Providing a model of HIV community nursing

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'The complexity of care in the community has increased... nursing teams are required to find new ways to support complex care and manage workloads.' (Bennett, 2013)

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Foreword

Congratulations are due to the authors and to NHIVNA for this important and very timely document. The report is an invaluable resource for all who seek to deliver on our common ambition to ensure that people living with and affected by HIV live long and live well.

Community nursing specialists in HIV have a unique and critically important role in securing best outcomes for people living with and affected by HIV. Today we have the tools to deliver effective long term virological suppression of HIV. For those diagnosed in time with consistent access to high quality HIV care this translates into a near normal life expectancy.

Yet we know only too well that there are often barriers to overcome to ensure that everyone who needs high-quality HIV care has access.

HIV disproportionately affects people who may already be marginalised and who may have multiple unmet health and care needs. How to ensure equity of care?

It is the specialist nurses who work with people in their homes and communities who can overturn barriers, work across boundaries, join up services, and deliver specialist interventions in ways that make good care a reality. Living with HIV for the long term brings its own complications that impact on health and wellbeing and quality of life. The conditions of older age when coupled with HIV make care particularly complex, involving an array of care providers and services. It is the community nursing specialists who bring their knowledge and skills to bear to ensure that care is person centred, relevant, coherent and coordinated.

Why is this such an important document? The authors, all highly experienced and respected practioners, clearly set out a model for best practice, recognising that there is no one size fits all in HIV community nursing and that adaptation will be needed to match local and individual circumstances. The central concepts, including beliefs and values, goals, knowledge and skills, as well as evaluation and outcomes monitoring are all clearly set out. Case studies are included that illustrate the diversity of approaches to best care that are aligned with current standards and practice, emphasising care that is close to home, empowering and coordinated.

The report is particularly timely, aligning as it does with the recommendations within the latest British HIV Association Standards of Care for People living with HIV.

The Standards emphasise the importance of care coordination, flexibility, equity of access and the importance of specialist outreach into local communities. Within the multidisciplinary care team, it is the community nursing specialists in HIV who can turn these recommendations into reality for the people that most need them.

We are in difficult times, money is tight, the health and care system under unprecedented pressure.

Recognition is needed of the immense value that Community Nurse specialists in HIV bring to ensure joined up, equitable, person centred, effective care that delivers best outcomes, ensuring that people with HIV live long and live well.

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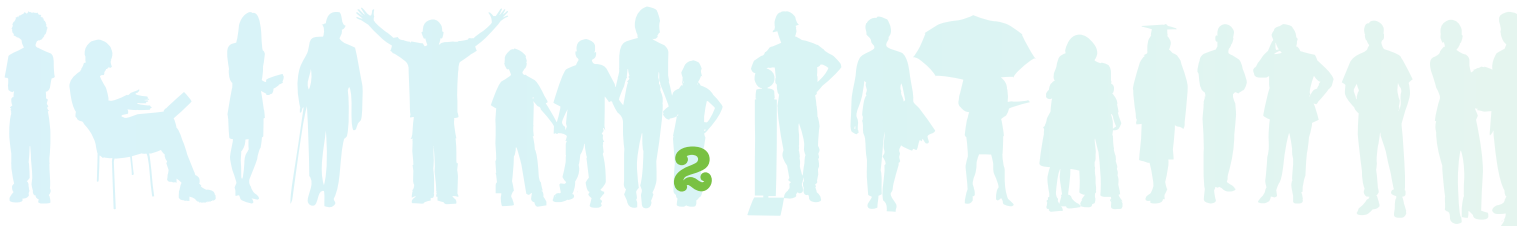

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Introduction

In the UK, the HIV epidemic is now over 30 years old, and there are over 88,000 people living with diagnosed HIV and accessing care (PHE, 2016a). HIV care continues to change and challenge, with an increasing ageing HIV-positive population, ongoing co-morbidities and the long-term effects of antiretroviral therapy (ART). In 2015, 6,095 people were diagnosed with HIV in the UK; 1,018 were aged over 50 years and 613 people with HIV infection died (under half of these were likely to be AIDS-related) (PHE, 2016a).

The role of the community-based HIV clinical nurse specialist (community HIV CNS) has a long and varied history in the context of HIV, with the first team in the UK—at St Mary's Hospital, Paddington—basing their care on the Macmillan nurse model. Initially, the community HIV CNS role was developed to provide specialist management for those living with HIV/AIDS who wanted to live (and die) at home and to have support and co-ordination of services plus the requisite palliative care for those who wished to die in their own homes. As HIV evolved, so the role developed in response, providing specialist advice and expertise around ART side-effects management and adherence to (at the time) complicated ART.

The current emphasis of the community HIV CNS role is one of complex case management, which Hutt et al. (2004) describe as 'the process of planning, coordinating and reviewing the care of an individual', 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).

More care is, and will increasingly be, required to support people to manage their long-term conditions and enable them to remain at home.

Community teams are increasingly required to find new ways of working to support complex care (see Appendix 1) and manage workloads more efficiently. District nursing is key to improving services for older people (Bennett and Nicholson, 2013).The community HIV CNS role is unique: we are the only HIV specialists to provide clinical care and guidance in the home.

The UK has an ageing HIV population (PHE, 2016a), living longer with HIV (Teeraananchai et al., 2017; Antiretroviral Therapy Cohort Collaboration, 2017) accruing multiple morbidities (Balderson et al., 2013; Rodriguez-Penney, 2013). Presently, there is community support for illnesses such as stroke, diabetes, congestive cardiac failure, emphysema, frailty and dementia. However, managing this in the context of ART drug interactions, hepatitis treatment, sexual health and adherence requires specialist HIV knowledge in the community. The community HIV CNS is the only community-based health care professional with specialised HIV expertise, knowledge and expertise in ART adherence, and linkage across multiple hospital disciplines (not only HIV) connecting these to primary care.

However, within London and across the country there remains a disparity in community HIV CNS service provision, with some boroughs having one community HIV CNS, others with two or three and some with no community HIV CNS service at all.

Borough	Patients*	HIV CNSs*
Westminster	1,488	1
Hammersmith and Fulham	1,041	
Kensington and Chelsea	935	
City and Hackney	1,609	2–3
Southwark	2,795	
Brighton and Hove	1,544	
Liverpool (city numbers only)	613	
Ealing	756	0
Hounslow	667	

(PHE, 2016b)

* Numbers of patients accessing HIV care and community-based HIV clinical nurse specialists

Although the community HIV CNSs have similar titles, like community matron, advanced nurse practitioner or clinical nurse specialist, they have (slightly) differing job descriptions and are funded, managed and work in different ways and, apart from some geographical groups, have little to join them as a cohesive team of specialist HIV nurses with a common purpose. There is no defined model for HIV community nursing.

Who is this document for?

As there is no established model for HIV community care, this model offers guidance for HIV commissioners and those who influence specialist HIV care, such as consultants, senior registrars, public health and community services. The model should serve as the gold standard for HIV community care in areas of high HIV prevalence and need.

Key relationships

The community HIV CNS manages those underserved by other health services: people living with HIV who may be deemed not 'mentally unwell enough' for mental health services but who, for general HIV and voluntary services, are incredibly challenging to manage; those who are housebound, too infirm or ill to access services but with no ongoing physical concerns who require a GP consultation or district nurse referral; those who have stopped accessing care or have poor health engagement, either lost to follow-up or poor attendees at their HIV services, or who may be viewed as HIV 'stable' but living with other long-term conditions for which they need complex management and support, such as diabetes, arthritis, other physical health problems, dementia or cognitive impairment, people who are not motivated to self-care and may lead unconventional, socially complex lifestyles with little or no routine, chaotic individuals who need care management and support to live an undetectable 'HIV healthy' life.

The role of stigma as a barrier to accessing care should not be underestimated, and has been highlighted in many studies around not only HIV, but also sexual health (Meyer, 2016), mental health (Conner et al., 2016; Coleman et al., 2017) and self-stigma (Oexle et al., 2017).

Stigma was also discussed as a barrier to accessing care in the King's Fund report 'The Future of HIV services in England' (Baylis et al., 2017), which also highlighted the fragmentation of HIV care and stated that most GP practices, even in large cities, have relatively small numbers of patients with HIV, and therefore HIV is likely to remain a minor part of the work of most GPs for the foreseeable future. The role of GPs in relation to HIV is poorly developed, due to many barriers to effective shared care. MacLellan et al. (2017) identified these barriers as a lack of well-established relationships between HIV specialists and GPs, complex commissioning arrangements, patients' lack of trust in primary care and concern about stigma, incompatible IT systems, and lack of time, training and resources, concluding that commissioners should 'continue to commission care co-ordinators such as community nurse specialists to help complex patients navigate care'.

With an ageing population and reductions in health and social care, the community HIV CNS is well placed to recognise the effects on older people living with HIV at home, described as a potential 'social care time-bomb'.

