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O06: Never say never: Using injectable ARVs on compassionate grounds

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Never say never: Using injectable ARVs on compassionate grounds

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Conflict of Interest

I have worked on the steering group for The European nurse ambassador for Viiv health care.

Speakers are required by the Federation of the Royal Colleges of Physicians to disclose conflicts of interest at the beginnin g of their presentation, with sufficient time for the information to be read by the audience. They should disclose financial relationships with manufacturers of any commercial product and/or providers of commercial services used on or produced for patients relating to the 36 months prior to the event. These include speaker fees, research grants, fees for other educational activities such as training of health professionals and consultation fees. Where a speaker owns shares or stocks directly in a company producing products or services for healthcare this should also be declared. Finally, other conflicts of interest including expert functions in health care or healthcare guidance processes should be declared (eg if the professional is a member of a health board). The Federation considers it good practice to also make speakers' disclosures available in digital format(s) relating to the educational event.

Key points

- Brief overview of LAI In Brighton
- Introduce you to Joseph
- Look at the MDT approach to his care
- Delivery of LAI injectables off license
- The outcomes of above

Long-Acting Injectable ARV therapy in Brighton

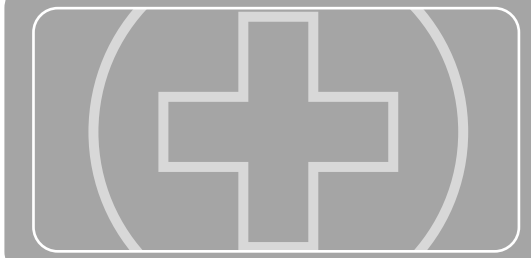
Long Acting ARVs in Brighton so far: approximately 80 people on Long Acting Injectables. All but one are virologically suppressed.

This presentation looks to explore the case of this individual who I will call Joseph.

Joseph's medical history

2012- diagnosed following use of PEP in his 20's. Started on ARV's

- 2013- first documentation of sporadic adherence, noted mental health affecting ability to take medication. High VL at this point 1064965
- 2014 – link in the community team



2017- diagnosed with TD2M and Hep C, declined treatment for HCV

- 2018 Had GC, STS, dental issues and Untreated Hep C. Discussions of a DNACRP began.
- 2019 professional meeting to discuss DNACRP given young age. Then had a DVT, ,an abscess and HCV still untreated.

- 2020 high VL, HCV untreated plus other ongoing issues mentioned in previous years. DS1500 granted. Engaging in third sector community support and CHIVVS
- THEN COVID! started HCV treatment, was having daily support from CHIVVS with taking ARVs. DNACRP cancelled.

What is a DS1500

- Now known as a SR1 form

- Clinicians to complete this form if these two conditions apply:
- Has a progressive disease
- Due to this disease, they may die within 12 months.

What the Special Rules are for

The Special Rules allow people nearing the end of life to:

- get faster, easier access to certain benefits
- get higher payments for certain benefits
- avoid a medical assessment

An adult or child is nearing the end of life when they are likely to have less than 12 months to live.

If a person is likely to have less than 12 months to live, they can make a fast-tracked claim to the following benefits (for which they are eligible):

- Personal Independence Payment (PIP)
- Universal Credit (UC)
- Employment and Support Allowance (ESA)
- Disability Living Allowance (DLA) for children
- Attendance Allowance (AA)

The role of clinicians

Clinicians can be asked to provide medical evidence on an SR1 form to support a benefit claim made under the Special Rules.

> The SR1 form has replaced the DS1500 form.

A bit of Josephs social history

Joseph lives independently.

Joesph uses crystal meth on a weekly- daily basis, usually slamming.

He was brought up in care

Enjoys travelling, which he commenced doing in 2022

Long-Acting Injectable therapy and Joseph

Joseph commenced Long-Acting Injectable Therapy in sept of 2022, on “compassionate grounds”. Due to growing concerns regarding his rapidly decling health and public health as he was sexually active.

