

Economic Assessment of the Community HIV CNS role

Shaun Watson, Community HIV Clinical Nurse Specialist

Background - Setting the Scene

The face of HIV is ever-changing and challenging with an ageing HIV positive population, long term effects of antiretroviral therapy (ART) and rising rates of HIV and sexually transmitted infection. In 2014 there was an estimated 103,700 people living with HIV in the UK with 613 deaths (PHE, 2015). The role of the community based HIV clinical nurse specialist (Community HIV CNS) has a long and varied history in the context of HIV. In 1987 the first community team in the UK (at St Mary's Hospital, Paddington) was formed and based their care on the Macmillan nurse model. Since that first Community HIV CNS team formation it can be argued that HIV set the benchmark for other Community CNS roles within long-term conditions. Initially the Community HIV CNS role was commissioned to provide specialist management for those living with HIV/AIDS who wanted to live (and die) at home and be supported with the relevant expertise to provide support and co-ordination of services plus the requisite palliative care for those who wished to remain in their own homes. As HIV evolved, so the role developed in response, providing specialist advice and expertise around HIV care, side-effect management and adherence to (at the time) complicated ART. The current emphasis of the Community HIV CNS role is one of complex case management (see appendix 1) which has been described as 'the process of planning, coordinating and reviewing the care of an individual' (Hutt et al, 2004) and supporting HIV self-care and management. Self-care is considered a primary form of care for patients with chronic conditions who make many day-to-day decisions, or self-manage, their illness (Bodenheimer, 2002)

The role is unique. However within London and across England there is a disparity of Community HIV CNS service provision with some boroughs having one community HIV CNS (e.g., Westminster (1437 patients accessing HIV care), Hammersmith and Fulham (1059 patients accessing HIV care), others with two or three (City and Hackney (1565 patients accessing care), Southwark (2810 patients accessing care), Brighton (1524 patients accessing care), Liverpool (640 patients accessing care, city numbers only) and some with no community HIV CNS service at all (e.g. Ealing (739 patients accessing care), Hounslow (627 accessing care). Although the Community HIV CNS's have similarly named titles (Specialist HIV nurse, Community Matron, (Advanced) Nurse Practitioner) they have (slightly) differing job descriptions and are funded, managed and work in different ways and (apart from some geographical groups) have very little to join them as a cohesive team of nurses with a common purpose.

On the whole, Community HIV CNS's see people underserved by other health services, those deemed not 'mentally unwell enough' for mental health services but who for general HIV services and voluntary agencies are incredibly challenging to manage; they case manage those who are housebound, too infirm or ill to access services but with no ongoing physical concerns to require a GP consultation or district nurse referral; they manage and support those who have stopped engaging (either

are lost to follow up or poor attendees) with their HIV services or who may be 'HIV stable' but living with other long term conditions for which they need complex case management and support (such as those with physical problems, dementia or cognitive impairment); they support people who are not motivated to self-care and may lead 'unconventional', socially complex lifestyles with little or no routine, chaotic individuals who need case management and support to live an undetectable 'HIV healthy' life.

The overarching remit for most Community HIV CNS is the management of a cohort of patients to prevent avoidable hospital (re)admissions and speed up discharge from wards. However, our roles are many and varied with the main functions being:

- Optimisation of Antiretroviral therapy (ART). Ensuring ART is taken as directed, monitoring adherence and general medication checks (including drug alerts, out of date medications, correct storage etc.) is central to most referrals to the Community HIV CNS. Discussion with and support for community and/or hospital pharmacies, home delivery of medication services, district nurses and carers. Teaching and supporting individuals to fill their medicine compliance aids (dosette boxes). In some cases, patients are happier to see a nurse out of the clinic situation where they feel they can be more honest about their adherence and other issues with medications.
- Complex case management and care coordination (See Appendix 1) – liaison with other agencies to provide streamlined care provision for advance HIV disease and co-infection (such as hepatitis, tuberculosis, mental health related issues, neuro-cognitive changes, drug and alcohol related problems and changes associated with ageing) Some teams work closely with HIV positive sex workers, street homeless or hostel dwellers, those with learning difficulties, poor literacy and language comprehension. Working with pregnant women ante and post-natal in order to prevent mother to child transmission. The HIV CNS in this situation has an ongoing relationship with patients, as they are generally not constrained by limits to the amount of visits offered, which is often negotiated with the patient many of who have continuous HIV CNS support for the majority of their lives. Preventing unscheduled, avoidable admission is integral to the work of many specialists. For example, intervening if a patient needs symptom control and referring to their GP, community services or appropriate acute service well before the patient is forced to attend the emergency department.
- Vigilance or 'check-in' service – where there are concerns about a patient's clinic attendance and engagement, adherence, lifestyle, housing, domestic situation (issues such as domestic violence, safe guarding and vulnerable adults, child protection concerns, support and testing of children etc.). The HIV CNS supports those who frequently disengage or track down those lost to follow-up and encourage clinic attendance or engage in the community. The HIV CNS is uniquely placed to assess the home situation where other organisations may not do home visits or may not visit alone the Community HIV CNS has been able to build up trust, confidence and motivate individuals back into care.
- Side-effect management of other long-term conditions and medications,

working closely with GP's and specialist HIV clinics. The HIV CNS acts as a triage, often seeing patients at home before they go to see a GP to assess and advise on health issues. In this situation they often take a more holistic approach assessing what else may be happening with the patient such as home stressors (finance, housing problems, family issues) that may not be obvious to a GP or clinic.

- Rescue work - Community HIV CNS's provide support with initial HIV diagnosis, general health issues and some (limited) support with housing and welfare issues such as professional letters of support, onward referral to appropriate agencies and advocacy as needed. Support around intimate partner disclosure and onward testing. The Community HIV CNS is best placed to identify issues within family situations and can provide local knowledge of services, support etc. This could be described as 'rescue work' which involves the early detection of impending deterioration and taking pre-emptive action to prevent adverse events. Examples include detecting chest infections, picking upon incorrectly prescribed medication, addressing anxiety caused by illnesses or highlighting safeguarding or vulnerabilities.
- Supporting patients with the management of the symptoms of advanced HIV disease, co-infection and palliative care support, working alongside other CNS teams (such as blood borne virus, street homeless, tuberculosis nurses), Macmillan and hospice teams. Completing/leading Continuing Care Assessment processes for individuals needing long-term placements or having increasing care needs.
- Advocacy – HIV CNS's offer emotional and psychological support with clinical appointments or helping resolve issues with other services (such as GP, DN, Dentist, Social services, MH services, housing support etc.)
- Liaison between HIV specialist services, primary care, social care and voluntary teams, shared working with other agencies (hospital, therapies, Addiction Units, mental health services, learning difficulty services, dental care, social work and voluntary groups) Encouraging patients to register and use GP services appropriately. Some CNS's offer out of hour's support and/or communication about who to contact.
- Referral and access to respite, rehabilitation and ongoing care teams such as Mildmay, Hospice services, Riverhouse, Positive East, THT, Food Chain, CAB etc. Some CNS's have responsibility for the appropriate use of the allocated budgets for access to Mildmay or local hospice Day Care and in-patient services. The HIV CNS's have often acted as gate keepers to money for specialised rehab and respite service with commissioners relying on their clinical expertise to effectively assess and evaluate care needs and refer on appropriately.
- Teaching and advice on HIV related issues, specific HIV information, general HIV advice, ARV advice and information. The CNS can often offer ad hoc training on specific situations such as issues with nursing homes or homeless people's units. We often highlight areas for development and support such as testing services within hostels.
- Support for the newly or recently diagnosed, which can range from management of anxiety, denial to disengagement from care.