People over the age of 50 now represent one-third of people living with HIV, but the social care, health care and welfare systems are not ready for this growing cohort (Terrence Higgins Trust, 2017). The overarching remit of many community HIV CNS roles is to prevent avoidable hospital admissions and speed up discharge from hospital wards for a caseload of HIV-positive patients. Piercy et al. (2016) stated that 'community-delivered specialist nursing care... is resource intensive but services with this provision were convinced of its value improving health outcomes for the most vulnerable.' In England in 2013/14, over 1.2 million bed-days were lost because patients remained in hospital after they were medically ready to be discharged (Gaughan et al., 2016), and studies have shown that preventing discharge delays could save between 11.2 and 30.7% of total hospital costs (Landeiro et al., 2016). A Royal College of Nursing (RCN) and Office of Public Management (OPM) study by Watson (2016) showed potential cost savings across the scope of care, from reduction in GP visits, drug wastage, ambulance calls, A&E and hospital admissions (see Appendix 4).

The community HIV CNS has a unique role and should be viewed as a seamless extension of the HIV network reaching outwards, not an add-on service. For most patients with complex needs living with HIV, the community HIV CNS is the ONLY solution (see Appendix 3). For example, mental health, social care and district nurse services may be unable to be involved due to their strict referral criteria (many services work in a locality and have very limited ability to work outside of set care boundaries).

A generic community matron is unable to collect and start ART for patients at home. The community HIV CNS is skilled to recognise the effect of other physical and psychological illnesses and their effects upon HIV, such as poor ART adherence and long-term HIV health; they are accessible for joint working and/or assessment for home visits (they are the only HIV specialists available for joint home visits) meaning that the patient can be assessed in their home rather than transfer for inpatient review, which may also incur carer support and transport costs. The community HIV CNS can offer home screening and monitoring for other long-term conditions (such as cardiovascular disease, liver, bone and renal issues etc.) and ensure not only adherence to ART but to all other medications that the patient is taking (with short interventions such as drug monitoring and compliance aid management), thus having life-long effects on all medications.

They are best placed to access hard-to-reach patients and are in place for new and future interventions and innovations, such as home testing and ART depot injections.

However, community HIV CNSs across the country lack cohesive service standards with common outcomes. Their tasks are many and varied with the main roles being:

- **Optimisation of antiretroviral therapy (ART)** – ensuring ART is taken as directed, monitoring adherence and general medication checks (including drug alerts, drug–drug interactions, noting 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 supervising individuals to fill their medicine compliance aids/'dosette' boxes. In some cases, patients would prefer 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. The community HIV CNS may also play a role in secondary dispensing, often rationalising medications into one compliance aid to ensure adherence, not only to ART but to other medications taken by the patient (Jelliman, 2014).
- **Engagement in care** – often patients, for a variety of reasons, fall out of care, and one of the main roles of the community HIV CNS is to re-engage someone back into care. Patients often feel guilty or too embarrassed to come back, fearing 'a telling off'. Sometimes patients may need escorting back into a service or the community HIV CNS can become the link to re-engagement. Nurse-led remote management, monitoring and prescribing for patients who cannot or do not attend hospital or who have opted out of treatment or ART. (Jelliman, 2017; Jelliman et al, 2017)
- **Specialist HIV nursing assessment/health enquiry** – monitoring for specialist HIV and general health issues (including full system assessment and screening, discussions around lifestyle, diet, nutrition, exercise, smoking, drug and alcohol use, sexual health, health monitoring, screening and observations).
- **Complex case management and care coordination** (see Appendix 3) – liaison with other agencies to provide streamlined care for advanced 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 women ante- and postnatal to prevent mother-to-child transmission. The community HIV CNS in this situation has an ongoing relationship with patients, as they are generally not constrained by limits to the number of visits offered which is negotiated with the patient; many have continuous community HIV CNS support for life. Preventing unscheduled admissions 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 (Watson, 2016).

- **Vigilance or 'check-in' service** (Leary, 2011) – where there are concerns about a patient's clinic attendance or engagement, adherence, lifestyle concerns, housing issues, their domestic situation with issues such as domestic violence, safeguarding and vulnerable adults, child protection concerns, support and HIV testing of children etc. The community HIV CNS manages those who frequently disengage or attempt to re-engage those lost to follow-up, encouraging clinic attendance or engagement in the community. They are uniquely placed to assess the home situation where other organisations may not carry out home visits or may not visit alone. The community HIV CNS can build up trust, confidence and motivate individuals back into care or provide the service at home.
- **Side-effect management of other long-term conditions and medications** – working closely with GPs and specialist HIV clinics. The community 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 the community HIV CNS often takes a more holistic approach, assessing what else may be happening with the patient, such as home stressors (finance, housing and/or family issues) that may not be obvious to a GP or clinic.
- **Rescue work** (Leary, 2011). – general management and support with diagnosis, general health issues and some limited assistance with housing and welfare issues such as letters of support, onward referral to appropriate agencies and advocacy as needed. Management and support around intimate partner disclosure and onward testing. With frequent home visits 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 early detection of impending deterioration and taking pre-emptive action to prevent adverse events. Examples include detecting a chest infection, picking up incorrectly prescribed medication, potential drug–drug interactions or addressing anxiety caused by illnesses.
- **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. Advanced care directives and discussing 'do not attempt resuscitation'.
- **Advocacy** – the community HIV CNS helps patients voice their needs and concerns by offering emotional and psychological support with clinical appointments or speaking up for patients and helping to resolve issues with other services. Support may be needed due to actual or perceived stigma, or the feeling that there will be stigmatisation (such as GP, district nurse, dentist, social services, mental health services, housing support etc.).
- **Liaison between HIV specialist services, primary care, social care and voluntary teams** – such as 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 self-care and manage their illness, to register and use GP services appropriately. Community HIV CNSs offer information about who to contact out of hours, and act as triage services preventing unnecessary outpatient or GP appointments.
- **Referral and access to respite, rehabilitation and ongoing care teams** – such as Mildmay Hospital UK (London), Hospice services, Sussex Beacon (Brighton), Positive East, Positively UK, Terrence Higgins Trust services, Food Chain and local Citizens Advice Bureaus. Some community HIV CNSs act as 'gate-keepers' to specialised budgets for rehabilitation/respite services or local hospice day care and inpatient services, with commissioners relying upon the expertise of the community HIV CNS to effectively assess and evaluate care needs and refer on appropriately.

- **Teaching and advice on HIV-related issues** – the community HIV CNS often offers ad hoc training or advice on specialised HIV information (such as transmission or infection risk fears), general HIV knowledge, ART use and specific situations such as issues with nursing homes or homeless persons' units, often highlighting areas for development and support, such as testing services within hostels, as well as supporting peer educators, recently diagnosed courses and chairing local or national HIV groups. They teach and supervise doctors, nurses, student placements and other allied health professionals.
- **HIV, hepatitis B/C testing** – such as point-of-care home testing, which is often opportunistic and responsive to local need.
- **Support for the newly diagnosed** – which can range from managing individuals with high levels of anxiety or HIV denial, significant physical and intellectual deficits in cases of late diagnoses, to supporting those who have disengaged from care.
- **Provision of stable patient clinics** – some community HIV CNSs are non-medical prescribers, providing prescribing within HIV clinics and community-based management and symptom control. Some offer monitoring, i.e. home phlebotomy service, both routine and emergency, which take appointments out of the system in acute centres. There are some that offer community interventions delivered at home for patients who cannot attend clinic due to physical, financial and psychological constraints (Jelliman et al. 2017).
- **Research and audit** – as the community HIV CNS sees complex patients at home, they are well-placed to offer valuable insight into long-term care needs and issues of ageing with HIV and other co-morbidities.
- **Integration** – how can community nursing be integrated into the HIV team? In some clinics existing clinic based CNSs undertake home visits for limited tasks. In Liverpool the LCC offers a comprehensive community nurse-led service. (Jelliman et al, 2017)

The value of home visits in HIV care

Pauline Jelliman • Lead Nurse, Liverpool

District nursing as an organised movement began when William Rathbone, a Liverpool merchant and philanthropist, employed Mary Robinson to nurse his wife at home during her final illness. In May 1859, William Rathbone's wife died. He said:

"It occurred to me to engage Mrs Robinson, her nurse, to go into one of the poorest districts of Liverpool and try, in nursing the poor, to relieve suffering and to teach them the rules of health and comfort. I furnished her with the medical comforts necessary, but after a month's experience she came to me crying and said that she could not bear any longer the misery she saw. I asked her to continue the work until the end of her engagement with me (which was three months), and at the end of that time, she came back saying that the amount of misery she could relieve was so satisfactory that nothing would induce her to go back to private nursing."

Seeing the good that nursing in the home could do, William Rathbone and Florence Nightingale worked together to try to develop the service. When too few trained nurses could be found, Rathbone set up and funded a nursing school in Liverpool specifically to train nurses for the 18 'districts' of the City – and so organised 'district nursing' began (Queens Nursing Institute [QNI], 2012).