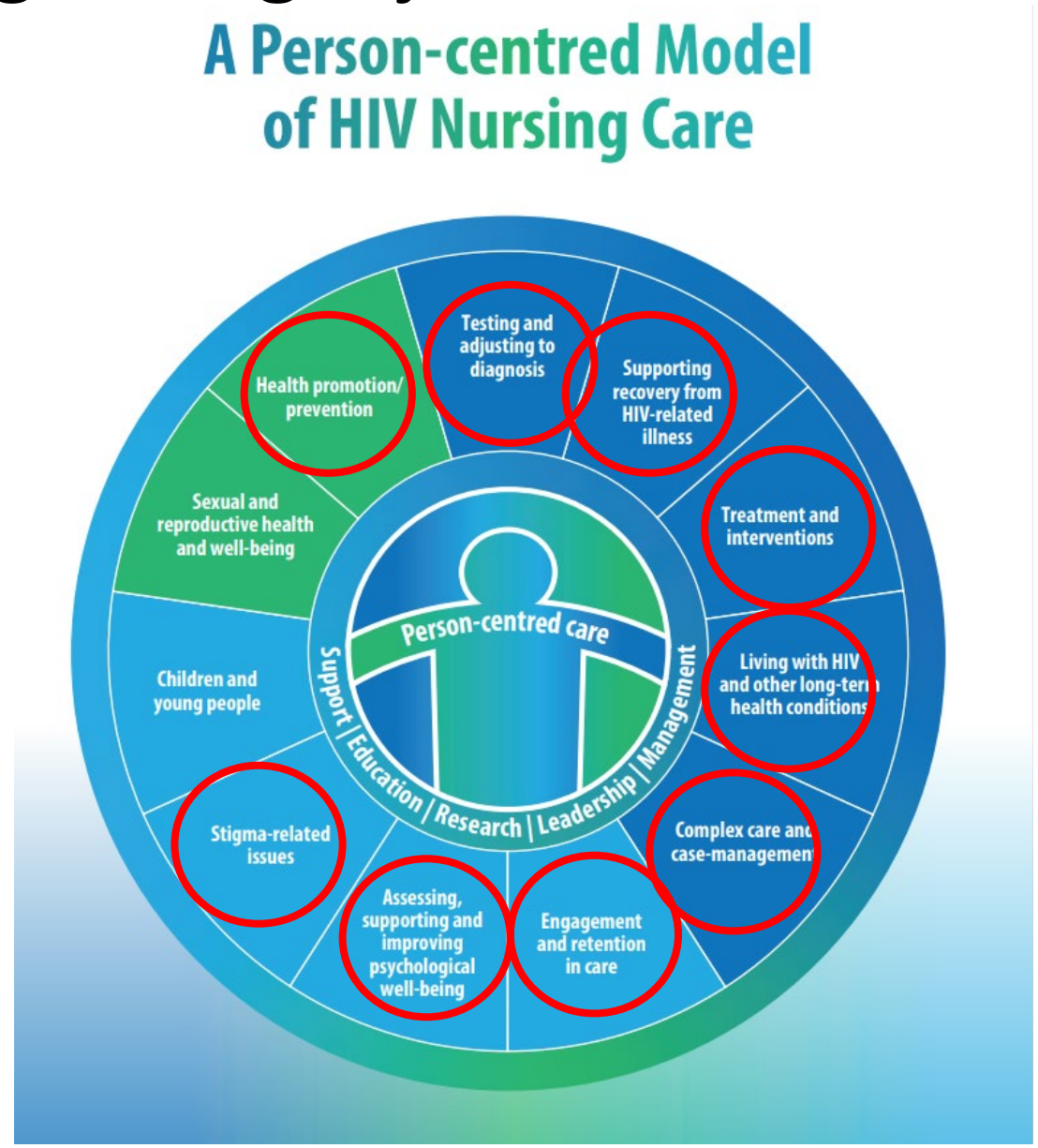
Blood results prior to starting LAI:
VL- >10000000 (max the lab can report).
CD4: 49.

