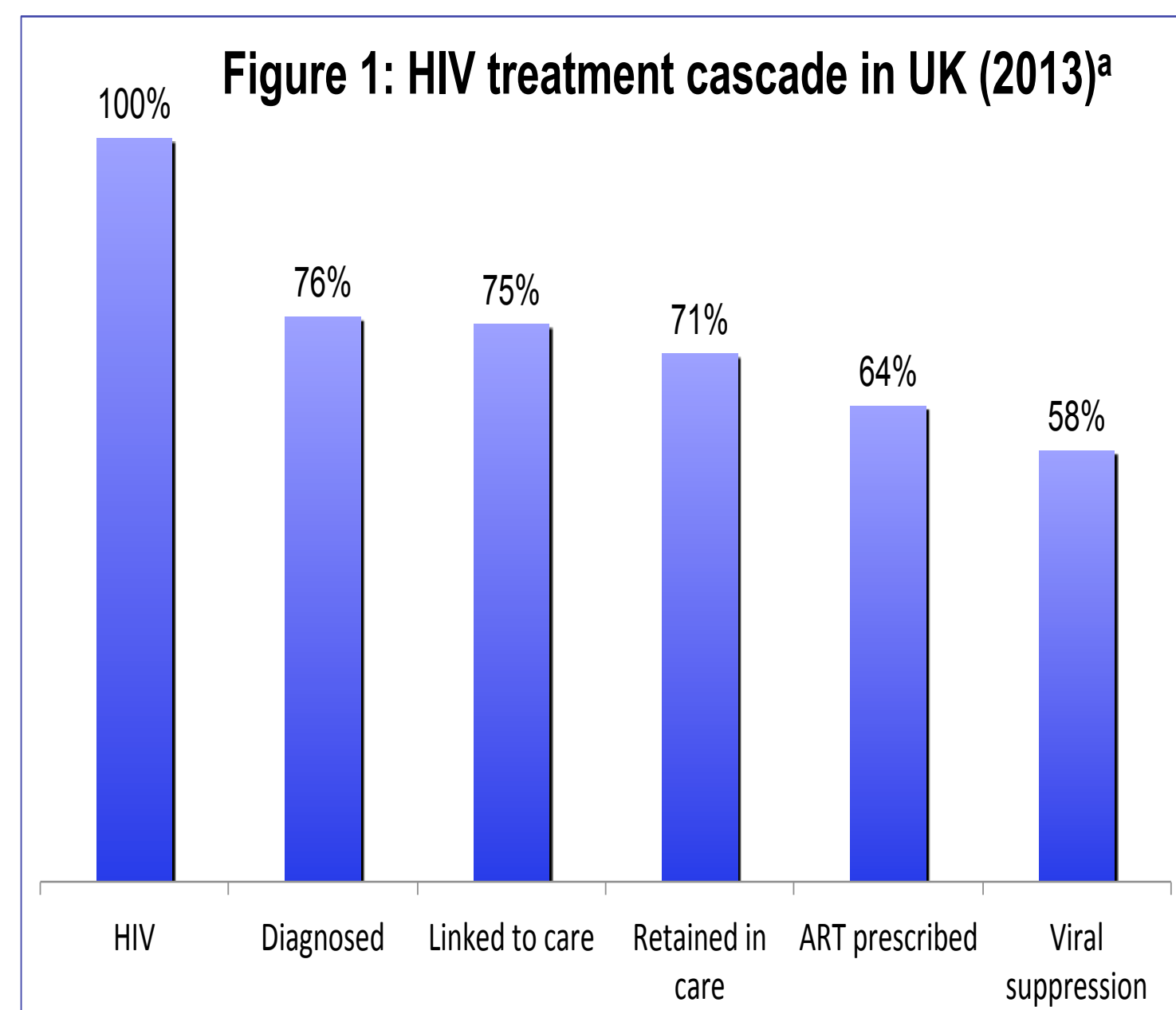
PATIENT PERSPECTIVES ON THE HIV TREATMENT CASCADE IN THE UK

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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.
- 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.