One could argue that the value of home visits undertaken by nurses is underpinned by the fact that in 2012, 150 years of district nursing was celebrated. This demonstrates longevity attributable to quality care, cost effectiveness and meeting the needs of patients.

According to Van Royen (2002), the value of home visits is debatable in the context of general practitioners. He acknowledges that, despite a decline in home visits over the past two decades, they remain an important component of a GP's routine and workload, as numbers of vulnerable, chronically ill or elderly patients increase. However, Van Royen states that compared to surgery consultations, home visits can be time-consuming, and less efficient in terms of required therapeutic and diagnostic interventions. He alludes to home visits being somewhat unsafe when required out of hours.

Nicolaides-Bouman and colleagues (2004) concur, stating that although a number of trials which examined the effects of home visits were positive, others were not. The study found that the use of institutional care services was reduced by adopting preventive home visits, which maintained or improved functional status. The authors found that outcomes were dependent upon differences in characteristics of the intervention programme, and the selection of the target population.

Laurant et al. (2005) suggest that multi-disciplinary team (MDT) working has led to nurse practitioners or specially trained nurses undertaking more home visits. Seeing patients at home can be effective and important particularly in improving the safety of medication management, monitoring for different chronic diseases, management of long-term physical or mental ill health/disability and problems related to old age. Provision of support to family members or friends can also be provided during home visits.

The King's Fund report (Baylis et al., 2017) identified nine characteristics of good quality care in district nursing. They are:

- Caring for the whole person
- Continuity of care
- Personal manner of staff
- Scheduling and reliability of appointments
- Being available between appointments
- Valuing and involving care providers and family members
- Nurses acting as advocates and coordinators
- Clinical competence and expertise
- Patient education and support for self-management

One could argue that a majority of the above characteristics would be difficult to achieve in a hospital clinic setting or GP surgery, where time limits apply, but would be achievable and more meaningful during a home visit.

The current UK situation of an ageing population, and an increase in complexity and accruing multiple morbidities in the general population, is mirrored and well documented in the HIV community. There is already community management for these morbidities (stroke, diabetes, COPD, frailty, memory, etc.) which is delivered via home visits; however, managing this in the context of HIV drug interactions, HCV treatment, sexual health, adherence, etc. does require HIV specialist knowledge in the community.

Currently, the only community-based health care professionals with i) HIV expertise, ii) expertise in adherence support and iii) linkage across multiple hospital disciplines (not only HIV), and connecting these to GPs, is the HIV community CNS.

Patients default from attending HIV clinics for many reasons, and could be deemed psychosocially as well as medically complex. Because of issues highlighted by Jelliman and Porcellato (2017), many rooted in stigma, patients who have HIV are less likely to access generic health and social care services, and primary care. The value of home visits by a specialist HIV community nurse with expert knowledge, skills and experience should therefore not be underestimated, and outcomes can be measured by case studies. These can often show how harm is averted as a consequence, measuring quality care. Home visits undertaken by community HIV nurses provide a seamless extension of hospital HIV clinics, and are best placed to integrate HIV into primary care (MacLellan et al., 2017).

Patient case study 1

‘Kate’

27-year-old woman diagnosed during antenatal screening with second child. First child found to be HIV positive – child now 6 years old. Younger child 2 years old. Previously lived in Holland where she had leave to remain as an EU resident, very involved with HIV support groups. Moved to UK because of disclosure issues, leaving father of the children in Holland.

Social history

Kate evicted from privately rented flat, due to non-payment. Adult social care arranged B&B, one room for mother and two children. Referred to our team for poor adherence of Kate’s own meds and concerns around child meds. Non-attender for all appointments for both herself and children.

Community nurse specialist HIV home assessment

Difficult owing to presence of children and lack of engagement from Kate. Patient very guarded: no eye contact, lack of trust. Inadequate living conditions in B&B, safety issues with medication lying around in easy reach of children, poor heating, poor nutrition (largely fast food). Children not attending school, no structure to their day. Took several home visits over 10–12 months to build trust, whilst maintaining professional boundaries. Issues with Kate’s living environment, possible safeguarding issues etc. had to be addressed in a particularly careful manner.

Plan

- Partnership working with women’s and children’s social care, adult social care, HIV paediatric unit, health visitor, Terrence Higgins Trust (support and applying for emergency funds), school nurse, GP, mental health team and community pharmacy.
- Encouraging Kate to attend appointments for herself and child.
- Encouraging Kate to arrange school/nursery attendance for children.

Outcomes

- Mother and child now both undetectable, and attending appointments.
- Older child is now attending school. School nurse is aware of her HIV and has had HIV training. Younger daughter attending nursery.
- Family now rehomed in a two-bedroom flat.
- Kate is in the process of returning to adult education.

Despite successes, the role and value of the specialist nurse is questioned in times of financial pressure, with specialist nurses being asked to take on other duties, down-graded/re-banded or posts frozen (Quinn et al., 2014). A study by Jelliman and Porcellato (2017) demonstrated the need for HIV specialists, stating that without specialist HIV services:

'...vital engagement with people living with HIV may be lost. This can impact retention in treatment and care, which not only optimises health and well-being via meaningful engagement and effective ART, but also contributes to prevention strategies.'

The impact of the HIV community service is summed up in Table 1 below.

Table 1: Impact of key community HIV CNS activities (Watson, 2016)

Improving quality and care experience	Reinforcing safety
• 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	• 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
Increasing productivity and efficiency	**Demonstrating leadership**
• 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	• Educating the wider healthcare team and acting as a mentor • Identifying and implementing service improvement and efficiencies • Sharing good practice and innovation

Patient case study 2

'Tara'

Tara is a 40-year-old woman of mixed race heritage who has suffered much trauma in her life. Diagnosed with HIV aged 28. Has depression with psychotic symptoms and a history of oesophageal candida, shingles, perianal herpes, multi-zonal HPV disease, as well as alcohol abuse and cannabis use. CD4 count nadir 17cells/mm3. Referred to our team due to erratic engagement in services and poor adherence.

Social history

Living with sister (and sister's four children) with whom she has a volatile relationship. Previously living in hostels. Eligible for more benefits than she is receiving. Poor literacy. Single. No children (they died in childhood). Not working.

Community nurse specialist HIV home assessment

Lost to follow-up when I first met her and needing surgery for multi-zonal HPV disease. Fluctuations in mood affect her ability to take medications and attend appointments. Ashamed of diagnosis. Poor adherence. Not engaging in HIV or mental health services.

Plan

Frequent visits as needed. Build up rapport and trust. Remind about appointments and accompany when appropriate. Ensure attendance for surgery for multi-zonal HPV disease and refer to Mildmay Mission Hospital for respite and adherence support afterwards. Support with adherence in community. Signpost to local HIV charity for help with benefits. Psychological support regarding self-stigma. Support engagement with psychiatrist. Advocacy. Vigilance.

Outcomes

Tara's sister evicted her from her room in her property and she became homeless. I advocated for her at the local council and she was in emergency housing the same day. She moved to a hostel with support 24/7 and then onto a room in a shared house with 2 hours of support a month provided.

She underwent surgery for multizonal HPV disease twice, both times followed by an admission to Mildmay to support adherence. I advocated for her and supported her in re-engaging with psychiatric services and after my suggestion she was allocated a trainee mental health social worker who supported her in getting ID (passport and driving licence) to enable her to open a bank account (now needed for benefit payments). Adherence still erratic despite many strategies. Engaged with recovery service and reducing cannabis use. Registered with new GP. Engaged with dental services (several teeth extracted), opticians (glasses dispensed), Moorfields eye hospital (pterygium diagnosed). Ongoing vigilance, advocacy, support for physical and mental health and psychosocial needs.

What is a nursing model?

A nursing model can be described as 'a representation of reality' (McFarlane, 1986), or a simplified way of organising a complex phenomenon (Stockwell, 1985). Nursing models have been described as 'conceptual tools or devices that can be used ... to understand and place complex phenomena into perspective, giving the viewer an indication of what the real thing is like'. (McKenna, 1997). There are many models and no one model fits all (McCrae, 2013); many nurses work around models designed to support the nursing process where care is assessed, diagnosed, planned and evaluated.

Why do we need a model for HIV community nursing?

The simple answer is that there isn't one. However, for commissioners and those funding community HIV CNSs there is a need to clearly define and make explicit the value and added value of the community HIV CNS role.

'The ultimate purpose of community nursing is to work collaboratively in providing safe and effective holistic nursing care to people in or near their home; enabling people to make choices, self-manage and maintain control over their quality of life.'

(Bennett and Nicholson, 2013)

Community HIV nurses have a multitude of core skills and knowledge for assessing and providing care in the home environment: antiretroviral adherence and monitoring (assessment and management), symptom control, pain management, timely hospital discharge, rehabilitation, maximising independence and provision of support and advice to the individual, carer and their family. Community HIV CNSs have developed additional skills in response to the ever-changing needs of the HIV population they serve, such as long-term condition and co-morbidity management, identifying and managing those with exacerbations of serious illnesses. Individual community HIV CNSs and teams have devised their own way of working in the community setting to suit local need and/or guidance. This may be along the lines of Orem's Self Care model (Taylor and Orem, 2006), or based on Roper and colleagues' Activity of Daily Living model (Roper et al., 2000), working alongside the nursing process of assessment, diagnosis, planning, interventions and evaluation of care (see Appendix 2).

