





SusQl Case Study Report: A Novel Care Pathway for Stable HIV Patients – a streamlined and sustainable countywide approach for Northamptonshire



Team Members:

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- Ms Eleanor Ingate, PA to Service Manager and Consultant Lead in NISHH
- NISHH administrators, nurses, pharmacy and medical team

Background:

The increasing robustness and tolerability of antiretroviral treatment regimens for HIV over the last decade allows practitioners to seriously consider the impact and necessity of multiple attendances by patients to hospital sites for pathology testing and examination. Most adherent patients are now physically stable, living normal lives with personal and other employment commitments. Yet across the UK, most stable HIV patients attend NHS services with the same frequency and undergo the same/similar pathology investigations as those HIV patients who are relatively newly diagnosed or considered unstable. Changing the clinical pathway for very stable patients to achieve a reduction in face-to-face appointments has the potential to provide environmental, financial, social and clinical benefits whilst maintaining patient confidence and safety.

As the countywide Clinical Service Lead for Northamptonshire Integrated Sexual Health and HIV services (NISHH), it is within my brief to be able to deliver this system-wide change with a specific quality improvement and sustainable focus. With key members of the service team across all work streams, including junior through to senior team members, and capturing patient voices, we aim for this new pathway of care for "Very Stable" HIV patients to be rolled out across the entire HIV cohort of Northamptonshire with clear benefits and value very easy to see.



Specific Aims:

To reduce the frequency of face-to-face appointments and phlebotomy testing for a defined 'very stable' section of the county HIV patient cohort in Northamptonshire from twice a year to once a year.

Methods:

We reviewed our service and identified the existing minimum 6-month cyclical attendance pathway applies to all HIV patients, regardless of the stability of their condition and treatment. We therefore proposed dividing the existing HIV cohort into three, as defined below;

- Cohort A / "Very Stable" patients: A definition of a "Very Stable" HIV patient was agreed between the county HIV consultants. Patient meeting the criteria will require annual attendance. Please note: "Cohort A" patients will be referred to as 'Very Stable' in correspondence with patients.
- Cohort B: Patients considered stable who still require more frequent (6 monthly) monitoring due to adherence issues or resistance to antiretroviral regimens requiring medication changes.
- Cohort C: Patients new to the service or newly diagnosed with HIV infection. They will have not commenced antiretrovirals or have commenced recently but their viral load is not yet undetectable. Cohort C will also include patients who are pregnant or clinically unwell with an HIV related illness. Cohort C will require frequent (sometimes monthly) monitoring with specific additional tests depending on their current issue.

The three Cohorts were explained to all staff in the HIV arm of the service known as the Summers Unit (SU). A detailed flowchart depicting what investigations are required for the individual Cohorts at specific time points was developed (Appendix 1). With this change, the pharmacy team will be required to accommodate a mid-cycle Pharmacy Prescription Review by telemedicine. (See flowchart in Appendix 3).

All patients registered with the SU were sent a letter (Appendix 2) notifying all patients registered with the NISHH countywide HIV cohort of potential upcoming changes to their attendance schedule. This letter was sent via our electronic Text Link system. The letter indicated that changes would be discussed with every patient at their next face to face appointment and that no patient would be moved to the annual pathway without their consent.

At each patient's next doctor appointment, a joint decision between the patient and the HIV doctor will be made as to whether this new pathway is suitable for the patient. It will be emphasised to the patient that emergency access telephone and attendance arrangements will remain in place. This system will have a safety net for patients who become unwell or pregnant whereby the patient will simply transition seamlessly back to Cohort B or C monitoring schedules. To reinforce this information a detailed document including a pictorial flow chart (Appendix 3) will be offered to every patient during this discussion and for them to take home. Patients designated as suitable for and consenting to being in Cohort A/Very Stable will have this documented in their EPR and will begin the 12- month review schedule from this appointment.

Measurements:

We audited the HIV patient cohort data on our electronic records system (Lilie). This included a search for information of patients categorised as being stable on the HARS national dataset. Initial results suggested that 73% of the cohort were likely to meet criteria for 'Cohort A/very stable' status. However, HARS relies on clinicians filling in forms every time there is a clinical contact and is not always up to date. By looking additionally at individual pathology results held on the ICE pathology system for Viral Load, and at individuals in clinic, we are finding that there many patients not picked up by the HARS dataset who are eligible to move to cohort A. We are therefore confident in the assumption that 90% of our patient cohort will be eligible to move to Cohort A in the next 6-12 months. This figure will become a "soft aim" for service staff and while not possible within the 10-week project phase of the competition, this will be measured annually using the same audit processes as previously defined.

