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Changes in the Model of Care

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From Dying to Living: Health Promotion and Prevention

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Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest. I have received honoraria from Viiv and Gilead previously.

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What has changed in 40 years?

- 1985 – 98% of people with HIV were GBSM, haemophiliacs or injecting drug users.
- 1995 – It was recognised that women and children were now a significant feature of the ‘AIDS epidemic’. 1n 1994 AIDS related deaths were at a high (1531).
- 2005-2026 – HIV related deaths continue to fall, testing rates are higher so HIV prevalence rises, migration drives a rise in heterosexually acquired HIV within the UK and undiagnosed HIV continues to fall.

AIDSMAP (2023) HIV in the UK – then and now

Life expectancy

1996

- The average life expectancy of a 20 year old diagnosed with HIV was 10 years.

2026

- A 2023 review published in *Lancet HIV* reported average life expectancy was to be anywhere from 70.8 years to 74.6 years for a 20-year-old newly diagnosed with HIV in North America and Europe.
- But studies have shown that starting HIV therapy with a CD4 count under 200 reduces life expectancy by an average of eight years compared to someone starting at a CD4 count over 200.

1.The Antiretroviral Therapy Cohort Collaboration. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *Lancet HIV.* 2017 Aug;4(8):e349–56. doi:10.1016/S2352-3018(17)30066-8

2.Kalichman SC, Hernandez D, Kegler C, Cheery C, Kalichman MO, Grebler T. Dimensions of poverty and health outcomes among people living with HIV infection: limited resources and competing needs. *J Community Health.* 2015 Aug;40(4):702–708. doi:10.1007/s10900-014-9988-6

Co-morbidities versus dying of HIV related illness

Pre/early ART era

- Very poor life expectancy.
- People were weighing up risks of taking early ART regimes versus possibility of surviving better – failure (concorde trial 1988-1991), toxicity, Steven Johnson's Disease.
- Serious ART side effects and reactions were common – pick your poison.
- Many people didn't live long enough to collect co-morbidities.
- Opportunistic infections were more common – PML, Toxoplasmosis, KS, Cryptococcal meningitis, PCP, disseminated TB.
- HIV Associated Neurocognitive Disorder was prevalent.

Now

PLWHIV may have more co-morbidities and at an earlier age than the general population. These include:

- Cardiovascular disease (CVD)
- Neurological disease
- Anaemia
- Osteoporosis
- Liver disease
- Renal disease
- Frailty
- Mental illnesses
- Many non-AIDS-related cancers
- Chronic lung disease
- Type 2 diabetes
- Non-AIDS-associated infections