Care is holistic, focused on self-care, prevention and behaviour change, and is rarely task-oriented.

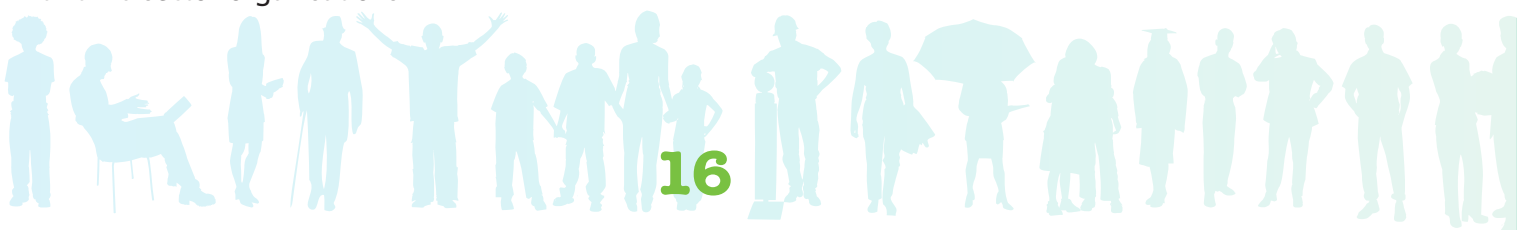
The changing health and social care environment requires improved integrated care services (NHS England, 2015), and to respond to this the HIV community nursing workforce needs to be:

- Resilient and adaptable, able to cope with unpredictable situations sometimes under less than optimal circumstances
- Confident in lone-working and making autonomous decisions, often without immediate or remote support
- Skilled at proactive and anticipatory care, working with individuals and care providers to enable them to recognise acute or chronic changes in their condition or wellbeing, using advanced practice skills for assessment, diagnosis and prescribing
- Skilled and effective at working in partnership in a multidisciplinary team
- Able to work effectively with care providers to support them in their role to meet person-centred outcomes, for example in end-of-life care – to be in the place of choice wherever possible
- Skilled in behaviour change or coaching strategies to support individuals to be empowered and confident in managing their conditions and wellbeing through secondary prevention
- Able to conduct risk assessments and risk mitigation to ensure interventions can be delivered safely to people at home
- Able to recognise where safeguarding or mental health is compromised and assess the individual's mental capacity to consent
- Able to prevent unnecessary hospital admission and facilitate timely discharge
- Confident in higher-level communication skills, such as appreciative enquiry, that enable the use of effective communication skills to negotiate care plans and establish a co-productive relationship
- Strongly focused on enabling individuals to take responsibility for their self-care
- Effective users of technology, promoting its use with people in their care
- Able to apply population-level health and wellbeing initiatives, building strong relationships with third-sector organisations
- Able to use appropriate outcome measures to evidence the effective use of community nursing services
- Skilled in the management of a caseload, workload and resource utilisation
- Confident in their individual professional development and in supervising colleagues and students
- Able to manage change through flexibility, innovation and strategic leadership. (NHS England, 2015)

These attributes are recognised as key characteristics for generic district nurses and are described in other documents (Queens Nursing Institute, 2015; Health Education England, 2015a), but are applicable to the wider (HIV) community nursing workforce.

(HIV) community specialist nurses are vital to delivering integrated care; as care coordinators they often work at the interface of health and social care systems and services, and in addition to their clinical expertise, they can have a unique insight into a patient's holistic needs.

Nurses often take the lead in co-ordinating care and case management. They can, and frequently do, work across geographical and service boundaries, collaborate with social, voluntary and other care professionals (such as housing, drug and alcohol, blood-borne virus and street homeless teams) in the planning, managing and co-ordinating of care for people with complex long-term conditions and needs (RCN, 2005).



Central concepts and components of a community HIV nursing model

Most nursing models have four concepts as their cornerstones, but may describe them differently (Murphy et al., 2010).

Person (recipient of nursing actions)
People (adults) living with or affected by HIV with complex physical and/or psychosocial needs

Environment (recipient's specific surroundings)
Community/home or designated home (nursing or residential home, hostel), street homeless. May also be seen in hospital, outpatient clinic, other community setting such as HIV support agencies, church, café, park

Health (wellness or illness state of the recipient
Complex HIV needs with ongoing co-morbidities and/or ongoing physical and/or mental health issues

Nursing (actions taken by nurses on behalf of or in conjunction with a recipient, Fawcett, 1995)
Patient-centred assessment, care planning, implementation, evaluation
Complex case management
Medicines management
Vigilance and rescue work
(Re)-engagement in HIV services

At a basic level, there are three key components to a nursing model:

- A set of **beliefs and values**
- A statement of the **goal** the nurse is trying to achieve
- The **knowledge and skills** the nurse needs to practise (Pearson et al., 1996).

Beliefs and values

We believe that people living with HIV have the right to high-quality, holistic care that enables them to maintain health and well-being. Every patient has the right to access to treatment which is non-judgemental and planned in collaboration with the patient and others involved in their care.

Nursing goal

We strive to:

- Engage complex, underserved and 'hard-to-reach' patients living with HIV
- Prevent deterioration of health
- Prevent unnecessary hospital admissions
- Optimise adherence to ART and effective monitoring
- Prevent onward transmission of HIV
- Promote self-management, general good health and wellbeing using a patient-centred approach
- Coordinate generalist care for physical, psychosocial and emotional needs

Knowledge and skills

The knowledge and skills required may include:

- Advanced HIV knowledge and expertise (including knowledge of health beliefs, comorbidities issues associated with MSM, women, adolescent and ageing issues)
- Communication skills (including counselling and motivational interviewing skills)
- Nurse prescribing (such as ART, TasP, PrEP)
- Holistic assessment (including drug & alcohol issues, psychological and emotional factors)
- Effective MDT working (including across clinical pathways and networks)
- Health promotion (including risk assessment, risk reduction and recognition of vulnerable adults/safeguarding)

National HIV Nursing Competencies (National HIV Nurses Association, 2013); Advanced Nursing Practice in HIV Care: guidelines for nurses, doctors, service providers and commissioners (NHIVNA, 2016).

Patient case study 3

'Stuart'

Stuart is a 57-year-old man who has sex with men (MSM), late diagnosed. Intensive treatment unit (ITU) admission with Pneumocystis carinii pneumonia (PCP). HIV at time of admission: CD4 count 32 cells/mm3 (6%), HIV VL >500,000. Previous history of osteoarthritis (exacerbated by long-term steroids whilst in ITU for PCP), psoriasis.

Further diagnoses since Stuart's HIV diagnosis – bilateral hip replacement, avascular necrosis, psoriatic arthritis, chronic back pain, depression, lipoedema, irritable bowel syndrome, recurrent herpes. Referred to our team pre-surgery. Whilst in hospital, expressed concerns around methicillin-resistant Staphylococcus aureus (MRSA) and confidentiality.

Social History

Eldest of seven brothers unaware of MSM and diagnosis. After HIV diagnosis lost his job. His relationship broke up, moved to level-access accommodation. No local social support. Smoker. No alcohol.

Community nurse specialist HIV home assessment

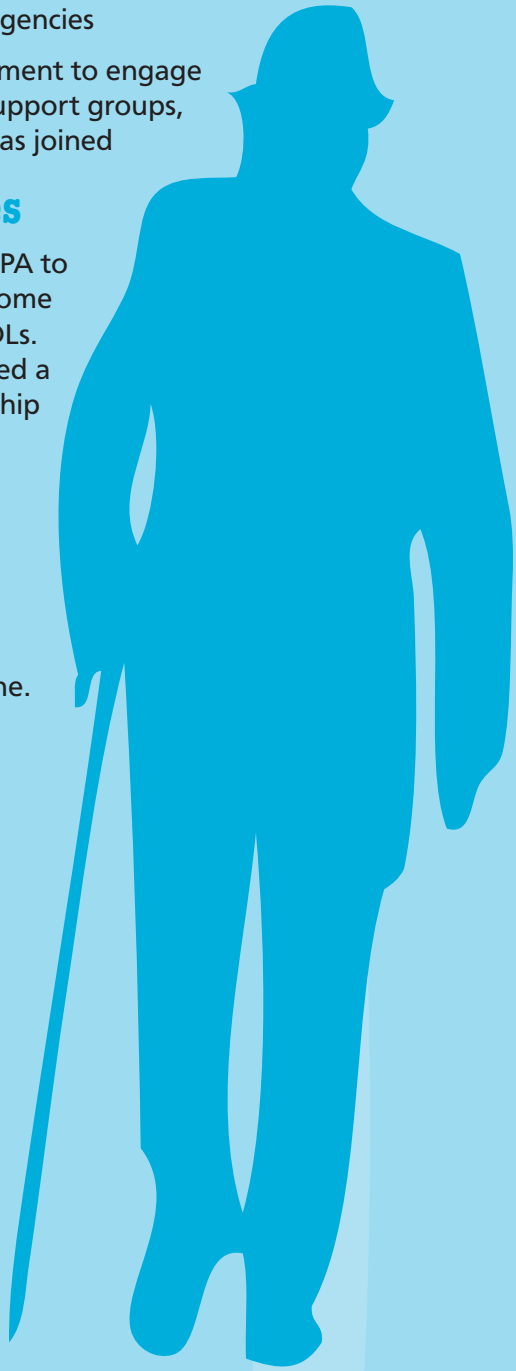
Stuart feels isolation, depression, low self-esteem, no future goals/aspirations, paranoia. Displays lots of anger around HIV, self-stigma. Chronic pain – not managed well. Urine incontinence, suffering in silence, erectile dysfunction. Unable to maintain activities of daily living, unable to maintain home environment. Anxiety with his operation looming: very wary and untrusting of health care professionals. Particularly worried about hospital acquired infections.