Social sustainability:

Patients who attended the clinic during our project phase were surveyed. To avoid bias, the patients were asked to complete the survey without staff assistance and before information was disseminated to patients on the proposed cohort changes. Approximately 10% (102 of the entire 950 patient HIV cohort) were surveyed. The survey focused particularly on environmental and social impact factors with full list of questions available in Appendix 4.

Impacts on staff have been reviewed informally through conversations about current pressures on their job plans. Pressures are compounded by ongoing and unpredictable colleague sickness absence related to covid, increasing demand and complexity of the cohort, increase Trust requirements around training and mandatory training and movement of trained staff relating to retirements and promotions. Freeing up staff time would allow focus on difficult cases and time to discuss issues that might affect adherence to medication.

Clinical and health impacts:

Over time, it is possible that the desire to be classified as "Very Stable" might drive HIV antiretroviral adherence.

There is considerable pressure with expanding demand on the sexual health, contraceptive and HIV service in the county. The county has an increasing population with an increase in those from higher HIV acquisition risk areas of the world. This project offers potential clinical benefits by freeing up staff time (as per above in social impacts), allowing the cover other pressure points within the service and crucially, allowing nurses to undertake important non patient facing activities.

Environmental sustainability:

Emissions factors from the Carbon factors Greener NHS Team 2020-21 were applied to a list of all consumables (excluding PPE) used in a single appointment including processing of blood tests. The weight of the consumables (excluding PPE) was obtained to calculate a waste reduction saving using emissions factors from Rizan et al 2021¹. PPE emissions factors which include disposal were taken from Rizan et al 2021².



Detailed travel data for 77 patients was used to develop a mean return distance. The emissions factor for average car of unknown fuel from the UK Gov BEIS greenhouse gas emission database was used to determine an average CO2e per patient journey.

Economic sustainability:

The cost of all consumables used in the 6 monthly appointment was obtained from the NHS Supply Chain and Aggresso system website used by the Trust procurement team.

Although the change will remove up to 855 x 30 minute Band 6 nurse appointments per year, actual costs in pounds have not been included as "direct savings". It is not anticipated that these hours will be "let go", and instead will enable current Band 6 nurses to undertake higher value work as outlined in Social and Clinical impacts.

Results:

Clinical and Health outcomes:

Discussing the change with each individual and moving all eligible and consenting patients to Cohort A /Very Stable will take a full 6-month cycle to complete. Therefore, it is too early to determine if the pathway will improve health outcomes for patients. However, preliminary discussions with some patients who are not currently eligible has suggested annual attendance that would be linked to their adherence could be a powerful incentive to improve their adherence to medication. The additional time gained by staff may also be supportive in helping to focus discussions on adherence and other issues that prevent categorisation into Cohort A.

The proven U=U (undetectable is untransmissible) is a powerful public health aim and anything the service can do to achieve 90% viral load undetectable levels within the cohort should be strongly encouraged. This would have a significant positive impact on the wider public and reduce the frequency of new HIV infections locally and in the UK. We plan to measure this impact at our first review of the new "Very Stable" cycle.

Social sustainability:

100 HIV positive patients completed the survey. We found that;

- 84% of respondents indicated that the environment was important to them. 10.6% indicated it was not and the remaining 5.4% were not sure and/or did not see the link between the NHS and the environment.
- 84% of respondents answered 'yes', it would be helpful if the number of routine appointment attendances was reduced. 9% responded 'no', however subsequent anecdotal discussions with two patients determined both had not understood that emergency access would remain in place. This suggests that the face-2-face appointment with the doctors before moving the patient into Cohort A is an important opportunity to provide reassurance. 3% of patients who answered 'not really' subsequently indicated they were retired and it made no difference to them personally. Thus, there was over a 90% approval rating for this change.
- 95% of respondents approved the method of communication (Text Link system). The remainder either did not like it or did not specifically answer the question but mentioned preferring email



communication or concerns re Google security. Anecdotally, some of this might relate to some patients not having a smart phone which needs to be considered to ensure fair distribution of all information.