- Some Community HIV CNS teams provide stable patient clinics. Some are nurse prescribers providing acute clinics and community symptom control. Some offer monitoring i.e. taking blood samples both routine and emergency, which take appointments out of the system in acute centres. There are some that offer a community virtual clinic for patients who cannot attend clinic due to physical, financial and psychological constraints. Adapted from Leary (2010)

Economic Assessment of the Community HIV CNS

With funding from the Burdett Trust for Nursing, the Office for Public Management (OPM) and the Royal College of Nursing (RCN) delivered a collaborative learning programme designed to empower nurses to understand, generate and use economic evidence to continuously transform care. All too often the Community HIV CNS is seen as a luxury (rather than essential) service and the purpose of this economic assessment was to demonstrate the value of the Community HIV CNS role.

This Economic Assessment presents the costs and the benefits of providing a community CNS HIV service. It uses a cost avoidance approach to demonstrate the value of the service and illustrates the impact of the role through 3 case studies.

Intended audience

The intended audiences for this economic assessment are HIV commissioners, Clinical Reference Group and lead HIV clinicians, other Community and hospital CNS's. The impact of Community HIV CNS interventions are set out in Table 1 (Adapted from National Cancer Action Team, 2010).

Table 1: Impact of key Community HIV CNS activities

<p>Improving Quality and Care Experience</p> <ul style="list-style-type: none"> • Managing complex, individual and changing information and support needs of patients and carers • Supporting patients in choices around treatment and care • Enhancing recovery and delivering care flexibly and closer to home 	<p>Reinforcing Safety</p> <ul style="list-style-type: none"> • Delivering safe, nurse-led services • Using vigilance of symptoms and drug toxicity to trigger rescue work • Identifying and taking action to reduce risks • Facilitating rapid re-entry into acute services, if appropriate
<p>Increasing Productivity and Efficiency</p> <ul style="list-style-type: none"> • Intervening to manage treatment side-effects and/or symptom control, preventing unplanned admissions. • Providing nurse-led services that free up consultant resource. • Empowering patients to self-manage their condition. 	<p>Demonstrating leadership</p> <ul style="list-style-type: none"> • Educating the wider healthcare team and acting as a mentor • Identifying and implementing service improvement and efficiencies • Sharing good practice and innovation

What are the issues?

Adherence is complex – there are no other community services that monitor adherence to ART. Some patients lack knowledge, comprehension and motivation to take ART and need support, others are unable to manage complex medication regimens or have memory issues that make adherence difficult. Patients, on the whole, are expected to self-care with their ART and other medications. Many complex patients live alone and are unable to manage their medications, for example those with dementia or cognitive impairment, sight or manual dexterity issues. District nurse (DN) services will not routinely refill or manage compliance aids (dosette boxes) only for very complex (usually bed bound patients) and home delivery may only blister pack those medications prescribed by the HIV clinic with patients sometimes having 2 blister packs to manage. Some DN teams will not accept referrals for patients who are ambulatory and could (in theory, but for a wide range of complex reasons do not in practice) get to their GP or HIV clinic (this is 95% of my caseload).

For those who need care, Social service support care workers have the competence to prompt medications only, therefore they will open up the blister pack or a dosette box and prompt the patient to take them, but they are not knowledgeable or competent to refill dosette boxes or recognize problems such as missed medications, drug errors etc. Support workers do not organize the refilling or delivery of medications, this is the responsibility of the patient. Some patients may be able to link adherence to collecting a daily prescription, such as methadone, but this will only work if the community pharmacy agrees to supervise ART and many will not supervise or blister pack medications that they don't dispense or prescribe.

Therefore, if the Community HIV CNS role were decommissioned, the patients we support would be expected to manage their ART and refill dosette boxes unsupervised which may lead to over/under-dosing, missed doses or stopping completely (drug wastage), potentially leading to ART resistance, ill health, prolonged periods of hospitalization or onward transmission of HIV.

Complex Case Management – for some patients the Community HIV CNS may be the only point of contact at home as they rarely see their GP or do not have referral criteria for a district nurse, mental health nurse/support worker or social services support. Therefore, for these patients, the Community HIV CNS role is vital to monitor their general health, assessing for safe-guarding issues and concerns around vulnerabilities (such as drug and alcohol use, housing, poverty, debt etc.). As many patients now only attend specialist HIV clinics once or twice a year the Community HIV CNS service provides a 2-4 weekly (sometimes weekly) service to manage ongoing issues. Without this service there can be a potential for severe ill health, periods of hospitalization with the potential for socioeconomic or mental health issues to go unnoticed and unsupported until crisis occurs.

The Costs of the service - drilling down the economics of the Community HIV CNS Role

This economic assessment will highlight an hourly rate for my role as a Community HIV CNS (band 8a) and compare to other services that would need to be in place if this role was no longer commissioned. The hourly cost is £46 (see footnote)

The Benefits of the Service

Who benefits from the Community HIV CNS service?

- Patients with complex HIV needs (usually around adherence or medicine management, mental health needs)
- Carer and family of patients feel supported.
- The HIV clinic – patients are managed and supported at home with ART adherence and are kept engaged with the HIV service.
- The GP – HIV patients have additional community management/vigilance at home with this role where there may be no other services available
- Other Specialities and social care – the Community HIV CNS provides vigilance, rescue work and management for those who may not meet criteria for other services but who may need rapid referral at some point.
- Borough/commissioners – undetectable patients reduce risk of further ill health, hospitalisation and onwards HIV transmission.