Renal and cardiac co morbidity

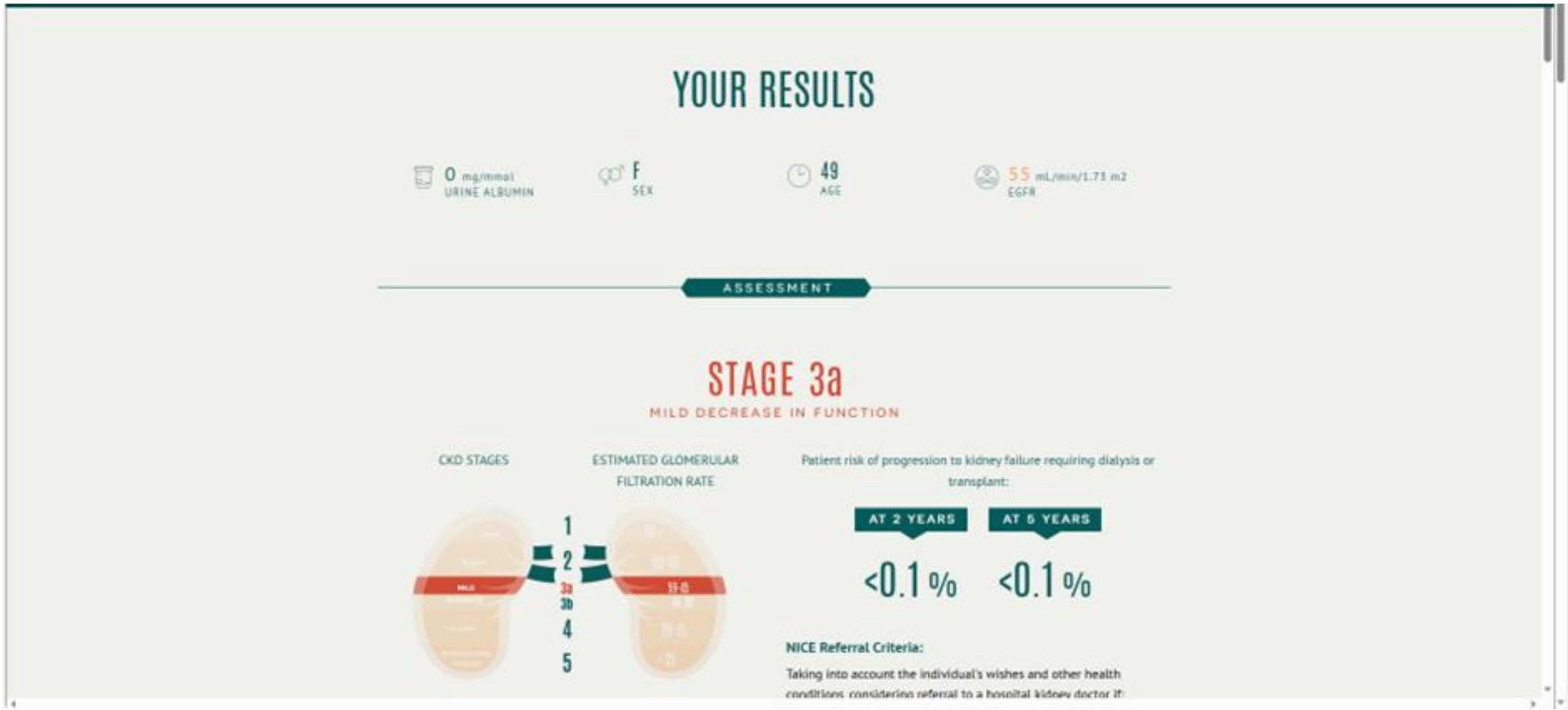
Pre ART era

- HIVAN - HIVAN is a severe kind of kidney disease that can affect people living with HIV. It's associated with a high viral load and low CD4 count (<200 in 80% of cases) and can rapidly lead to kidney failure. Treatment involves starting or continuing antiretroviral therapy.
- HIV associated cardiomyopathy – (HIVAC) is a spectrum of heart muscle diseases in people living with HIV, most commonly presenting as dilated cardiomyopathy with impaired ventricular function. Outcomes are less favourable in PLWHIV.

Now

- Renal decline due to advancing age is common.
- We need to be trying to preserve renal function for patients.
- Fanconi's syndrome – TDF associated proximal tubulopathy.
- Cardiovascular disease prevention is key. Treating HIV, smoking cessation, REPRIEVE trial (Statins), exercise.
- Consider QT interval prolongation with certain ART's.
- Chronic inflammation is now known to be a factor.

https://kidneyfailurerisk.co.uk/



Psychological issues/stigma

Pre ART era

- HIV was viewed as a terminal illness, so people needed to confront their mortality at a young age.
- HIV related stigma was massive – HCP's refusing to care for people, full PPE when doing so.
- Many people came to terms with dying and then survived when HAART available – survivor's guilt, long term psychological effects.

Now

- PLWHIV have high prevalence of psychological distress and mental health issues - BHIVA Standards of Psychological support (2025).
- Psychology input remains very variable nationally.
- Intersectionality – Race, Sexuality, migration, stigma.
- U=U statement issued in 2016, importance of ensuring all PLWHIV are aware.
- Quality of life recognised as the '4th 90'.

Money and social issues

Pre ART era

- Living wills were a key part of HIV care.
- Many people took out the life insurance as they expected to die. They also gave up work as they were ill and preparing for death.
- Some of this cohort have never returned to work and this may affect their identity and sense of self.
- Infected blood scandal – surviving recipients only starting to get compensation now.

Now

- PLWHIV may be juggling jobs, caring responsibilities and appointments. This is particularly difficult for recent migrants in care roles.
- Some may be entitled to benefits but these are becoming harder to claim. Mindshift from HIV as a disabling disease to that of a chronic, manageable condition.
- Postcode lottery of third sector support.
- Life, critical illness and travel insurance more widely available but some inequity remains.