- Impacts on employment and salary were varied and more difficult to interpret.
 - 5.5% were self-employed but did not indicate if absence from work had negative impacts.
 - 7.7 % attended clinical appointments during work time that continued to be paid.
 - o 9% chose to attend on a non-working day or in non-working time. Anecdotally staff have been informed this is because patients do not wish to disclose their HIV status or presence of a longterm medical condition to their employers.
 - Notably, 20% took annual leave or sick leave to attend, again some anecdotally disclosing the same confidentiality reasons.
 - Notably, 36.6% indicated that they received no payment when they attended. The SU is very aware that we serve a high proportion of patients who are on zero hours contracts and work within the many warehouses in the county. However, we did not specifically capture this information. Anecdotally, we are aware that implications of losing earnings to attend appointments needs to be considered. This is a reason given to us by patients who fail to attend scheduled appointments despite receiving reminders. Many zero hours contractors are given very little notice to attend for shiftwork which does not enable them to cancel/reschedule as many commence work before clinic opening times and do not have access to their phones.
 - 24.4 % said this question was not applicable, potentially due to retirement.
 - o One patient indicated he was responsible for caring for a relative and needed to make alternative care arrangements to attend.
- Patients travelled varied distances in a range of 4-140 miles return journey to attend their appointments. The average return journey was 32.9 miles. This equates to an average cost of £9.20 per patient per appointment. The average time taken to attend appointments and return home/work was 110 minutes. Sexual Health and HIV services in the UK are classified as 'open access' which means patients can choose to be seen out of area. Northamptonshire is a rural county with many patients not living near the Hub sites.

The outcomes of the change in frequency of attendance for a large proportion of the cohort may increase staff job satisfaction. Staff will gain time for higher value work, time to cover existing pressure points and have appropriate time to reasonably fulfil their job plans. Staff are currently working within an environment of increasing patient numbers/complexity and demand within a decreased financial envelope following a tender process in 2019. A staff member noted

"if we can keep our patients well and safe and have time to concentrate and give more time to those who need more time...that can only be a good thing, right?"

Environmental sustainability:

For each face-to-face appointment removed, we will save 20.15 kgCO2e attributed to blood tests (including laboratory processing), consumables used and waste disposal. Additionally, an GP appointment letter is no longer required, reducing emissions further by 0.011 kgCO2e per appointment. The mean return travel per patient journey was 32.9 miles, equating to a mean of 10.2 kgCO2e. Therefore, the total saving per face-to-face patient appointment equates to 30.36 kgCO2e.



We project that within circa 12-18 months 90% of the total Northamptonshire HIV cohort could be Cohort A patients (855 of the existing patient cohort). This would suggest a potential annual carbon saving of 25,957.8 kgCO2e, equivalent to 74,763 miles - 108.3 return journeys from Northampton to Glasgow.

Economic sustainability:

There were no specific Trust investment costs required to undertake this project. Dedicated time at senior doctor level was required to both design and implement the system.

The potential financial savings for the Trust are estimated to be £52.52 per patient appointment (including purchase and disposal of consumables and laboratory blood test processing). Based on 90% of the existing patient cohort moving to Cohort A within the next 12 - 18 months, this would suggest a potential annual saving of circa £44,904.60.

It is expected we will gain approximately 350 nursing hours across the year (based on 700, thirty-minute appointments being removed. Again, a 90% roll out would increase this to 427 hours). The cost of staffing changes has not been included in these savings because it is considered that the staff would remain in place as outlined in the social sustainability section. This might however not be the case should similar changes be implemented in other HIV services within the UK. There will also be a saving in laboratory staff testing time.

Barriers encountered

There exists within the NHS service(s) staff members and patients who do not like or deal well with change. It is infrequent that patients are asked specifically about the social impact of their attendance to NHS sites and many NHS staff feel that patients wish to attend regularly. However, the patient survey showed a clear and strong patient voice in favour of reduced attendance. This supported the subsequent detailed discussions with staff to explain the merits of and request support for this change programme.

Conclusions:

The potential financial and environmental savings across the UK, where in 2019 there were nearly 99,000 HIV patients accessing care³, are irrefutably significant. However, this pathway re-evaluation does not need to be limited to HIV care programmes with multiple outpatient pathways seeking to manage chronic conditions. However, there is no incentive for NHS staff to reduce attendances if their services are dependent on payment allocated per attendance. For our integrated sexual health service, we are on a block contract making this change possible.