Added Value¹

- Vigilance – for isolated patients who rarely seek support elsewhere.
- Lost to follow-up and poor engagement – the HIV CNS is well placed to visit and support those who may find it difficult to attend or who, for many reasons, may be anxious, embarrassed to visit the HIV clinic.
- Rescue work – recognition of safeguarding issues, vulnerable adults, mental health crisis, acopia, social, financial, housing issues and general ill physical and mental health.

What benefits can be monetised?

- Adherence – there is a cost to the wastage of medication of approximately £500-600 a month per patient (BNF, 2016). By supporting patients' adherence we prevent potential ill health and onwards transmission of HIV.

¹ HIV CNS role on a band 8a (with transport and IT costs) is £63431 (2015/16 figures as given by Chelsea & Westminster finance department) plus 22.5% on costs = £77702.98. Curtis and Burns (2015) cost a band 8a specialist nurse (hospital based) at around £65/75 per hour of patient related work However, for the purposes of this study I have looked at my own hourly rate of £46 per hour worked (£77702.983 divided by 1687.5 hours worked per annum)

- Poor engagement and those Lost to follow-up - there will be a payment by result tariff that can be applied to each patient visit (awaiting figures from PHE). All of our patients are complex.
- Engaging patients back into care will benefit their general health and allow assessment of potential health issues.
- We prevent periods of ill health whether that is calling out a GP, ambulance or hospital visit all of these have a significant cost implication.
- Vigilance – there are cases where the HIV CNS will be the only Healthcare Professional who will see the patient at home therefore we provide a service that covers mental health/social support where patients do not meet their strict criteria.

Monetized benefits: costs avoided

Avoiding waste

From information from Chelsea & Westminster's lead HIV pharmacist the average cost in London of ART is £5100 per patient per year (British National Formulary, March 2016) but this accounts for patients having home delivery (and a price reduction negotiated through the HIV consortium) without this costs are approx. £500 per patient per month (the cost of patients being on a protease inhibitor is slightly higher at around £560 per patient per month). The British National Formulary (BNF, 2016) price would be on average £670 per patient per month. For example, a patient on Darunavir, Ritonavir Truvada would be costed at (list price) £297.90 + £19.44 =£355.73 =£673.07, however each patient is on different regimens so the costs will change. Therefore, if most referrals to Community HIV CNS's are for adherence management and this is unsupported (for those patients who have poor motivation, engagement or adherence) there is the potential for wastage, which would cost on average £2000-3000 per person (6 months unsupported adherence). Within the context of a caseload of 60 – 70 patients, if, for example, 50% of patients without the intervention of an HIV CNS wasted their ART, the cost of the waste to the system would be £162, 500. If this figure rose to 80% of patients, the costs would be £260,000. This does not include any additional costs that would be incurred elsewhere in the system through contact issues (phone calls, letters), clinic visits, consultations and investigations.

Treatment and Prevention

Economic modelling has suggested that Treatment as Prevention (TasP) is a cost effective approach and is likely to be cost saving over time. Analysis undertaken by Public Health England in developing this policy (NHS England, 2015) shows that 1,800 new HIV infections will be prevented. In terms of quantifying the cost of one prevented transmission, lifetime costs per-case are estimated at £280,000 - £360,000, therefore resulting in an overall saving of £500 - £647 million to the NHS (Brown et al, 2013). In my Community HIV CNS role 20% (12 patients) of my caseload are sexually active, some as paid escorts others in sero-discordant relationships or single. Avoidance of onward transmission is a vital part of the Community HIV CNS role and cost implications of not managing and supporting patients effectively could incur a

potential on cost of (12 x £280,000 - £360,000) £3.360,000 – £4.320.000. Consideration should also be made here around pregnancy and the costs of vertical transmission to the child and costs involved.

There are significant costs avoided by the intervention of the HIV CNS on a case by case basis. These include:

- 1) Avoidance of a hospital (re)admission is central to the role of the Community HIV CNS. A hospital bed per night is between £252 – 500 per day (for a palliative care bed). Therefore, avoidance of a week in hospital is between £1776 – 3500. (Curtis and Burns, 2015).
- 2) Avoidance of ambulance calls to 'see, treat and convey' to hospital range from £231 – 254. To hear and treat over the phone is £44 and refer on adds to £155-180 (Curtis and Burns, 2015).
- 3) Avoidance of a GP visit is £55-65 per 17 minute surgery appointment or £38-45 home visit (for 11.7 minutes).(Curtis and Burns, 2015)
- 4) Avoidance of assertive Outreach (mental health) is costed at £51 per hour with crisis resolution at around £30,167 per case/per year or £39 per hour.(Curtis and Burns, 2015)

Demonstrating the impact of the HIV CNS through case studies

To demonstrate the impact of the Community HIV CNS interventions I will consider what would happen in absence of this service. For each key activity area I will consider what other services or care providers there might be take on those activities if the role was not in place. In the London borough of Westminster, I currently have an active caseload of between 60-70 patients, 95% of whom were referred for concerns around adherence, disengagement and general ill health, around 20% (12- 14 patients) of my case load are in sero-discordant relationships and/or sexually active. I have selected three case studies that reflect some of the scope of my role. Case 1 and 2 show the costs saved and I want to highlight case 3 as an unknown quantity.

Case study 1 - Dan

Dan, 53 – was referred to the community HIV CNS for management and support following discharge from hospital (5-month admission plus hospice care) after an initial late HIV diagnosis. He was commenced on ART and was discharged from a hospice rehabilitation unit with a 6 month package of care that involved daily carers (twice a day re-ablement package costing £2,096) hospice day care and a weekly HIV CNS visit. Dan is independent with most activities but needs a stick to mobilise. Dan lives alone and has a strained relationship with his adopted family (his father has terminal cancer and his sister has isolated herself from the family), he states has no one he calls a friend. Prior to admission Dan was seeing a Community Psychiatric Nurse (CPN) weekly and a psychiatrist every 2 months due to long term mental health issues. On his request, these services were not restarted.

Week 1 – Full assessment, refilled ART dosette box, discussed medication, general health, Dan felt re-ablement (two visits a day) was intrusive but agreed to continue with them. Discussed his father, who had terminal cancer. Agreed to visit weekly initially. All old medication removed from house. (90 minutes)

Emailed referrer to update, telephone call to HIV Clinic CNS to stop Septrin (Corimoxazole) as his GP is adding this to blister pack

Week 2- taking ARV's well, no side-effects. Discussed ART side-effects, concern that he is taking too much medication. Talked about his embarrassment over HIV status. (45 mins)

Week 3 - Feeling low, managed to take medication, feels that day care is not for him and wants to stop, encouraged to continue. Discussed carer's role and how Dan could manage if care stopped. (60 mins)

Call to day care manager and discussed options for Dan that was proactive.