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

METHODS

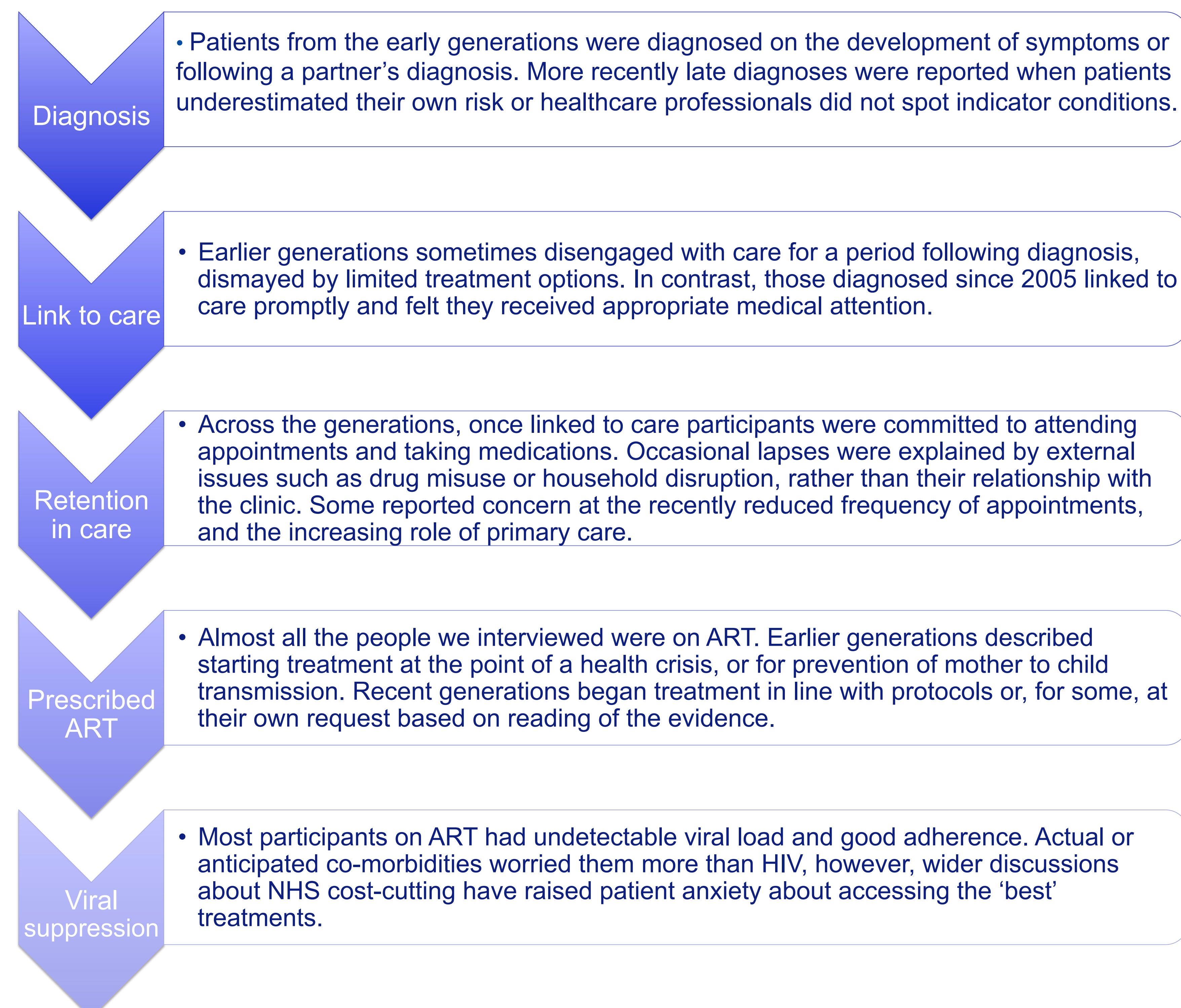
- Interviews with 50 HIV-positive adults from two large HIV clinics in London.
- Participants were purposively selected from four 'HIV generations', based on ART development – diagnosed pre-1996 (n= 11), 1997-2005 (n=14), 2006-2012 (n=16), and since 2013 (n=9).
- Interviews were semi-structured around 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.

SAMPLE

Age	Ethnicity
• 20-35: 8	• White British: 27
• 36-50: 27	• White European: 10
• 51-59: 9	• Black African: 6
• 60+: 6	• Mixed: 3
	• Asian: 2
	• Other: 2

Gender / sexual identity
• MSM: 29
• Heterosexual women: 12
• Heterosexual men: 4
• Bisexual men: 5

RESULTS: ANALYSIS



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

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DISCLOSURE OF INTERESTS

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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 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."

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 non-judgemental approach to how patients' live their lives, "you want to feel that you can tell them the truth and not be judged".

* Pseudonyms