The social benefits of our pathway change are significant both for staff and patients. Staff have been under increasing pressure and report disappointment at not having sufficient time to deal with those who need particular additional care/time. Our hope is that the freed-up appointment time will allow time to focus on those that do not adhere to their medication and to understand this on a person-byperson basis, with the aim of solving any barriers. It is the only way we will achieve all patients being virologically undetectable and therefore the virus being untransmissible.



We plan to review the cohort system after 12 months. At this time, and with hindsight, we would try and interview the patients from a more detailed perspective to look at cohort demographics and how/if this related to some of the answers given. For example, are all the patients on zero hours contracts foreign citizens and if they are, is there an easier way to make their transition into UK society and hopefully their attendance and adherence easier. We would also seek to be fully reassured about the safety of the system and identify any unforeseen problems that may have arisen.

The environmental savings indicated in this project, were considered "staggering" by our staff. Indicating these savings in terms of equivalence to car journeys made it relatable and simplified staff understanding, and they voiced that it was still overwhelming to see the NHS effect on the environment. On completion of this project, we will seek recognition of the value of our outcomes from our colleagues within our Trust with its many outpatient departments. We would then try to extend it to a system wide approach across our county (which has three NHS Trusts and Primary Care) as the county moves towards integrated care systems.

References

- 1. Rizan C, Bhutta M, Reed M, Lillywhite R. The carbon footprint of waste streams in a UK hospital. Journal of Cleaner Production 286 (2021) 125446. https://www.sciencedirect.com/science/article/abs/pii/S0959652620354925
- 2. Rizan C, Reed M, Bhutta M. Environmental impact of Personal Protective Equipment supplied to health and social care services in England in the first six months of the COVID-19 pandemic. Journal of the Royal Society of Medicine; O(0) 1–14, DOI: 10.1177/0141076821100158
- 3. www.nat.org.uk (National Aids Trust)



Appendix 1: Summers Unit Pathology Monitoring 2022

Baseline Assessment (new diagnosis, transfer in to SU) SU nurse assessment & investigations as listed (List 1) Book Dr review Assessment Decision on frequency of monitoring (Cohort A/B/C) Any additional tests eg. latent TB from low incidence Criteria for Cohort A - If patient has stable HIV infection with: VL<40 consistently for at least 2 years Same ARV regimen for at least 2 years or recent simple switch No acute HIV issues requiring COHORT C additional monitoring Acute HIV issue/s requiring more frequent monitoring COHORT A COHORT B Annual Monitoring Programme 6 monthly Monitoring Programme (Dr annually & pharmacist at 6/12 interval) Annual Medical Dr Review - face2face or Telemed: 6 month appointment with SU nurses: Dr assesses. Documents tests required on Investigations/review as listed (List 2) EPR (list 3) or book Dr appt if wishes Add to CA list to review/text results in 2 weeks and 6 month ARV patient to be seen script as appropriate (d/w Drifabnormal results, all results to be Book appointment (SU nurses/other) documented in appropriate section of EPR) within 2-3 wks for annual monitoring Add to admin CA list 5 months to book Dr Telemedicine bloods if does not need Dr review appointment at 6 months - Do NOT book appointment now Appointment with SU nurses/phlebotomy clinic: Annual Dr Telemedicine appointment: Investigations/review as listed in EPR including weight, bp, height, waist circumference, BMI Does pt need F2F appointment? - book Add to SU nurse CA list to review results in 2 weeks Assessment & 6 month script - d/w Dr if abnormal results Book routine 6 monthly phlebotomy appointment and list Update EPR with all results & calculate QRISK/FRAX required investigations in EPR (List 3) if required Add to admin CA list 5 months to contact pt and book SU Book 6 month Pharmacy review appointment nurse appointment at 6 months 6 Month Pharmacy Review appointment: Contact patient to check adherence/any ARV

Phlebotomy appointment:

- Bloods as listed in EPR
- Add to Dr CA list 2 weeks to review requested bloods/results & issue 6 month ARV script if ok