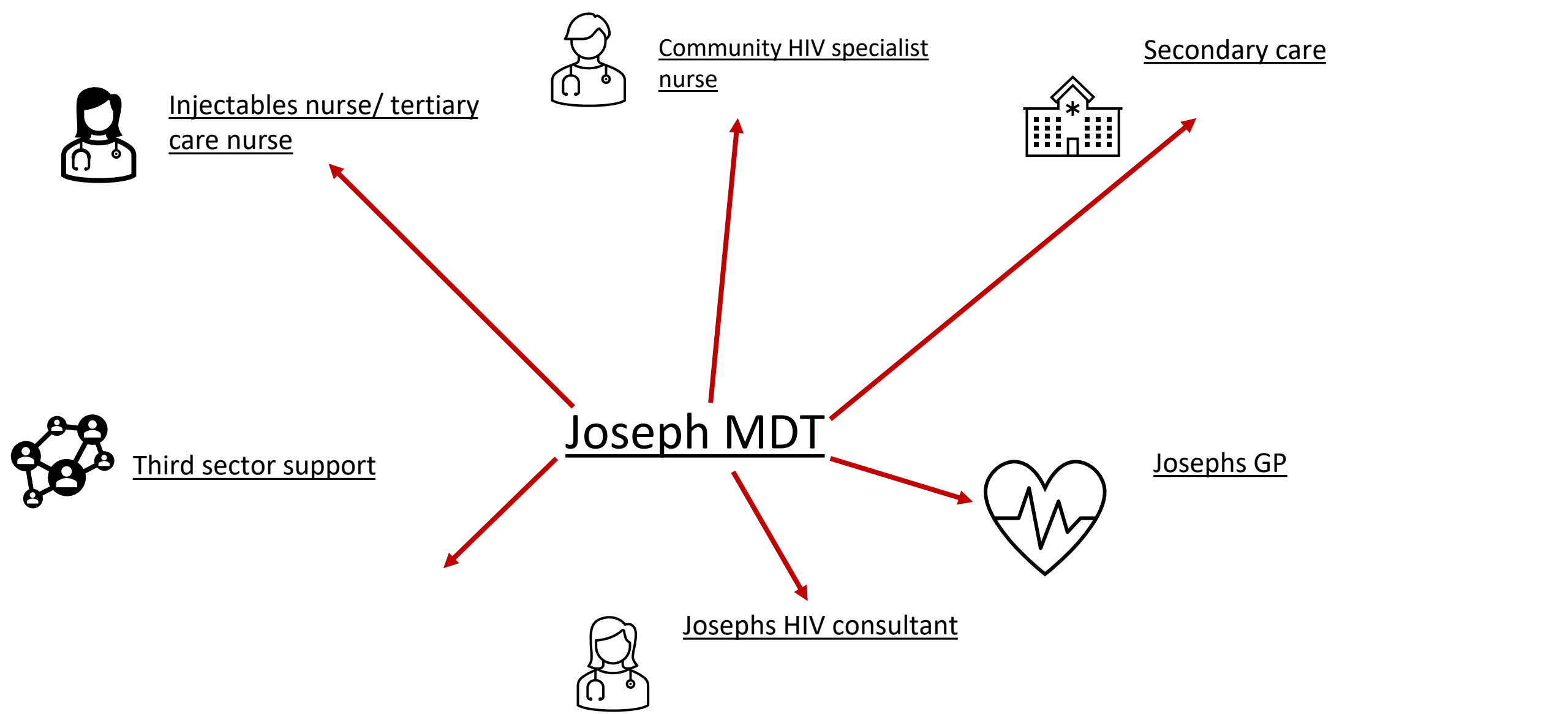
How did we deliver Josephs care?

