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). 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.a
• 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.

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.

• 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 fell 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.

REFERENCES

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 NHIR 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.

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 defiance 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 would 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