- Contact patient to check adherence/any ARV issues over preceding 6 months
- If no new issues requiring clinical review issue further 6 month ARV script to pt
- Add to admin CA list 5 months to contact patient to book annual Dr appointment review



LIST 1: Baseline/diagnosis/transfer in

- Confirmatory HIV test unless result in formal transfer letter from UK site
- CD4
- VL
- HLA B5701 unless result in formal transfer letter from UK site or pt already on abacavir
- HIV resistance test unless result in formal transfer letter from UK site or undetectable VL
- Hepatitis IgA Ab
- Hepatitis B cAb, sAg, sAb
- Hepatitis C Ab if positive check HCV -RNA
- FBC/differential
- U&E
- LFT
- Bone profile
- Lipid profile
- HbA1c
- Urinalysis, UPCR/ACR
- STI screening and syphilis serology (under GU number)
- QRISK3 score if aged 40yrs and over
- Bone fracture risk assessment FRAX score do every 3 years if aged over 50yrs, post-menopausal women, and other patients at high risk (hypogonadism, low body mass, smoking, high alcohol intake and glucocorticoid use)

LIST 2: 6 Monthly Follow-up SU nurse Appointment (Cohort B)

- VL
- CD4:
 - 1. Not on ART
 - 2. Started ART n last 6 months and previous CD4<350 (CD4 not needed if:
 - CD4 >350 on 2 occasions >1 year apart
 - If pt stable on ARVs with VL<40 for 2yrs and CD4 remains below 200)
- FBC not required in men stable on ART with VL<40 unless requested by Dr
- U&E, LFT, Bone profile
- HbA1c if requested at Dr review
- Lipids if requested at Dr review
- Urinalysis & if proteinuria send UPCR/ACR if on tenofovir or requested at Dr review
- If hepatitis B/C co-infection follow NHFT/NGH co-infection flowchart 2022
- STI screen (under GU number) where appropriate including hepatitis C (under SU number) if risk
- If previous HBV vaccination:
 - sAb<10: revaccinate with double dose up to 2 courses (once VL<40). If no response document and no further vaccination
 - sAb>10: boost 5 yearly (unless no ongoing risk)
- Weight, bp, waist circumference, BMI
- QRISK3 score if aged 40yrs and over
- Bone fracture risk assessment FRAX score do every 3 years if aged over 50yrs, post-menopausal women, and other patients at high risk (hypogonadism, low body mass, smoking, high alcohol intake and glucocorticoid use)



LIST 3: Annual Monitoring/Doctors guide (Cohort A)

- VI
- CD4 (not needed if CD4 >350 on 2 occasions >1 year apart) if:
 - 1. Not on ART
 - 2. Started ART n last 6 months and CD4<350

(CD4 not needed if:

- CD4 >350 on 2 occasions >1 year apart
- If pt stable on ARVs with VL<40 for 2yrs and CD4 remains below 200)
- FBC not required in men stable on ART with VL<40 unless requested by Dr
- U&E, LFT, Bone profile
- HbA1c consider if risk
- Lipids if >40yrs or other indication
- Urinalysis & if proteinuria send UPCR/ACR if on tenofovir or another indication to do
- If Hepatitis B co-infection: AFP, HBV-DNA, HBsAg, request liver USS, check follow up with hepatitis team and fibroscan (as per NHFT/NGH co-infection flowchart 2022)
- If Hepatitis C co-infection: check had AFP, liver USS, check follow up with hepatitis team and fibroscan (as per NHFT/NGH co-infection flowchart 2022)
- STI screen (under GU number) where appropriate including hepatitis C (under SU number) if risk
- If previous HBV vaccination:
 - sAb<10: revaccinate with double dose up to 2 courses (once VL<40). If no response document and no further vaccination
 - sAb>10: boost 5 yearly (unless no ongoing risk)
- Weight, bp, waist circumference, BMI
- QRISK3 score if aged 40yrs and over (please date)
- Bone fracture risk assessment FRAX score (please date)— do every 3 years if aged over 50yrs, postmenopausal women, and other patients at high risk (hypogonadism, low body mass, smoking, high alcohol intake and glucocorticoid use)
- Latent TB as appropriate as per BHIVA guidelines:
 - if from country of high (>151/100,000)/medium (40-150/100,000)TB incidence for latent TB infection (see links below for TB incidence by country)
 http://www.gov.uk/government/publications/tuberculosis-tb-by-country-rates-per-100000-people; http://www.who.int/tb/publications/global report/en
 - Consider if from low incidence countries for latent TB infection if additional risk factors 'such as exposure to a known TB case (which should be identified through routine contact tracing) or travel to or periods of time (>12 months) spent consecutively in higher incidence countries