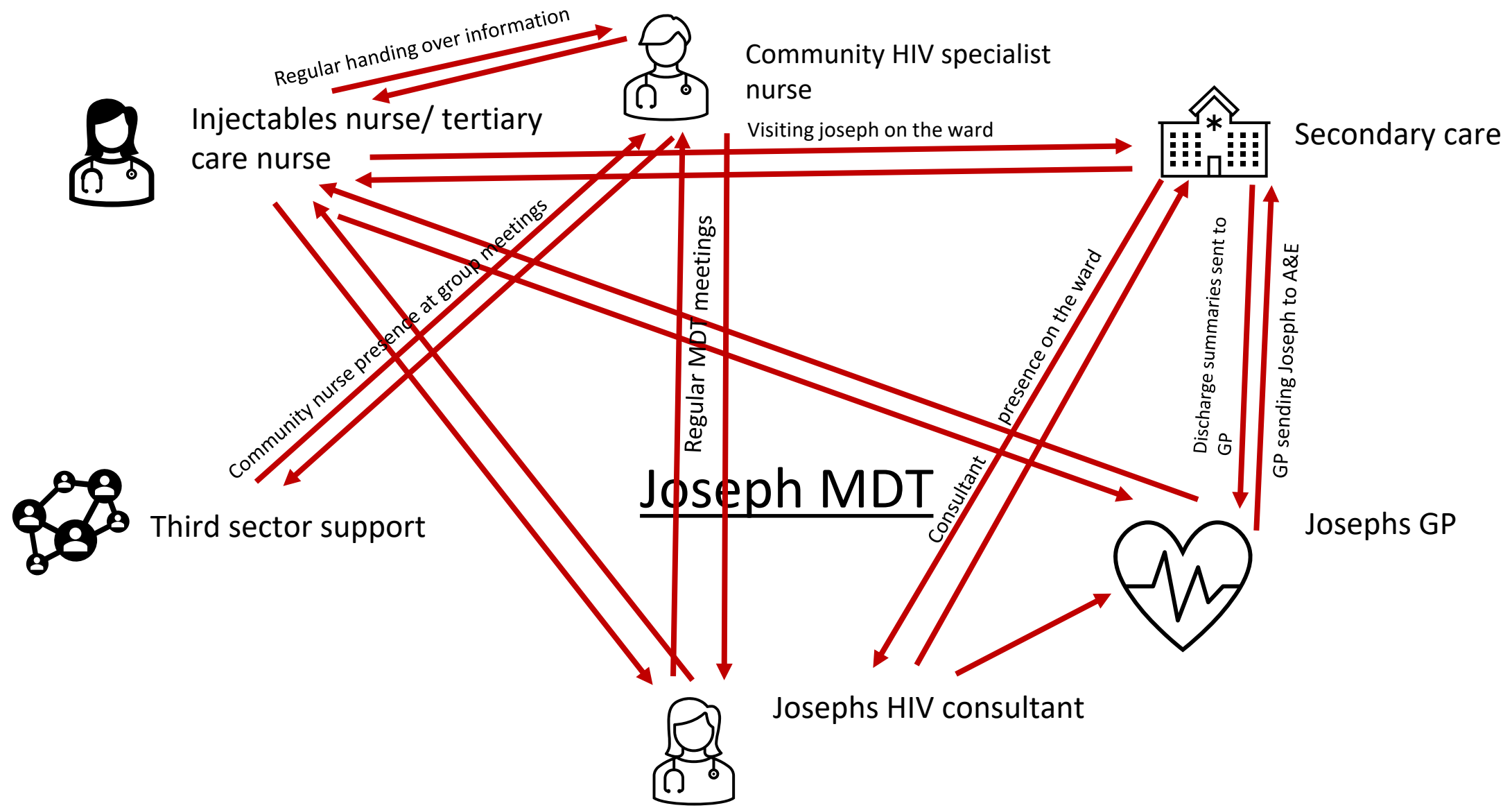
How Long acting injectables were delivered

- Joseph received joint care by the community team and outpatient HIV team, with named individuals liaising between services.
- So far Joseph has received his monthly injections in his home, the clinic, A&E, as an inpatient and rehab.
- **In two years, no injections have been missed.**
- This been possible by working in collaboration with Joseph and other HCPs to ensure he receives his LAI in a timely manner according to his needs.

How where long acting injectables delivered?