Week 4 – Cancelled re-ablement support, ART dosette refilled by Dan. Discussed benefit needs, Dan feels he has enough money and doesn't want to apply for PIP. (45 mins). Call to social services to support stopping re-ablement.

Week 5 – managing well, walking around his house with no stick, adhering well to medication but would like one pill a day if possible. (30 mins)

Week 6 – agreed to visit every 2 weeks – monitored medications, taking well. Talked about single tablet regimen options, discussed reasons for treatment, talked about his previous mental health illness and support feels he can talk to me about how he feels. (45 mins)

Visit 7 – Feels low, had seen GP this week who is happy with his care. Dan wants to talk to someone about his sex drive which he feels is non-existent since his diagnosis, talked around this and suggested referral to Erectile dysfunction (ED) clinic. (40 mins)

Visit 8 – Pleased that his blood results were good but wants to change doctors as feels embarrassed seeing the doctor he saw when he was first ill, talked about open access to HIV care and Dan may consider another clinic. Spoke to hospital based CNS, Dan can see a female doctor there if he'd find that easier. To discuss next visit. (45 mins)

Visit 9 – agreed visit every 3 weeks. Dan happy to swap to new doctor at hospital and see how it goes. Discussed his father's illness and that he may need to visit him which he's not looking forward to.

Visit 10 – Now walking without a stick, feels better. Visited his father who lives abroad which went well. Discussed his feelings of isolation despite attending a drop in most days, suggested a referral to HIV Drop in centre which he will consider. Asked him to look it up and research on the internet when he attends day care. Disclosed that he has been going to saunas for sex and does not use condoms, discussed the need for safer sex (he mentioned he was on treatment for gonorrhoea).

Visit 11 – Agreed to monthly visits. Still having unprotected sex in sauna’s discussed how to discuss HIV with strangers. Escorted Dan to HIV drop in where he was registered and discussed what they provide that would be of benefit to him.

Prior to Community HIV CNS involvement Dan was supported by:

Service	Frequency	Cost per session	Annual Cost
GP	Every 2 weeks	£54-65 (11 minutes)	£1080 - 1300
Community Psychiatric Nurse	weekly	£67-75 per hour	£1742 - 1950
Community Psychiatrist	Every 2 months	£107 -139 per hour	£642 - 834
Total Costs = £3462 - 4084			

Community HIV CNS built on supportive relationship and visited 18 times in the first year now monthly plus ad hoc calls. With support Dan stopped CPN outreach and psychiatrist visits. He would have some support from HIV day care services only (but this is short term (6 month)). Community HIV CNS referred Dan on to HIV drop in service and encouraged him to undertake self-management training.

Service	Frequency	Cost per session	Annual Cost
Community HIV CNS	18 visits per year	£46	£828
GP	Every 2 months	£54 – 65 (11 minutes)	£324 - 390
Total Costs = £1152 - 1218			

In absence of the Community HIV CNS Dan would need ongoing mental health management (if unsupported may need assertive mental health outreach). Dan does not fit criteria for district nurse involvement and his ART adherence would only be monitored at the HIV centre at his quarterly/biannual appointment.

Case Study 2 - Kim

Kim, 43, was referred to HIV CNS for adherence support and management, frequent attendee to emergency department. Initially referred 2 months earlier by her GP but all contact details and address were incorrect. Kim is a mother of 2 children (aged 12 and 14), they live in a large studio flat in a hotel, all the family live in one room and sharing a kitchen with 4 other rooms. Kim moved from India to the UK 15 years ago. She is married but her husband is in India caring for his parents.

Visit 1 – Assessment at home, Kim complains of breathlessness and pain, calls ambulance and visits emergency department at least once every two weeks. ART kept in a basket, not sure how much she is taking and agree to do sette and visit weekly to supervise. Kim wants to move to a one or two-bedroom flat, she wakes the girls most

nights in pain and they are expected to massage her back to help her sleep, sometimes this is in the early hours of the morning and they have missed school because of tiredness or their mother's attendance in ED. Understands she has HIV but unsure why she needs to take tablets constantly. (100 mins)

Visit 2 – dosette checked and refilled, discussed health concerns, complaining of backache, sleeping on a wireframe bed with a thin mattress (discussed options with social services, housing department feel she will be re-housed 'soon') (45 mins)

Visit 3 – call from Kim to say she feels breathless, visited, looked well but became more breathless as she related stories of pain and concern about her children's education, encouraged to register with GP opposite her hostel, called acute centre and arranged an appointment. (40 mins)

Call – breathless, difficult to understand what was happening, stated she was going to call an ambulance but advised I would call to see her later that day. (20 mins)

Visit 4 – looks well, explained what she can do when she feels panicked, advised not to call ambulance unless necessary, spoke to her children about their concerns for their mother. Kim feels isolated and gets anxious when she is alone, discussed the need for her girls to go to school. Discussion around her expectations and definite clash of cultures with her teenage girls. (60 mins)

Call from Kim's daughter's school requesting a visit to talk to the staff and counsellor about HIV and concerns the girls have raised. Kim agreed for me to do this. (10 mins)

Visit 5 – Linked in with local GP and referred to community complex care matron, joint visit arranged. Referred to Hospice day care for support, therapies and counselling, feels breathing is better, hasn't called ambulance in two weeks (45 mins)

Visit 6 – Joint visit with social services and community matron. Encouraged to call HIV CNS when Kim feels unwell, continue weekly visits and assess after a month. Community Matron felt that they had nothing more to offer and discharged Kim. Letter to housing to express concern for the girl's health sharing a room with their mother and the associated disturbed sleep (60 mins)

Call – Kim in severe pain, sleeping on floor. Advised to continue regular pain control as directed and referral made to pain clinic, call to housing re new bed.