Radiology

Request test and add to CA list in one month to review results (sooner if urgent)

Check results at one month:

- If results available Dr to review and document in EPR
- If results not available add to CA list to check in one month



Appendix 2: Summers Unit Patient letter ONE re Very Stable Pathway 2022

Message from Dr LR, Dr SH and Dr AMcK - 1.7.2022

Dear all

We hope this letter finds you well. It has been a real pleasure to see some of you again in the clinics following the lifting of the restrictions during the COVID pandemic. As a healthcare service, we have learned a lot over the time that we were unable to physically see you on the hospital site(s). We have also spoken to many of you about how we communicated with you and how we provided your medication during the national and local lockdowns. We have recognised that many patients at our service are 'Very Stable'. This means being both:

- · Clinically stable (your health is good/well managed), and
- · Virologically stable (virus is undetectable)

Research studies in this country and abroad show that 'very stable' patients can safely be seen less often for monitoring. Seeing patients less often has other benefits such as reduced travel, and time off work. If you are considered to currently be 'Very Stable', we are proposing to only see you once a year for your blood tests.

Very stable patients are those people who:

- 1. have had an undetectable viral load for at least two years, AND
- are clinically stable with no other health issues requiring management by the Summers Unit or which might affect your management with us.

We have developed some written information for you to explain this in more detail. This will be given to you, or sent to you after your next appointment with the doctor or nurse where we will take the time to explain all of this this to you. If you are pregnant or have any other conditions that we are currently managing, you will not be considered 'very stable' at the moment, but this is likely to change (for example after you have had your baby you may then be considered 'very stable'). You might also be considered very stable if you have recently needed to change medication because of side-effects or to simplify your drug regimen. We will not change your monitoring to yearly without speaking to you first and making sure we answer any questions you have. We are also here for you if there are any problems between visits, just as we are now.

We look forward to seeing you soon,

Best wishes.

Dr Lynn Riddell, Dr Sophie Herbert and Dr Anna McKendry

Details of Very Stable Pathway SU 2022

You should have received a letter via our text system on 1/7/2022. This was to advise you of how we will be monitoring **Very Stable** patients going forward. This document provides you with more details and an explanation.

We are going to be offering those of you that are 'very stable' some changes to the number of times that you are required to attend the hospital for blood tests. Essentially, you will only need to come to the hospital once a year. We hope this will help you with the social aspects of attending (cost, time off work, time out of your day, parking, impact on the environment, etc) and we are confident that from a medical point of view, provided you continue to take your medication as prescribed, you should remain well in terms of your HIV care.

"Very Stable" means being both:

- · Clinically stable (your health is good/steady/well managed), and
- Virologically stable (virus is suppressed/controlled).

For "Very Stable" patients, we have been able to review the current schedule of attendance at the Summers Unit. We have looked at how often <u>routine</u> blood tests are needed and where they can be taken. Based on our experience, we consider that "Very Stable" patients can be safely and effectively looked after without so many hospital attendances, provided you continue to take your medication and stay "very stable", **and** provided emergency contact arrangements remain in place. Our aim is always to make sure that you are managed safely and that you medication is working well to control your condition.

Summers Unit staff will now determine what is the <u>safe and essential monitoring/testing</u> that you require as an individual, and when physical attendance is not necessary. At the same time, we want to reassure you that emergency contact arrangements to our service will remain in place for anyone that needs them. We want everyone to continue to feel confident that both yourself and your condition are being well managed.

The points below outline our guidance for being considered "Very Stable":

- 1. If you have had a viral load that is less than 40 c/ml for at least two years, AND
- 2. You are clinically stable with no other health issues requiring management by the Summers Unit or that might affect your management with us.
- If you are pregnant or have any other conditions that we are currently managing, you might not be in this category <u>at the moment</u>.
- If you have recently needed to change medication because of side-effects or to simplify your drug regimen, and you meet the other criteria, you <u>might</u> still be considered "Very Stable".