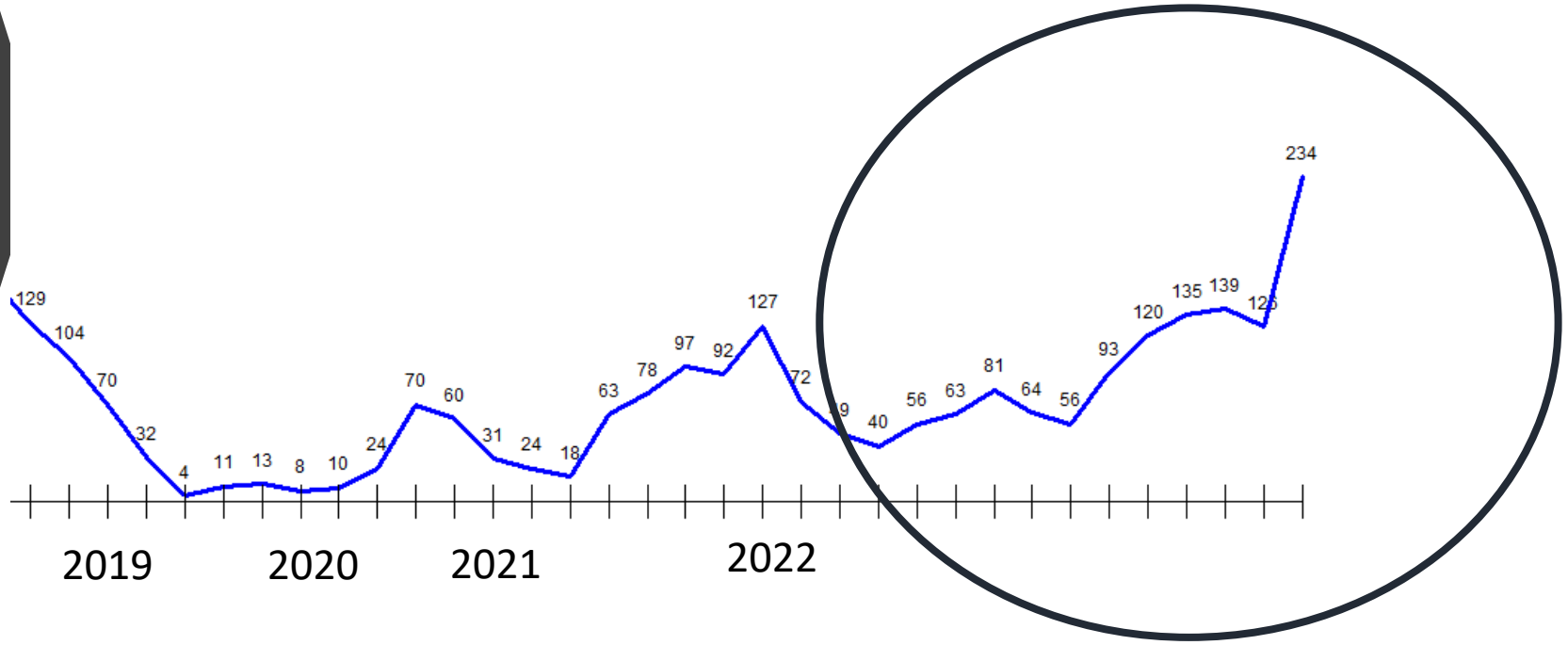

Community HIV specialist nurse
Secondary care
Injectables nurse/ tertiary care nurse
Joseph MDT
Third sector support
Josephs GP
Josephs HIV consultant


Regular handing over information
Community HIV specialist nurse
Injectables nurse/ tertiary care nurse
Visiting joseph on the ward
Secondary care
Community nurse presence at group meetings
Regular MDT meetings
Consultant presence on the ward
Discharge summaries sent to GP
GP sending Joseph to A&E
Joseph MDT
Third sector support
Josephs GP
Josephs HIV consultant