Plan

- Four-weekly home visits, with the aim for Stuart to remain as independent as possible, maintaining boundaries and managing patient expectation, MRSA education and empowerment for hospital admission
- Discussion with sister/ward staff re patient concerns and importance of adherence
- Co-ordinated partnership working liaising with various agencies: GP, rheumatology, HIV consultant, pain consultant, adult social care, occupational therapy, physio, rehabilitation unit, district nurses, podiatrist, speech & language therapy, care agencies, neurologist, mental health, Citizens Advice Bureaus and advocate agencies
- Encouragement to engage with HIV support groups, which he has joined

Outcomes

Stuart has a PA to assist with home situation/ADLs. Has developed a fair relationship with his GP. However, he remains socially isolated and still has not disclosed his HIV to anyone.



What informs this model of community HIV nursing?

- The Code; Professional standards of practice and behaviour for nurses and midwives (Nursing and Midwifery Council, 2015)
- NICE guidance community assessment (National Institute for Health and Care Excellence, 2016)
- Five Year Forward View including New Care Models and integrated care, sustainability & transformation (NHS England, 2014)
- Long-term conditions (NHS England, 2017)
- Co-ordinated care for people with complex chronic conditions (King's Fund, 2013)
- Compassion in practice (Department of Health, 2012)
- Leading Change, Adding Value (NHS England, 2016)
- Ageing (Uncharted Territory: a report into the first generation growing older with HIV, 2–17) (Terrence Higgins Trust, 2017)
- District Nursing Guidelines (Framework for Commissioning Community Nursing, NHS England; District Nursing – harnessing the potential, RCN, 2013) (NHS England, 2013; Royal College of Nursing, 2013)
- The future of HIV services in England (Baylis et al., 2017)
- The future of primary care: creating teams for tomorrow (Health Education England, 2015b)
- Advanced Nursing Practice (NHIVNA, 2016)
- Shared Care (MacLellan et al., 2016)
- NAT (HIV Support Services – the state of the nations, 2017)
- King's Fund: Case management: what it is and how it can be best implemented (King's Fund, 2011)
- King's Fund: Avoiding hospital admissions: what does the research evidence say? (King's Fund, 2010)
- BHIVA Standards of Care (BHIVA, 2013)

The following is adapted from Care in Local Communities (Bennett and Nicholson, 2013)**. The service model consists of three core elements:**

1 Population and caseload management

Managing and being accountable for an active caseload and providing population interventions to improve community health and wellbeing. Surveillance of caseload and local population needs. Working with a range of health and social care partners (including GPs, voluntary sector and community services) for health protection and improvement for adults and their care providers, at home and in other community settings.

2 Support and care for patients who are unwell, recovering at home and at end of life

Delivering a timely response when specific expert health intervention is needed, e.g. with short-term health issues, sudden health crises, or when patients are discharged from hospital or have a sudden deterioration in a health condition. Providing interventions within the home including venepuncture, prescribing etc. Working with other community specialist nurses, including community matrons, Macmillan teams to deliver specialist care including palliative and end-of-life care.

3 Support and care for independence

Providing leadership and prioritisation of supportive care to help patients stay well and manage their independence at home. For example, advice on nutrition, help to manage medicines, advice on 'assistive technology' such as telehealth and telecare, working with patients and their families to help them care for themselves. Leading on and delivering a range of local services (e.g. GP, voluntary and community organisations, or local authority).

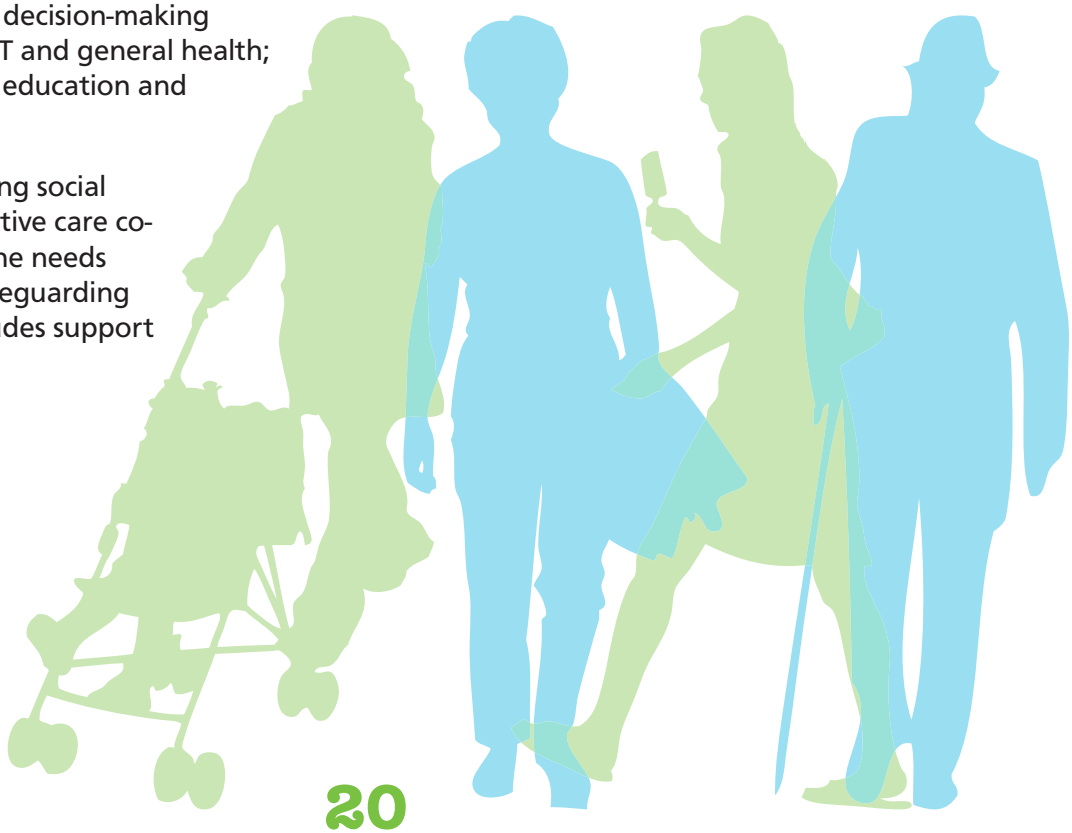
Working together with patients to deal with more complex issues over time. For example, to meet continuing and long-term health needs.

The community HIV CNS values the uniqueness of individual patients and understands the complexity of care within home or community settings. The dynamic nature of care in the community calls upon the community HIV CNS to build on their strong foundations, which include:

- **Strong values and behaviours** – the 6 Cs (Care, Compassion, Competence, Communication, Courage and Commitment) underpinning the service and delivery (Department of Health, 2012) (see Appendix 3)
- **Trust** – which starts with therapeutic relationships between patients and care providers
- **Partnerships across GP and other services** – collaborative working across agencies to support care; this may include working not only with GPs but also drug & alcohol support agencies, palliative care services, street homeless and housing services
- **Supporting transition of care** – working with health and social care professionals to provide seamless support, including discharge planning, transition to residential or hospice care; training/ teaching sessions on HIV to residential and nursing home staff, which may include using positive speakers
- **Supporting patient choice** – working with patients and care providers to encourage active participation in care and decision-making around issues such as ART and general health; promote the use of peer education and support
- **Managing risk** – reducing social isolation through supportive care co-ordination, supporting the needs of care providers and safeguarding vulnerable patients; includes support around child protection

The community HIV CNS model builds on the strong foundations and, coupled with innovation, this provides opportunities to develop new ways of working which include:

- **Making every contact count** (NICE, 2007; De Normanville et al., 2011) – is about encouraging and helping people to make healthier choices to achieve positive long-term behaviour change, providing opportunistic public health interventions, and supporting the health and wellbeing of care providers;
- **Maximising efficiency** – use of productive community services and innovation to enhance care;
- **Integrated working with health and social care** – developing strengthened ways of working with partners to maximise resources;
- **Delivering complex care** – supporting care in community settings which could include joint visits with other specialist teams, reducing avoidable hospital admissions and promotion of early discharge;
- **New technology to enhance care** – the use of Skype calls, Patient Knows Best, tele-health and mobile technology to support complex care in the home.