School visit – spoke to staff and girls re HIV and Kim's issues. (90 mins)

Visit 7 – Dosette refilled, noted that some doses missed, explained ART medications and reasons to take analgesia on a regular basis. Chased up day care referral and arranged to escort to first appointment. Social services arranged care package cleaning and some shopping. (45 mins)

Prior to Community HIV CNS involvement

Service	Frequency	Cost per session	Total
Ambulance Service	20 call outs	£231 -254	£4620 - 5080
Ambulance service	50 calls per year	£7 per call answered	£350
GP	18 visits	£54 – 65 (11 minutes)	£972 - 1170
Total costs = £5942 -6600			

Kim is complex with ongoing educational and psychological needs. By providing ongoing health education and supporting Kim's insecurities around her health (and her child issues) the Community HIV CNS has reduced her need to make emergency calls significantly as well as her need for further support. The Community HIV CNS has built a good relationship with Kim and her daughters and Kim responds well to their interactions but has much anxiety about mental health and social service workers, and therefore she refuses to see them and requests that the Community HIV CNS is present at all meetings, consequently these services have pulled away and rely upon the Community HIV CNS to refer as and when needed. Due to Kim's poor education and language issues she has difficulty in arranging and remembering appointments and struggles with some daily activities, Kim unable to refill dosette boxes herself, this cannot be carried out elsewhere as she is also prescribed generic medications and needs one dosette box to ensure she doesn't get confused and misses doses. Kim was very reliant upon her GP, ambulance and emergency department to solve health (and sometimes child care) issues but since Community HIV CNS set up support services she now only calls every 2- 3 months.

In the first year the Community HIV CNS visited Kim 24 times (weekly initially then 2- 3 weekly) £46 x 24 = £1,104.

Case study 3 - Harry

Harry, 67, is a retired cleaning supervisor and was referred to the Community HIV CNS for adherence support and assessment of cognitive and memory issues due to vascular dementia. He lives in a one-bedroomed flat with his partner of 50 years George, 85, who is the main carer and also has vascular dementia, which manifests in poor short term memory. Harry regularly attends the HIV clinic and has managed his ART since diagnosis in the late 1990's. Harry was discharged home with a 6 week re-ablement package (2 visits a day) and one week's medication in a dosette box.

Visit 1 – Initial assessment at home. Harry in bed asleep. Spoke to Harry's partner, George, about his concerns, he is unsure why they have a re-ablement package as he provides cleaning, shopping and laundry. George, states they haven't been told anything, carer's arrive and leave after 10 minutes. Discussed vascular dementia, what signs to look out for and potential problems. Harry appears to be managing his

medications well, knows what he takes and why, stored well, ordered system, no concerns raised. No one else visits, they have different GP's at different practices, (maybe easier to see the same one). The whole situation feels vulnerable (90 mins)

Call to social services, call to care providers to express concerns about the care package set up (20 mins)

Email referrers to express concerns about this situation

Visit 2 – Unaware that Harry admitted to hospital but George not sure which one, thinks it was Hammersmith but after 30 minutes chasing up Harry discover it's in Hampstead. Spend 90 minutes talking to George about their history, HH's HIV and his concerns. Discussed moving Harry to George's GP. (90 mins)

4 x calls to hospital to discuss discharge, no call to tell me when he was going home, called by George to say he was home. (30 mins)

Visit 3 - Harry discharged home confused about who I was but eventually remembered he has run out of Nevirapine but has 4 months of Kivexa, not sure why this is as Harry clearly states he only takes one a day and talks through all his medications correctly. George states he wants to and had had nothing to do with his partners medications. (60 mins)

Call HIV clinic CNS to order more and arrange to collect, express concern that there is no Nevirapine. (10 mins)

Call from clinic to say Harry has been allowed to double dose (no information about this) Now clinic want to blister pack medications on a weekly basis. Agree to collect 4 weeks and deliver one pack a week and monitor (120 mins)

One week's blister pack delivered and explained to HH.

Visit 4 – Call from Harry to say he has run out of medications. Harry in bed. All medications out of blister pack and extra Kivexa placed in empty punched out holes, Harry states that the box was empty when I delivered it. Agreed to let me take away all extra medications. George concerned that he hasn't been out of bed, carers still visiting and he feels insulted by it. Check carer's notes and note that they stated they visit for an hour each morning, George states they only attend for 5-10 minutes only. (60 mins).

Call care agency to challenge what is happening and then social services. Call GP and speak to Practice Nurse (45 mins)

Visit 5 – Harry alone, George out shopping. Again says he received an empty box, there should be two day's medication remaining, but the blister pack is empty. Decanted all medications into red dosette box to see how this goes, ensured Harry watched me. Looked for carer's notes to write what had happened but not there. Harry stated they had not seen anyone. (45 mins)

Called social services to be told that he had been reassessed and Harry told them that he didn't need help so the package of care was cancelled, told that I can re-refer if

needed, expressed my concerns that Harry has dementia and cannot manage medications, George has dementia too and I am their only point of contact (30 mins).

Visit 6 – Harry in bed, appears to be managing red dosette box well, discuss options with George who is concerned about Harry staying in bed, lack of enthusiasm etc. (45 mins)

Refer to district nurse (30 mins).

Call to remind Harry to attend outpatient's appointment

Visit 7 – Called to collect ART from hospital but told that Harry had collected 2 months. At home 22 Nevirapine and 18 Kivexa missing from 2-months supply, patient adamant that he has taken only once a day, explain that there is a large amount missing and he agrees that I can take the surplus and leave him with one weeks supply. (60 mins)

Visit 8 – call the day before to say that Harry is concerned that he has no ART explained that there should be 4 days left but he says that box is empty, agreed to see the next day but when I arrived he had gone to emergency department. Call from ED to ask why he had no medications and that he was accusing me of taking it all, explained to doctor what had happened and asked for him to be admitted. Called DN & GP to discuss medication issue and arrange support. DN agreed to see when discharged. Called to see Harry in ED he does not want to see me again as I had taken all he medications, explained reasons why and this was an agreement with clinic and his consultant, explained he was in pain and was using Nevirapine for this. (120 mins)

Update - DN to visit daily to supervise ART and CNS to liaise and support, overdosed on 4 days in one, DN now daily visits with medications...plan residential care if this fails. HIV CNS visits weekly.

The Community HIV CNS was the only source of community management, assessment and support, referring to the DN service was initially difficult as Harry had no physical needs and was ambulatory but unable due to his dementia had no drive to visit his GP and both partners had different GP's in different surgeries and therefore there was no joined up approach to care. Without a Community HIV CNS service there was other service to assess and support Harry's adherence and his overdosing may have remained unchecked as the HIV centre allowed double dosing for some time. Harry's partner would have remained unsupported as he had little personal support and didn't meet the criteria for Admiral nurse (dementia) support, his health would have deteriorated leading to the need for more social service input and potential hospitalisation. The initial care package would have continued unchallenged and vulnerabilities not recognised unless Harry had frequent admissions (he had already admitted to two different trust's hospitals with little communications between them).