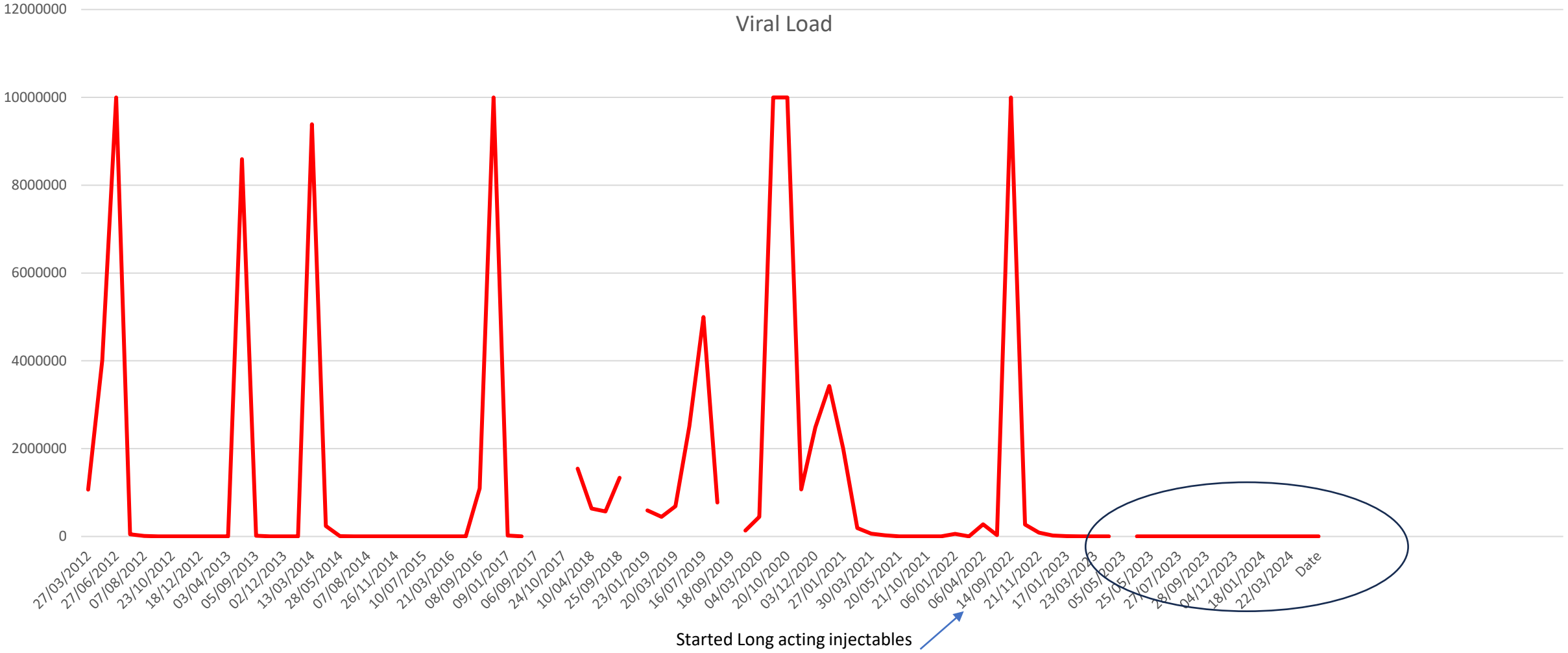
Clinical outcomes

CD4 count

Intervals on the X axis are varied as the CD4 monitoring varied throughout that period of time. The circle shows when LAI were commenced.



Outcomes so far: the infamous Viral Load.