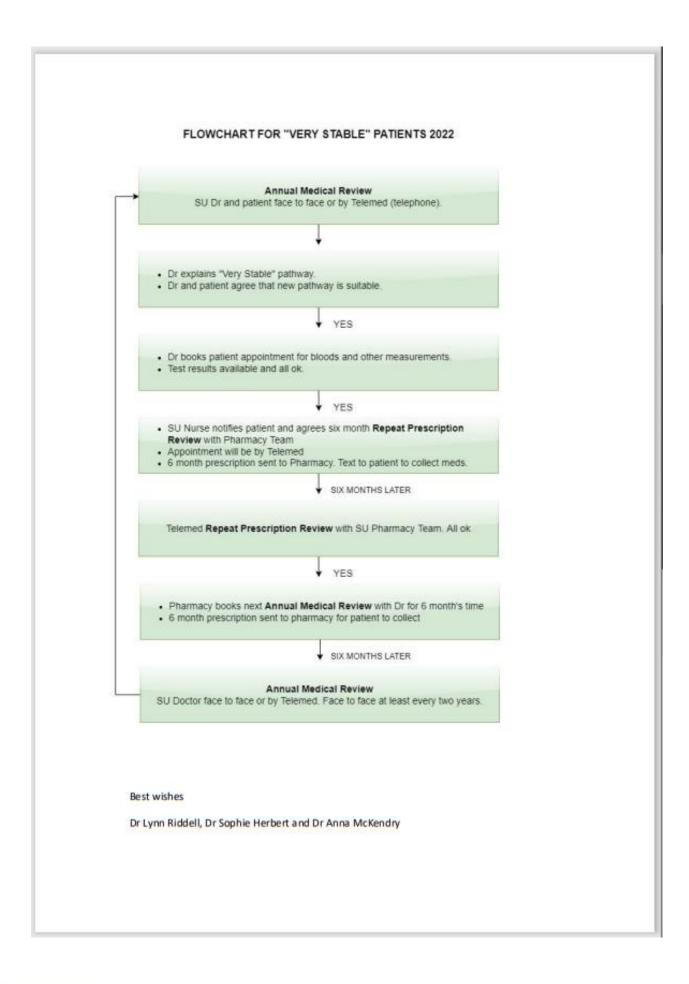
If you are not considered "Very Stable" currently, do not worry. This simply means that you require the same level of monitoring/testing that we had in place before the pandemic. Anyone who does not meet the above criteria might well be considered "Very Stable" at a later date. At all times, we will discuss this change and any concerns with each of you on an individual basis.

What are the changes?

The main change is that those who are "Very Stable" will only need to attend the hospital site(s) for blood testing and physical measurements <u>once a year</u>. Other than these yearly attendances, you will be offered telephone management if it is safe to do so. During a telephone appointment, if any issues in your care are identified by either you or NISHH staff, you will be offered/asked to attend a hospital site. If you are considered "very stable" and do not want to move to only having bloods taken once a year, just tell us. After we have run this system for a period of time, we will ask you for your feedback. Please see the flowchart on the next page to help you understand the process. Again, do not worry about it if you do not understand it or do not have the time to take it all in. Staff in the Summers Unit will explain it all to you.

PLEASE SCROLL DOWN TO SEE THE PICTORIAL CHART ON THE NEXT PAGE





Appendix 4: Patient Questionnaire Summers Unit 2022.

Patient Questionnaire SU 2022 Patient ID When you attend an appointment at the Summers Unit NGH /Ashwood, how do you travel? car/bus/train/bike/walk/other If you use a car, is it petrol or diesel and how many miles do you travel each way If you use a bus, how much does it cost you and about how many miles is it each way To attend on site, are you incurring any of these other expenses parking fee/childcare/other Do you have to take time off from work (you still get paid) to attend your appointments or do you have to take this time to attend clinic as annual leave or unpaid leave? From the time you leave to come to your appointment at the Summers Unit until the time you are back doing your normal day, approximately how many hours is it? If we could reduce the number of times you have to attend for ROUTINE appts but still make sure you have emergency access when you need it, would this help you? What times of day would it suit you to attend for blood tests? Over the pandemic lockdown period when you were not able to attend the hospital, did you receive the letters we sent to your phone telling you about how we would be managing your prescriptions etc? What did you think of this method of communication? Are environmental issues important to you? Thank you