The community HIV CNS service

Referral to the community HIV CNS service

There are six main reasons for referral to the service:

1 **Complex case management** – For example the case management of complex physical and psychosocial needs, support of multidisciplinary team management (joint visits and working), rationalising appointments and care needs.

2 **Community-based HIV assessment, treatment and care** – for example, onward referral and signposting to hospice/specialist HIV services. Complex case management and care coordination such as discharge from ward, care packages etc.; signposting to other services (such as Citizens Advice, HIV support services) and assisting with registering with GP/dentist; supporting and managing self-care and issues around pregnancy.

3 **Vigilance and rescue work** – For example: complex patients with concerns about home life, drug and alcohol use (chaotic lifestyle, hard to engage, street and recreational substance use and 'chemsex' issues); vulnerable adults (safeguarding issue, domestic violence, safe discharge from hospital, assessment of home and function at home); cognitive impairment (including HIV associated neurocognitive disorder, dementia complexes and capacity issues).

4 **Engagement** – Re-engage those lost to follow-up or poor attendees, integrate back into system with HIV clinic outpatient services.

5 **Optimising adherence and medicines management** – starting, monitoring and managing ART use (including 'dosette' refilling/ observation, liaison with community pharmacies) and directly observed therapy; management of general ill-health, side-effects and co-morbidities.

6 **Management of psychosocial Issues** – For example psychological and emotional support (such as anxiety, depression and issues around stigma and isolation); screening for mental issues and HIV-associated neurocognitive disorders/ dementia with onward referral (if available), management of those not directly supported by mental health services or joint visits required.

For an example of a referral pathway see Appendices 5 and 6.

Discharge from the community HIV CNS service

Some patients will be engaged with the community HIV CNS for many years, and may never move on from ongoing community management. However, some patients may be discharged from the community HIV service if: they are demonstrated to be stable on ART and thus discharged back to their HIV centre; the initial identified risk has stabilised; they engage poorly with the community service, or achieve the initial goals they set (such as management of their medications, disclosure of HIV status or re-engaging with the HIV centre). They will also be discharged if they remove themselves from the HIV service completely by moving out of area or changing clinic.

Added value to the HIV community service could include:

- Phlebotomy
- Non-medical prescribing/clinical assessment and examination
- GP clinic engagement – residential and nursing homes, closer working with GPs, monitoring of other unsupported long-term conditions
- HIV/HCV/STI testing
- Signposting – debt advice, Citizens Advice
- Support to other agencies, education for other professionals, support with social issues, especially for those who have no recourse to public funds
- New diagnosis – risk assessment for/and partner notification
- Medical review – annual health review, blood pressure, weight, stable HIV clinic, triaging sick patients, 'clinic at home'
- Testing of children – adolescent engagement

Patient case study 4

‘Maya’

24-year-old woman with mild-moderate learning disability (LD). Diagnosed with HIV aged 17 following rape as a young teenager. Newly diagnosed with HIV-related encephalopathy and psychosis. Admitted to Mildmay Mission Hospital for rehab. Referred to community HIV CNS team to facilitate admission to Mildmay and support on discharge.

Social history

Prior to encephalopathy, lived in own flat and was attending college (access course). Mother (who also has LD) lives nearby. Brother (who has severe learning disability) is at boarding school and at mother’s at weekends. Aunt often comes to London to support. Post discharge from Mildmay, needing 24/7 care and support from mother and aunt (washing, dressing, meals, escort in community as wanders and gets lost).

Community nurse specialist HIV home assessment

First home visit I supported with dosette box. Family complaining that Maya is very drowsy during the day. Had been taking olanzapine in the morning, switched to night. Walks hesitantly, orientation and road-safety issues, needs support with ADLs. Obese, poor dietary intake. Not engaged with learning disability team. Confusion regarding appointments with OT and physio. Family need support caring for Maya. There are safeguarding concerns as the family were locking her in the flat ‘for her own safety’ (she wanders). Both Maya and her family lack basic knowledge on HIV.

Plan

Organise case conference and MDT action plan. Chase social work input and LD appointments as required. Find short-term activities for Maya whilst awaiting social work input. Liaison with occupational therapy (OT) and physiotherapy (occasional joint visits) re. their ability to manage ADLs and, in particular, road safety and orientation. Refer to dietitian. Refer to Food Chain lunches (local HIV NGO) and cookery course when appropriate. Support letter for PIP application and taxi card. Education of family on HIV (particularly transmission, treatment and that it cannot be cured.) Safeguarding referral if required.

Outcomes

Successful case conference. In attendance: Maya, mother, aunt, GP, consultant HIV physician, consultant psychiatrist, consultant learning disabilities physician, occupational therapy and physiotherapy, LD psychologist, social worker, HIV community CNS. No safeguarding referral required. Referred to Mildmay day services (outings, computers, gardening), local drama group for those with LD, young adults group at local charity Body & Soul. Eighteen months later HIV and mental health now well controlled. Consistently undetectable VL, 100% adherence. More mobile and able to self-care. Discharged by OT and physio. Engaged with LD team. Dedicated social worker, carers twice a day. Appropriate benefits in place. Goes to gym, has lost weight. Less dependent on family, has made friends. Mother managing without visits from aunt. Now travelling independently to and from Mildmay day services. Volunteering with elderly locally. Noticeably more confident, alert, active and brighter in mood.

What outcomes could the community HIV CNS measure?

We recommend that HIV community nurses could record the following outcomes, which can then be audited and used for commissioning purposes:

1 Adherence as a reason for referral – percentage of patients who are or remain undetectable after CNS adherence management intervention

2 Number of patients with a documented adherence assessment (HIV service specification [NHS England, 2013])

3 Number of patients lost to follow-up who have been brought back into acute services (HIV service specification [NHS England, 2013]; BHIVA Standards of Care for People Living with HIV 2013 [British HIV Association, 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 [NHS England, 2013])

5 Number of patients who require adherence interventions (medicine compliance aid monitoring, refilling/supervision) (HIV service specification [NHS England, 2013])

6 Number of patients with a personal care plan who show evidence of patient-driven outcomes? (BHIVA Standards of Care for People Living with HIV 2013 [British HIV Association, 2013])

7 Avoidance of emergency admissions (and clinic appointments) for acute HIV-related conditions that should not usually require hospital admissions (HIV service specification [NHS England, 2013]) (interventions involve holistic case management, empowering patients to self-manage their HIV, referring to peer support groups and local voluntary agencies, risk and safeguarding assessment)

8 Case management for people discharged from hospital with HIV-related conditions and reduction in readmissions to hospital within 30 days (interventions include comprehensive assessment and follow-up, onward referral, refer to social service re-ablement teams) (HIV service specification [NHS England, 2013])

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 Commission for Quality and Innovation [CQUIN] [NHS England, 2013])

As well as the above, the community HIV CNS holds a wealth of information that could be used for collection of additional HIV and AIDS reporting system (HARS) data, capturing local data, including the type and level of physical and psychosocial complexity they see as well as numbers and complexity of 'out-of-area' referrals, especially those areas with no community HIV support.