Service	Frequency	Cost per session	Total
Hospitalisation for Harry	2 weeks plus	1776 – 3500 (per week)	£3552 - 7000
Hospitalisation for George	2 weeks plus	1776 -3500 (per week)	£3552 - 7000
Total £7104 – 14000 plus			

Conclusion

In areas of high HIV prevalence and complexity the Community HIV CNS is an essential part of the multidisciplinary team. The potential for escalating costs if the role were to be decommissioned is clear. As sole case managers for the majority of our cohort we take a leadership role in smoothing and initiating care pathways and make a demonstrable contribution to patient health, experience and safety.

The Community HIV CNS and referrer’s audit (appendix 2) highlights not only the scope of the many roles taken on by Community HIV CNS’s in high prevalence areas but also our knowledge, skills and experience. In these times of cost pressures Community HIV CNS’s need to think about the value they add and look to what we can measure to show this worth, which may involve thinking outside of the HIV box. We should celebrate our uniqueness and highlight our role in gaining an insight into a patient’s home life and the circumstances affect their health and that make them who they are. We provide a vital role that it would take many services to replicate, without this role patient’s would remain unsupported and unmanaged in the community. What we feel as ‘standard HIV management’ around adherence can prevent not only wastage of ART but the potential to prevent future ill health and onwards transmission. We are flexible, we have changed and adapted our role to our patient’s needs. Look at your caseload and think about all the patients for who you are the sole point of contact, the input you have and the likely consequences of your service no longer being there and cost up the mental health, community nursing support, GP and social care services required to fill out your role. We aren’t a luxury service and we never have been but we need to show this either through outcomes or by assessing our worth alongside other services. For the Community HIV CNS role to be an integral part of the multidisciplinary team we need to be seen not as community nurses but as clinical nurse specialists who manage people at home. It’s not just about adherence!

For discussion

The role of the Community HIV CNS is an essential service for a relatively small but physically and psychosocially complex number of patients within each HIV clinic (an assumption could be made that if 10% of those accessing care are deemed to be complex in Westminster that equates to around 140 patients of whom I see just under half). The role manages and supports patients at home and has scope to become more effective such as managing disengagement, lost to follow-up and health promotion.

Currently, most referrals to the Community HIV CNS service are for adherence management and support and the consequences of poor adherence, potential ART wastage, rebounding viral loads and onwards transmission should not be underestimated. HIV is often the hook to hang other issues too and the Community HIV CNS's often deputize for palliative care, mental health and other primary care services, with many of us managing patients with moderate mental health issues on a regular basis and by doing so we may be preventing anxieties, breakdowns in their mental health and the potential mental health crisis with the need for emergency psychiatric care and ongoing crisis resolution support. Even though the Community HIV CNS role has been in place for many years we need to be a visible and integral part of the multidisciplinary team, someone who can have influence and credibility across the care pathway.

There is a definite clear and understandable need for the Community HIV CNS role in areas of high prevalence and HIV complexity and the role could be further enhanced by allocating a Community HIV CNS to large HIV clinics allowing greater scope to the role such as venepuncture, nurse prescribing, advanced history taking and physical assessment. The Community HIV CNS role should be an extension of the HIV clinic rather than a community service provision that they can tap into. Roles could be adapted to suit an individual HIV clinics cohort such as working closely with other specialist agencies for example, drug and alcohol teams, gay men's services, homeless teams. Forging links to local GP and other community services in a cohesive way as, due to open access to HIV services, we currently do not have open access to all HIV clinics electronic notes and result system, therefore we rely upon paper notes and 3rd party help to book appointments and arrange prescriptions etc.

We need to develop a national model of HIV Community Nursing (Tunncliffe et al, 2016) to ensure a cohesive service across HIV high prevalence areas this could also include a dependency score for community patients and allow for the development of measurable outcomes.

References and Further Reading

1. Curtis L. and Burns, A (2015) Unit Costs of Health and Social Care 2015. Personal Social Services Research Unit. University of Kent.
2. Bodenheimer, T, MD, Lorig, K, RN, Dr PH; Holman, H MD; Grumbach, K MD (2002). [Patient self-management of chronic disease in primary care". *JAMA* 288 \(19\): 2469–2475.](#)
3. Brown, A.E., Gill, O.N. and Delpech, V.C. (2013). 'HIV treatment as prevention among men who have sex with men in the UK: is transmission controlled by universal access to HIV treatment and care?'. *HIV Medicine*, vol. 14, no. 9, October, pp.563-70.
4. Department of Health (2012). The NHS Outcomes Framework 2013/14.
5. Donald, F., Kilpatrick, K., Reid, K., Carter, N., Martin-Misener, R., Bryant-Lukosius, D., Harbman, P., Kaasalainen, S., Marshall, D.A., Charbonneau-Smith, R. and Donald, E.E., 2014. A systematic review of the cost-effectiveness of nurse practitioners and clinical nurse specialists: what is the quality of the evidence? *Nursing research and practice*, 2014.
6. Gomes, B., Higginson, I.J. and McCrone, P., 2009. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *The Cochrane Library*.
7. Hutt R, Rosen R, McCauley J (2004). *Case-managing Long-term Conditions: What impact does it have in the treatment of older people?* London: e King's Fund.
8. Jelliman P (2014) To dosette or not to dosette: that is the question. *HIV Nursing Journal*. 14(2); 3-9.
9. Leary, A. and Oliver, S. (2010). Clinical nurse specialists: adding value to care. *An executive summary*.
10. Leary, A., (2011) How nurse specialists can demonstrate their worth. *Gastrointestinal Nursing*, 9(6).
11. National Cancer Action Team (2010) Quality in Nursing. Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist. Department of Health.
12. NHS England (2015) Clinical Commissioning Policy: Treatment as Prevention (TasP) in HIV infected adult. <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/10/f03pc-tasp-oct15.pdf>

13. Purdy, S. (2010) Avoiding Hospital Admissions; what does the research evidence say. The Kings Fund.
14. Ross, S, Curry, N and Goodwin, N (2011) Case Management; what it is and how it can best be implemented. The Kings Fund.
15. Tunncliff, S.A., Piercy, H., Bowman, C.A., Hughes, C. and Goyder, E.C., 2013. The contribution of the HIV specialist nurse to HIV care: a scoping review. *Journal of clinical nursing*, 22(23-24), pp.3349-3360.

This case study was completed by **Shaun Watson**, Community HIV Clinical Nurse Specialist, Chelsea & Westminster NHS Foundation Trust in **May 2015**.

Shaun successfully completed a collaborative learning programme designed to empower nurses to understand, generate and use economic evidence to continuously transform care. The programme was delivered by the Royal College of Nursing and the Office for Public Management, funded by the Burdett Trust for Nursing and endorsed by the Institute of Leadership and Management.