www.nhivna.org

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NATIONAL HIV NURSES ASSOCIATION
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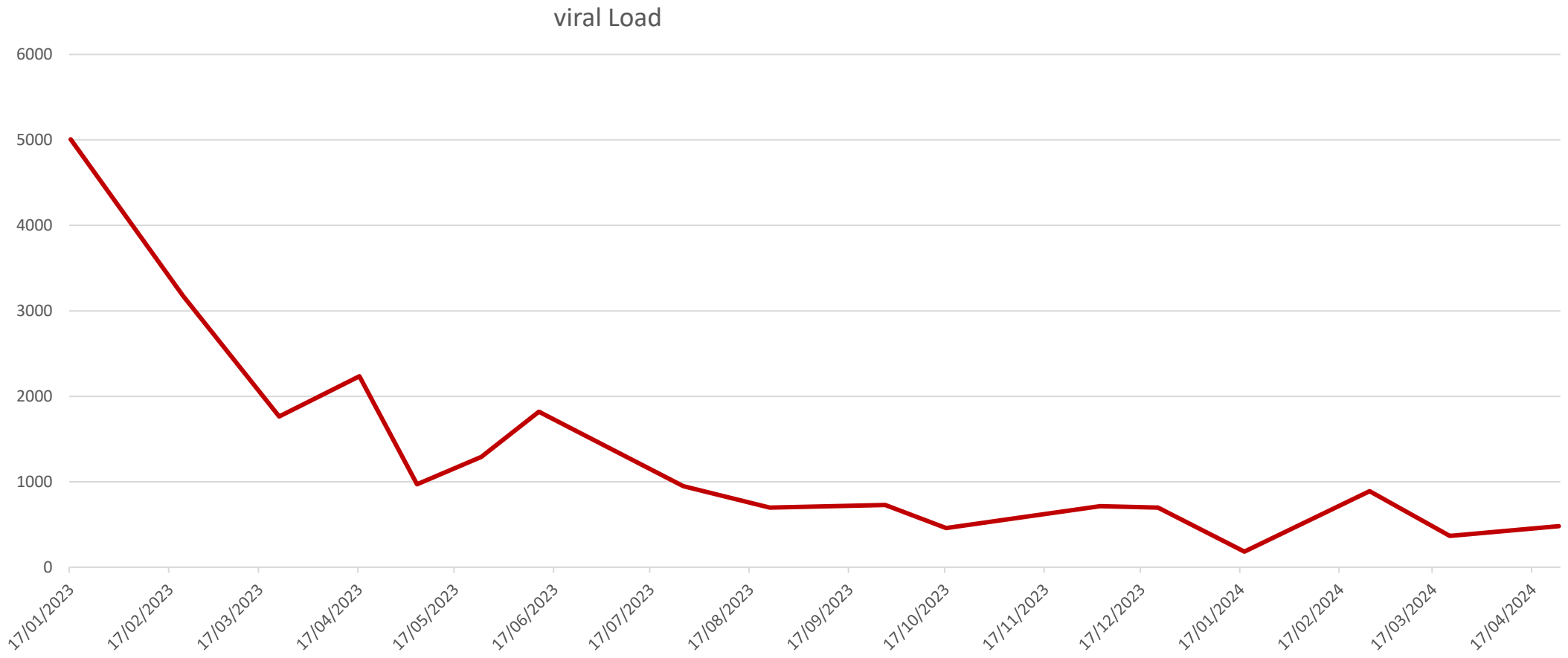
However,....


viral Load
6000
5000
4000
3000
2000
1000
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17/01/2023
17/02/2023
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17/12/2023
17/01/2024
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17/03/2024
17/04/2024

So why is Joseph not undetectable?

I don't know!

There is no resistance. It has been checked several times throughout, most recent showed no resistance to NNRT/ INSTIs

No missed injections, receiving monthly 2/3 doses

BMI in normal range, BMI:20. no concerns regarding muscle mass

All injections given by those who are competent to do so

No co meds which would interact with LAI

Other outcomes

Joseph is now going on regular holidays

Attending third sector community groups

Being seen monthly, more frequent monitoring of other long-term conditions

Having monthly sexual health screens.

What's next for Joseph?

- Joseph almost has an undetectable viral load, we have received agreement he can have Lenacapavir, as there is growing concern, due to not being undetectable resistance may develop to cab/ Ril.
- We will continue to support Joseph with the management of other long-term conditions such as diabetes
- Seeing Joseph regularly we can continue to provide therapeutic/ behavior changing interactions with him.

How could this be replicated in other areas?

To Delivers Josephs care, additional time was taken to ensure engagement and communication.

Regularly reviewed at ARV MDT due to not having an undetectable viral load.

Within the Lawson Unit, a business case was put forward in 2020, which meant there was allocated nursing time to the delivery of the service. This is not the case in smaller clinics and to deliver LAI may be expected to be done on top of an already busy case load.

For continuity and communication, the relationships between trusts and services need to be strong, these links are maintained through regular MDTs, training

Conclusion

- Joseph does not have an undetectable viral load but his CD4 count has improved, he is more engaged in care and has improved other outcomes.
- The working relationship between nurses in clinic and community was paramount to the delivery of Josephs care and is a good representation of nurses not only being administrators but also coordinators of complex delivers of care.
- Flexibility and co-ordination between; clinic “named nurses”, the HIV community team and third sector organisations were instrumental in Joseph's immune reconstitution and the life he now has ahead of him.
- Never say never!