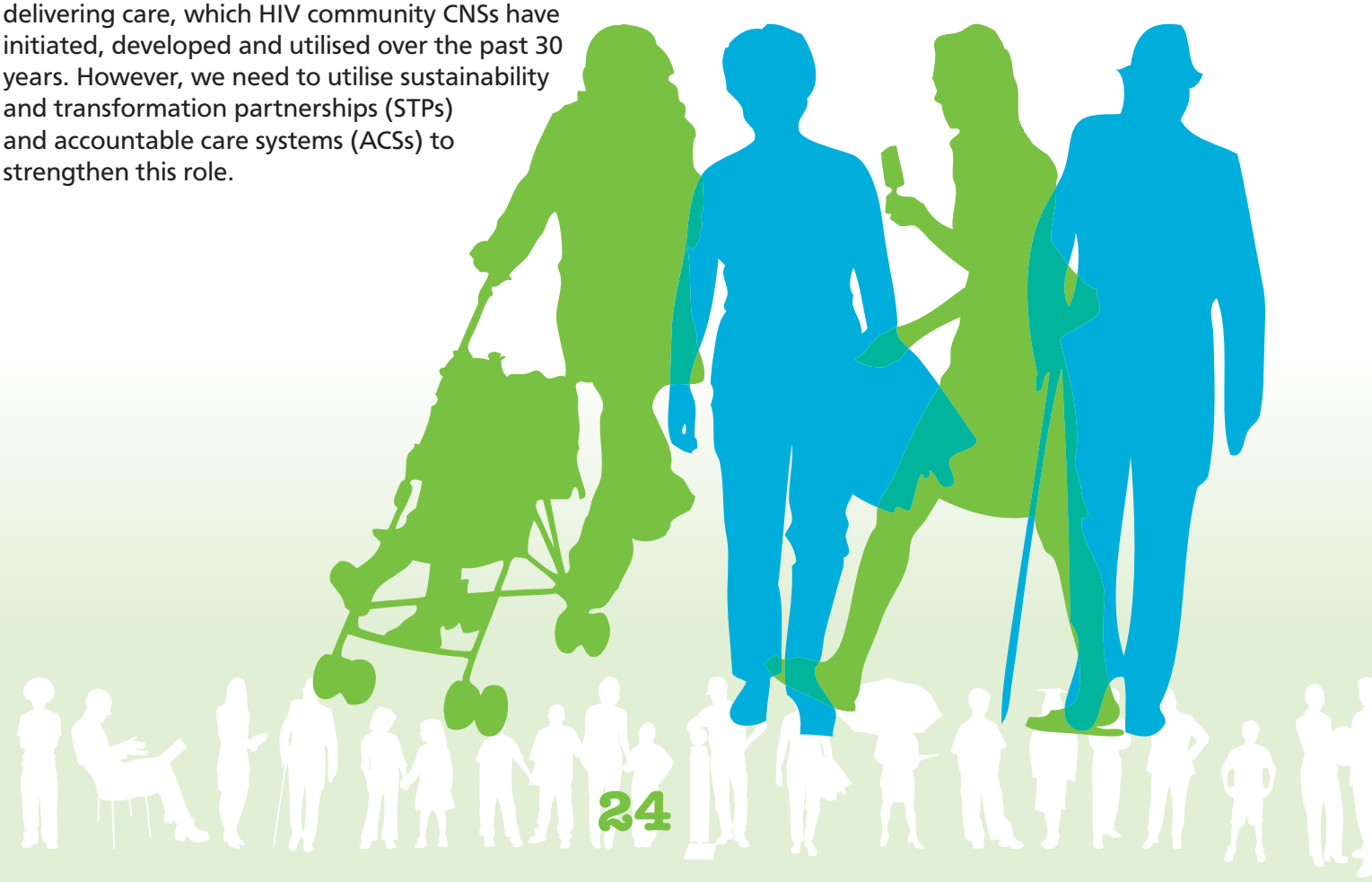
Summary and conclusion

Community HIV nurses have the skills and expertise to manage caseloads of patients with some of the most specialised, complex needs. There is a need to promote the role to ensure succession planning and longevity of the service.

HIV services must respect and recognise the importance of nursing, both in and out of hospitals. Only then will the service be capable of delivering truly patient-centred care, because it will be less about where care is delivered, and more about who is receiving it and what they want and need (adapted from Middleton [2014]). The King's Fund (2018) looked at future community care, stating that future models of community-based care should take a 'whole-person' approach, addressing people's physical health, mental health and social needs together. These factors are often closely related and interact to influence health and wellbeing, working closely with specialties, making communication easier across boundaries and empowering people to take control of their own health and care, involving families, carers and communities in planning and delivering care, which HIV community CNSs have initiated, developed and utilised over the past 30 years. However, we need to utilise sustainability and transformation partnerships (STPs) and accountable care systems (ACSs) to strengthen this role.

This model provides guidance for those working in and commissioning HIV community specialist nurse services. The HIV Community CNS is a unique, flexible and valued role that can significantly improve the patient experience and has been demonstrated to have significant cost benefits in reducing unnecessary hospital admissions, re-engagement and prevention of onward HIV transmission. The future of the community HIV specialist nurse is far from secure.

The community HIV specialist nurse should be seen as an integral part of a seamless, consultant-led HIV service, offering an essential element to HIV care and ensuring that people living with HIV who are unable to access hospital-based HIV services, or have disengaged with services, are effectively managed within their home.



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Appendix 1

What is a complex patient?

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 in the care and support of an individual, with no one person taking the lead.

Complexity may also be due to issues of ageing, language or literacy, that may require more time or additional support, or 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

Orem's Self-Care Deficit Model

The Self-Care Deficit Theory developed as a result of Dorothea Orem working toward her goal of improving the quality of nursing in general hospitals (Taylor and Orem, 2006). The model inter-relates concepts in such a way as to create a different way of looking at a particular phenomenon. The theory is relatively simple, but generalisable to apply to a wide variety of patients. It can be used by nurses to guide and improve practice, but it must be consistent with other validated theories, laws and principles.

The major assumptions of Orem's Self-Care Deficit Theory are:

- People should be self-reliant, and responsible for their own care, as well as for others in their family who need care.
- People are distinct individuals.
- Nursing is a form of action. It is an interaction between two or more people.
- Successfully meeting universal and development self-care requisites is an important component of primary care prevention and ill health.
- A person's knowledge of potential health problems is needed for promoting self-care behaviours.
- Self-care and dependent care are behaviours learned within a socio-cultural context.

Orem's theory is comprised of three related parts: theory of self-care; theory of self-care deficit; and theory of nursing system. The theory of self-care includes: self-care, which is the practice of activities that an individual initiates and performs on his or her own behalf to maintain life, health and well-being; self-care agency, which is a human ability that is 'the ability for engaging in self-care', conditioned by age, developmental state, life experience, socio-cultural orientation, health and available resources; therapeutic self-care demand, which is the total self-care actions to be performed over a specific duration to meet self-care requisites by using valid methods and related sets of operations and actions; and self-care requisites, which include the categories of universal, developmental and health deviation self-care requisites.

Universal self-care requisites are associated with life processes, as well as the maintenance of the integrity of human structure and functioning. Orem identifies these requisites, also called activities of daily living, or ADLs, as:

1. The maintenance of sufficient intake of air, food, and water
2. Provision of care associated with the elimination process
3. A balance between activities and rest, as well as between solitude and social interaction
4. The prevention of hazards to human life and well-being for the promotion of human functioning.

Developmental self-care requisites are associated with developmental processes. They are generally derived from a condition or associated with an event.

Health deviation self-care is required in conditions of illness, injury or disease. These include:

- Seeking and securing appropriate medical assistance
- Being aware of and attending to the effects and results of pathologic conditions
- Effectively carrying out medically prescribed measures
- Modifying self-concepts to accept oneself as being in a particular state of health and in specific forms of health care
- Learning to live with the effects of pathologic conditions

The second part of the theory, self-care deficit, specifies when nursing is needed. According to Orem, nursing is required when an adult is incapable or limited in the provision of continuous, effective self-care. The theory identifies five methods of helping: acting for and doing for others; guiding others; supporting another; providing an environment promoting personal development in relation to meet future demands; and teaching another.

The final part of the theory, the theory of nursing systems, describes how the patient's self-care needs will be met by the nurse, the patient, or by both. Orem identifies three classifications of nursing system to meet the self-care requisites of the patient: wholly compensatory system, partly compensatory system and supportive-educative system.

Orem recognised that specialised technologies are usually developed by members of the health care industry. The theory identifies two categories of technology.

The first is social or interpersonal. In this category, communication is adjusted to age and health status. The nurse helps maintain interpersonal, intra-group, or inter-group relations for the coordination of efforts. The nurse should also maintain a therapeutic relationship in light of psychosocial modes of functioning in health and disease. In this category, human assistance adapted to human needs, actions, abilities and limitations is given by the nurse.

The second is regulatory technologies, which maintain and promote life processes. This category regulates psycho- and physiological modes of functioning in health and disease. Nurses should promote human growth and development, as well as regulating position and movement in space.

Orem's approach to the nursing process provides a method to determine the self-care deficits and then to define the roles of patient or nurse to meet the self-care demands. The steps in the approach are thought of as the technical component of the nursing process. Orem emphasises that the technological component 'must be coordinated with interpersonal and social pressures within nursing situations'.

The nursing process in this model has three parts. First is the assessment, which collects data to determine the problem or concern that needs to be addressed. The next step is the diagnosis and creation of a nursing care plan. The third and final step of the nursing process is implementation and evaluation. The nurse sets the health care plan into motion to meet the goals set by the patient and his or her health care team, and, when finished, evaluates the nursing care by interpreting the results of the implementation of the plan.

What is the nursing process?

The nursing process is a set of steps followed by nurses in order to care for patients. Nurses can use it in many different ways to suit a particular patient or situation, but the process generally follows the same steps: assessment, diagnosis, plan, implementation, evaluation.

Assessment is used to get the patient's history, as well as a list of symptoms or complaints. Using the information gathered in the assessment, the nurse and other health care professionals can form a diagnosis.

Diagnosis is the determination of what's wrong with the patient, if anything. The assessment and diagnosis allow the nurse to develop a nursing care plan.

A plan of action for how to care for the patient may include goals set by both the nurse and patient, and determining how best to meet those goals.

Implementation sets the nursing care plan in motion in order to meet the patient's goals. Finally, the patient is evaluated by the nurse to determine whether or not goals were met.