You can contact Shaun by email shaun.watson@nhs.net.

Appendix 1 Complexity

What is Complexity?

Complex patients can be described as those living with HIV with many ongoing issues such as Hepatitis (B and C), tuberculosis, and opportunistic infections associated with HIV or other long-term conditions (diabetes, epilepsy).

Complexity may be professional due to the involvement of other health and social professionals that are involved in the care and support of an individual with no one person taking the lead.

Complexity may also be due to issues due to ageing, language or literacy issues that may require more time or additional support, ongoing mental health or drug and alcohol related conditions and issues around disclosure or stigma.

There may be physical complexity such as disability (blind, deaf or physically disabled) or cognitive impairment/dementia.

There may be socioeconomic complexity such as housing issues that impact on health (poor, inadequate housing or complex home lives, large families, non-disclosure of status) or financial issues such as immigration or debt that impact on health – poor diet, lack of heating, poor self-care etc.

Patients described as complex tend to have many ongoing health and social needs that require more skills, knowledge and time to manage.

Appendix 2

History of the Community HIV CNS and referrers Audit

The audit looked at current activity of 21 Community Clinical Nurse Specialists from across London, Brighton and Liverpool. The roles ranged from band 6 to 8a with nurses having between 10 and 31 years' experience within HIV care. Nurses had a range of academic experience with most having undertaken some HIV courses (ENB, University modules) and some with masters in advanced nurse practice, assessment modules, nurse prescribing, adult education and mentoring. Within London there is inconsistency within the London boroughs with some having one CNS whilst others had 2-3 and no one in several boroughs (see <https://www.gov.uk/government/statistics/hiv-data-tables> for data)

Referrals

All HIV CNS's stated that they had steady referrals over a year with most services reporting between 1-3 new referrals a month with just under half of all new referrals coming from HIV consultants, GP's other Doctors/registrars, a quarter from HIV nurses and the rest either self-referrals or other services allied to HIV care (pharmacists, voluntary services)

Referrer's Audit

A separate audit was sent to those who refer to the CNS service. 72 audits returned from London area, Liverpool & Brighton.

33 HIV Consultants

20 HIV Nurses (including outpatients, ward, Tb nurse & health advisers)

12 other (including HIV voluntary services)

5 Non HIV Drs (Psychologist, palliative Care)

2 Pharmacists

How often do you refer?

Frequently (more than once a year) - 64 (89%)

Less than once a year - 8 (11%)

Reasons for Referral

There were over 70 different reasons for referral therefore they have been put into themes starting with the most popular.

- Adherence (starting treatment, monitoring ARV use, directly observed therapy)
- Complex Patients (socially, physically, unable to attend clinic 'severe mental health')
- Vulnerable adult (safeguarding issue, domestic violence, safe discharge from hospital, assessment of home and function at home)
- Managing side-effects and co-morbidities
- Psychological/emotional support (isolation)
- Drug & alcohol issues (chaotic lifestyle, hard to engage, substance misuse)
- Lost to follow-up (poor attendance, 'wayward' patients)
- Cognitive impairment (capacity issues)
- Education (Self-Management, general HIV advice)
- Phlebotomy
- Social care (supporting letters, housing support, supporting other professionals)
- Onward referral (Mildmay, mental health services, signposting to other services, registering with GP/dentist)
- Pregnancy (discussion around vertical transmission)

Referrer's were then asked to rate the following 5 main areas of work for HIV CNS's the most popular were:

1. Vigilance – concerned about home life, safe-guarding, child protection, drugs and alcohol use
2. Chase up those lost to follow-up/re-engage with HIV clinic

3. Adherence – monitoring, managing side-effects
4. Psychological support – emotional not supported by mental health services
5. Onward referral – to hospice/ specialist HIV (Mildmay, Sussex Beacon etc.), discharge from ward etc.

Referrers were asked what other roles they feel the community HIV CNS team could perform. The most popular are listed into themes below:

- Phlebotomy, Directly Observed Therapy and Prescribing
- GP Clinic engagement (residential and nursing homes, closer working with GP's)
- HIV/HCV testing
- Signposting (Debt advice, CAB)
- Support (to other agencies, education for other professionals, support with social issues 'no recourse to public funds')
- New diagnosis (risk assessment for/and partner notification)
- Medical review (annual review, blood pressure, weight, stable HIV clinic, triaging sick patients, 'clinic at home')
- Testing of children (adolescent engagement)

There was some overlap with the work that Community HIV CNS's currently do which perhaps highlights that those who refer aren't clear about the roles of Community HIV CNS

In the Community HIV CNS audit the same questions were asked about their current caseload and the following were highlighted as the reasons why patients were referred to their service.

- Complex case management
- Adherence support/symptom control
- Lost to follow-up/reengage in a service
- Vigilance
- Onward referral (some nurse were gatekeepers to rehab/respite facilities)
- Psychological, lifestyle, self-management

Other – respondents added the following other reasons for referral:

- Contraception/fertility issues
- Point of Care testing (POCt) for negative partners
- Infant PEP support
- Domestic violence/Female Genital Mutilation
- Venepuncture
- Deliver ART to patient
- Mental health
- New diagnosis support
- Homeless patient support and support homeless team
- End of life care, support of other services with end of life care (hostels)
- Severe drug and alcohol use and mental health challenges surrounding this

- Monitoring those who have stopped ART
- Social/economic issues (as main reason for referral but all had adherence, psychological and complex need)
- Nursing home – education to staff and advocacy work for patient
-

Take an average week

Respondents were asked to look at their activity in an average week. This list below reflects not only the face to face work but also the many other roles that are taken on I suspect that many respondents take much of what they do as 'part of the role' or as insignificant but they all add to the hours we do within a day. The main themes were identified as:

1. Face-to-face contacts (between 6 to 24 patients a week)
2. Non face-to-face patient contacts (email, text, telephone) between 30 – 120 episodes a week
3. Professional contacts (telephone face to face/email/letters) between 30 -60 episodes a week.
4. Meetings – MDM, discharge, outpatient clinic meeting, new diagnosis clinic (between 1-2 hours a week)
5. Admin time – no one had admin support and time ranged between (2-4 hours a week)
6. Teaching and teaching prep between (around 2 hours a week)

Other work note included:

- Clinical supervision
- Weekly clinic, prep and review of results
- Management
- HIV prevention work (testing)
- Medical & nursing student placements mentoring and supervision
- Infection control link
- Data entry
- Audit and research
- Mandatory training
- CPD sessions/study days
- Network meetings
- Safeguarding/child protection meeting attendance
- Lunchtime teaching session with drug rep
- NHIVNA meeting
- Peer support
- Dementia lead for service
- Cover for walk in service
- Emergency script list and home delivery (3-8 scripts a day) and coordination of blister packs.