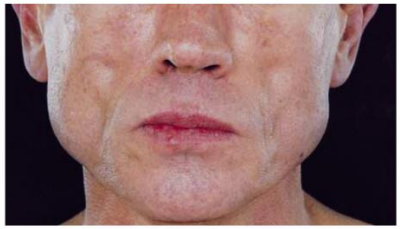
Weight

Early ART era

- Fat and muscle loss in advanced HIV – skeletal look.
- Lipodystrophy - HAART-induced lipodystrophy occurs in HIV patients receiving highly active antiretroviral therapy (HAART) most often after 3-4 years of treatment. HAART-induced lipodystrophy features fat loss from the arms, legs, and face with excess fat accumulation around the neck, upper trunk, and intra-abdominally. Thymidine Analogues.
- Lipoatrophy - Lipoatrophy refers to the loss of fat beneath the skin, which can occur in specific areas such as the face, arms, or legs, or more broadly across the body. Unlike lipodystrophy, which can involve both abnormal fat loss and accumulation, lipoatrophy specifically denotes fat loss without abnormal fat gain. This condition can lead to visible dents or irregularities in body contour, sometimes affecting both appearance and metabolic health.

Now

- Many patients struggle with excess weight.
- Weight gain is also associated with newer INSTI's and TAF (although conflicting evidence).
- Rise of GLP-1 agonists use (interaction with Rilpivirine).
- BMI monitoring – limitations of BMI as a measurement.
- Limited clinics who offer Nu-Fill available.



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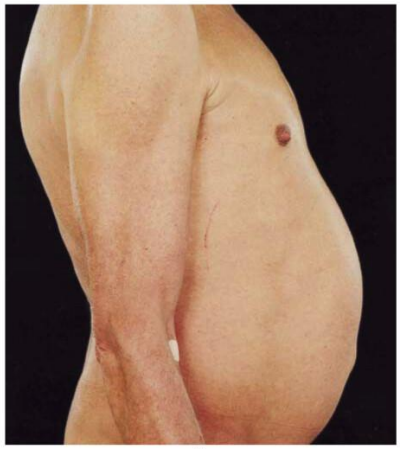

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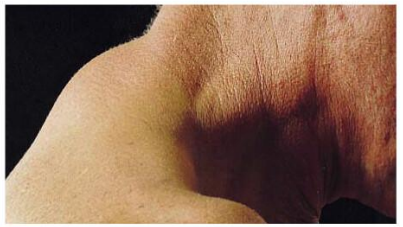

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HIV Monitoring

Pre ART/early ART era

- HIV antibody test first available in March 1985 (first generation) – 3 month window period.
- CD4 count measurements were frequent.
- HIV-1 viral loads become available in the mid 1990's but only measured down to 400-500 copies.
- HIV resistance tests were not widely available and only certain demographics had baseline testing.

Now

- 4th generation HIV antibody test available – 45 day window period.
- CD4 counts not routinely advised once patient immunocompetent.
- HIV viral loads are the cornerstone of HIV care and are increasingly sensitive.
- Genotypic and phenotypic resistance tests are available.
- All PLWHIV have a baseline resistance test now.
- Integrase resistance tests not routinely advised unless previous INSTI exposure.

Other monitoring

Pre ART

- Limited health promotion and prevention work as life expectancy was limited.
- The focus was on surviving as long as possible, managing HIV related illness and drug toxicity.
- Quality of life was poor for many PLWHIV.

Now

- Annual Q Risk once over 40 – limited usefulness once identified as high risk. Waist measurement also a useful tool.
- Frax scores every 3 years once over 50 (or younger if early menopause).
- REPRIEVE trial – new statin guidance.
- Frailty assessment and pathways increasingly important.
- Smoking cessation and other lifestyle advice a key part of our role.
- Annual check – lipid, eGFR and HBA1c monitoring.
- Focus is on living and ageing well with HIV.

Vaccines and prophylaxis.

Pre ART

- Limited vaccine recommendations.
- People with low CD4's advised not to travel abroad and to boil their water (Cryptosporidium).
- People stayed immunocompromised for longer so may be on prophylactic drugs for life.
- Pentamadine nebulisers for PCP prophylaxis.
- PEPSE only recommended from 2005, prior to this only given for occupational exposure (since 1990).

Now

- Very comprehensive BHIVA recommendations.
- HPV vaccination known to be of high value in preventing AIN and CIN.
- Monkeypox vaccination.
- New gonorrhoea vaccine.
- DoxyPEP.
- Covid and flu recommendations.
- Awareness that being virally undetectable is protective, even with low CD4 counts.
- PEP and PrEP.
- Treatment as prevention.

Conclusion

- In my career, I have been privileged to witness phenomenal advancements and changes in HIV care.
- However, HIV still adversely effects physical and mental health outcomes for PLWHIV.
- As our population lives even longer, prevention and promotion work will become even more vital.
- Consider when patients were diagnosed – pre or post ART. Those who took early ART may be frailer than those diagnosed today at the same age.