In areas where there is no Community HIV CNS cover some nurses report managing and supporting patients in cases where there may be harm to the patient. They may see them in drop in clinics (such as Riverhouse clinic which offers support for Ealing patients as there is no Ealing and the Community HIV CNS in Camden and Islington manage and support some patients in Enfield and Barnet where there is no cover)

Caseload and Case Management

This was described as those patients 'seen face-to-face within the last 12 months' but there was some confusion over what constituted an active caseload but the average caseload was noted to be between 65 and 80 patients per CNS (the lowest being 35 the highest 130)

On average most CNS's saw between 6 and 24 patients face-to-face each week with between 20 – 50 non face-to-face contacts which were described as text/email and phone call (timings were not asked). Some CNS's sited doing less home visits and running more clinic sessions.

HIV CNS intervention has been used to bring those who have disengaged in HIV services or lost to follow up and most nurses stated that they have brought between 5 and 25 patients back into the HIV services which was around 5-10% of their active caseload.

For those who see patients for adherence issues 100% had a documented adherence assessment with a patient driven care plan.

The Future

The audit highlighted other concerns from Community Specialist Nurses. From activity and referral data there is a clear need for the role, however recent changes within HIV have led nurses to feel anxious and uncertain about the future of the role.

"I have 25 years' experience in HIV. I am concerned about the future as I feel that it might be a role that is axed in the current financial climate. I have found that with voluntary and non-voluntary services are reduced I am having to pick up more than HIV related duties. I feel that our service is vital in reducing hospital admissions, keeping patients engaged in the service, increasing adherence and supporting patients with complex health needs who would otherwise be unsupported and vulnerable" (CNS caseload 75 patients, London)

"I have worked within HIV since 1992...I am concerned about the future of my role, especially as funded by CCG, and in my area the commissioners do not think HIV is a priority as only a few numbers infected compared to other boroughs. Also the service has prevented HIV related admissions, the services are not really hitting the radar. I'm pretty sure this would happen though in a few months if the role was decommissioned" (CNS caseload 58 patients, London)

"Working in HIV since 1991...in the community team for 8 years. Yes, I am concerned about the future of our role, though our team is extremely busy with a high patient workload, not always being face to face, increasingly, working more in the office

communicating with wider MDT –I don't have much time during the working week to be worried about our future" (CNS, caseload 65, Brighton)

"Our service is under review and so the future is not known, causing a lot of anxiety for job losses. The service is very proactive about service user feedback. There has been positive feedback from the service user survey and the monthly friends and family feedback" (CNS, caseload 35, rural area)

'Yes I am concerned about the future of CNS role that is why I moved to a service attached to a clinic so I can work in both departments' (CNS, caseload 60 patients, London)

'I can see how our service may be viewed as a presumed luxury but I am also aware that I have raised concerns about health issues, serious drug errors, safe guarding, abuse and poverty that would never be highlighted in a clinic.' (CNS, caseload 65 patients, London)

"Our team has been review numerous times; therefore, we are concerned for our future...it is difficult to capture the work of CNS's in data because of its varied nature. Some are involved in antenatal care, paediatric and general sexual health... here we are only involved in complex cases" (CNS, caseload 65, London)

Providing Outcomes

NHS Outcomes Framework (Dept. of Health, 2012) is structured around five high level outcome domains.

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

The Community HIV CNS is an integral part of the multidisciplinary team. We have influence and credibility across the care pathway. As sole case managers for most of our cohort we take a leadership role in smoothing care pathways and make a demonstrable contribution to effectiveness, patient experience and safety.

What outcomes could the Community HIV CNS measure:

1. Adherence as a reason for referral - % of patients that are or remain undetectable after CNS adherence management intervention.
2. Number of patients with a documented adherence assessment? (HIV service specification)

3. Numbers of patients lost to follow up that have been brought back into acute services? (HIV service specification, BHIVA Standards of care for people living with HIV, 2013)
4. Number of complex patients for whom you are the sole case manager in the community? (Complex care – percentage of patients that engage in care HIV service specification)
5. Number of patients who require adherence interventions (medicine compliance aid monitoring, refilling/supervision) (HIV service specification)
6. Number of patients with a personal care plan that show evidence of patient driven outcomes? (BHIVA Standards of care for people living with HIV, 2013)
7. Avoidance of emergency admissions for acute HIV related conditions that should not usually require hospital admissions (HIV Service Specification). Interventions involve holistic case management, empowering patients to self-manage their HIV, referring to peer support groups and local voluntary agencies, risk and safe guarding assessment.
8. Case management for people discharged from hospital with HIV related conditions and reduction in readmissions to hospital with 30 days Interventions include comprehensive assessment and follow up, onward referral, refer to social service re-ablement teams. (HIV Service specification).
9. Evidence of multi-agency coordination of care and service provision/integration for patients who are vulnerable or who have complex needs. Interventions used include clear referral pathways. (HIV CQUIN).

Without a Community CNS HIV Service

For most Community HIV CNS's replication of the service provided would necessitate more frequent (at least quarterly or bi-monthly) visits to the HIV service to monitor adherence, therapeutic drug levels or a monthly/fortnightly visit from a 'skilled up' district nurse service with support from hospital/community pharmacy to blister pack ART alongside their other medications. Patients may also require mental health input and/or social care input to allow them to function on a day-to-day basis. Structured visits to or home visits would be required from their GP or a practice nurse to assess their home situation and environment with onward referral as appropriate, if available. For some complex patients' successful management in the community requires their engagement and motivation, a lack of which is often one reason most are referred to the present Community HIV CNS service. Below is an example of the potential economic effects if there were no Community HIV CNS Service and replication that would be required:

District Nurse x 12 visits (£52 a visit)	£ 624
Mental health x 12 visits (£51 a visit)	£ 612
Increased GP Visits x 4 (£65 per 17 mins)	£ 260
Avoidance of One week in hospital x 1 week	£ 3000
Prevention of waste of ART (half a year's ART)	£ 3000
	Total= £ 7496

(with a potential for increased costs due to pharmacy costs, social care needs, ambulance calls and transfers, HIV clinic visits, bloods and other investigations, increased stay in hospital, increasing mental health emergencies)

Community HIV CNS (£50 a visit) x 12 visits a year = £600

If the average Community HIV CNS caseload is 60 patients this equates to approximately £412, 140 in potential costs if the service were not in place.