Evaluation may be performed during the implementation phase in order to make changes to the nursing care plan as needed. For example, if the patient gets worse, he or she may need to be reassessed to come up with a different diagnosis and plan of action. The nurse may also be evaluated at this point to determine how he or she cared for the patient.

Why is the nursing process used?

The nursing process is used to regulate patient care and how nurses interact with patients. By following a particular set of steps in the nursing process, a nurse knows exactly what to do to care for a patient and what comes next. The nursing process also allows nurses to keep better track of patient care in terms of record-keeping. As a nurse is writing up notes about a patient, he or she can mentally go through the nursing process and make notes about each step. This will help ensure that the nurse does not forget a step or notes about an aspect of patient care, and the rest of a patient's health care team will be able to follow the process the nurse used as well.

How are nursing theories applied to the nursing process?

Some nursing models deal directly with the nursing process. That is, these theories guide nurses in how to treat patients from assessment through to evaluation. Other nursing theories give a modified version of the nursing process, adapting them to fit the model of nursing. However, there are also nursing theories that do not apply to the nursing process. These theories may only apply to a specific aspect of nursing, such as assessment, rather than the nursing process as a whole.

Appendix 3

Compassion for practice – the six Cs

Compassion for practice – The Vision and Strategy for nurses, midwives and health care staff (2012) requires...

'... nurses, midwives and health care staff to deliver high quality compassionate care and to achieve excellent health and wellbeing outcomes.'

This has been captured in what is now called the *six Cs*. These six Cs will be reflected in many aspects of your current practice assessment documents. Mentors will be seeking evidence that you can demonstrate the professional behaviours reflected in the following six Cs.

- **Care** – we need to be able to measure the quality of nursing, midwifery and care giving to ensure that it is delivered on a consistent basis, first time, every time in the right setting and the right way.
- **Compassion** – the importance of recruiting nurses/midwives and care givers with compassionate values; measuring and assessing compassion; and the processes used to promote compassionate care, for example the use of annual appraisal and feedback.
- **Competence** – a high level of competence is required to deliver appropriate care, recognise a deteriorating situation, challenge poor practice or decision-making of others.
- **Communication** – good communication involves better listening and shared decision-making ('no decision about me without me') and making every contact count.
- **Courage** – it takes courage to stand up to poor care and to innovate, suggest and implement new ways of working.
- **Commitment** – commitment to take action together as a profession to unlock its potential.

Appendix 4

Economic Assessment of the Community HIV CNS

(section taken from Watson (2016))

With funding from the Burdett Trust for Nursing and the Office for Public Management (OPM) 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 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 three 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

Improving quality and care experience	Reinforcing safety
• 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	• 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
Increasing productivity and efficiency	**Demonstrating leadership**
• 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.	• 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 mental health or 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 recognise 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 the 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?

1. Patients with complex HIV needs (usually around adherence or medicine management, mental health needs)
2. Carer and family of patients feel supported.
3. The HIV clinic – patients are managed and supported at home with ART adherence and are kept engaged with the HIV service.
4. The GP – HIV patients have additional community management/vigilance at home with this role where there may be no other services available
5. 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.
6. Borough/commissioners – undetectable patients reduce risk of further ill health, hospitalisation and onwards HIV transmission.

Added Value[1]

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.

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.

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.

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.

Monetised 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 a different regimen so the costs will change. Therefore, if most referrals to Community HIV CNSs 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 £1,776–3,500. (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 two 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 (Co-trimoxazole) 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 a single tablet 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 a sauna, discussed how to talk about 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)	£1,080–1,300
Community Psychiatric Nurse	weekly	£67–75 per hour	£1,742–1,950
Community Psychiatrist	Every 2 months	£107–139 per hour	£642–834
			Total Costs = £3,462–4,084

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 = £1,152–1,218

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 dosette 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	£4,620–5,080
Ambulance service	50 calls per year	£7 per call answered	£350
GP	18 visits	£54–65 (11 minutes)	£972–1,170
			Total costs = £5,942–6,600

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

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 miss 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 2–3 times a year.

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, care providers 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)

Four 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. Yet again Harry 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-month's 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 week's 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 was 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	£1,776–3,500 (per week)	£3,552–7,000
Hospitalisation for George	2 weeks plus	£1,776–3,500 (per week)	£3,552–7,000
			Total £7,104–14,000 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 2016 audit highlights not only the scope of the many roles taken on by Community HIV CNSs in high prevalence areas but also our knowledge, skills and experience. In these times of cost pressures Community HIV CNSs 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 patients 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 patients' needs. Look at your caseload and think about all the patients for whom 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.

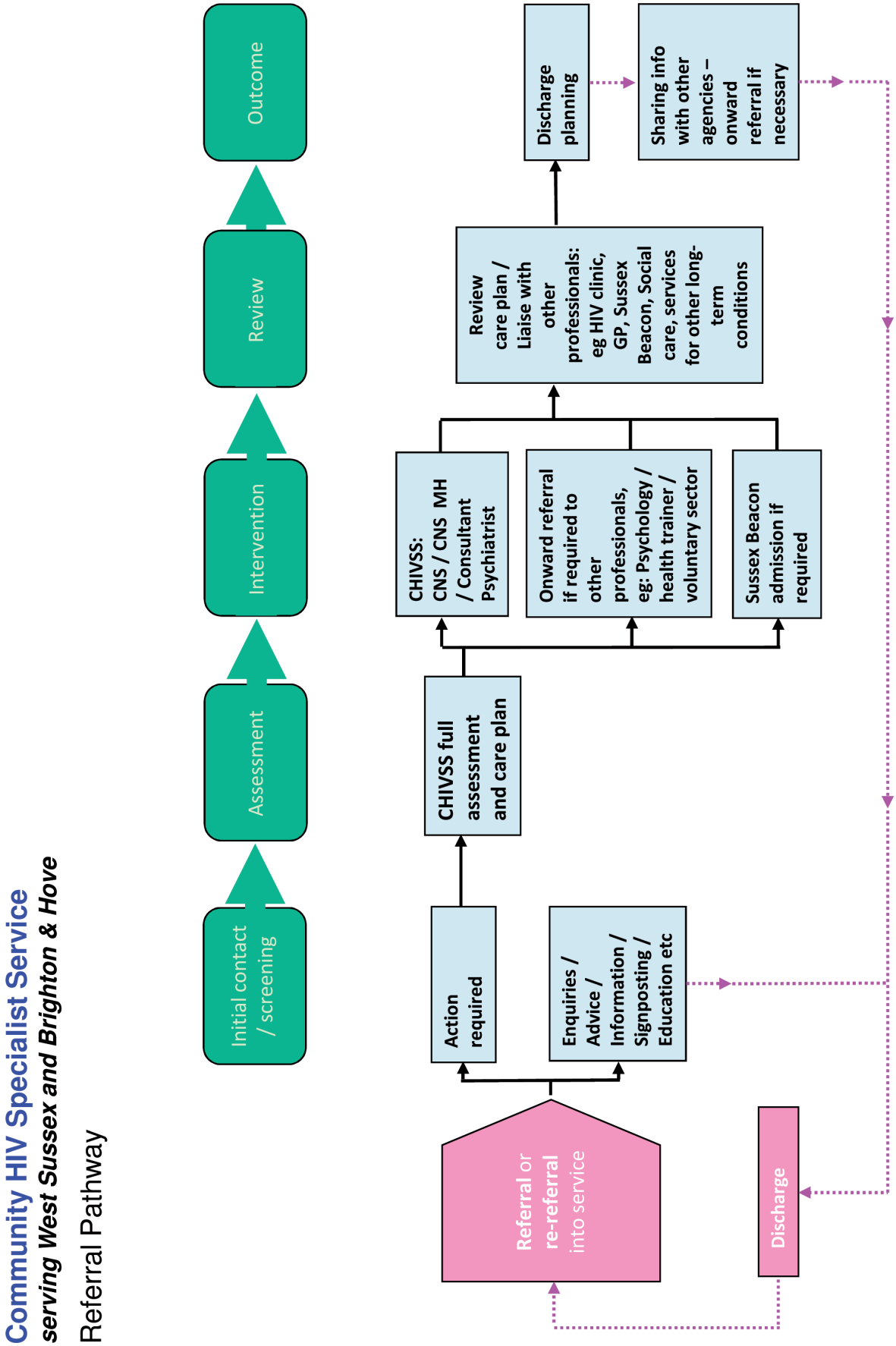
Currently, most referrals to the Community HIV CNS service are for adherence management and support and the consequences of poor adherence, potential ART wastage, rebounding viral loads and onwards transmission should not be underestimated. HIV is often the hook on which to hang other issues and the Community HIV CNSs often deputise for palliative care, mental health and other primary care services. Many of us manage 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 which would require 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—nurses 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 the clinic can tap into. Roles could be adapted to suit an individual HIV clinic's 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 results systems. Therefore, we rely upon paper notes and third-party help to book appointments and arrange prescriptions etc.

We need to develop a national model of HIV Community Nursing (Tunnicliffe 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.

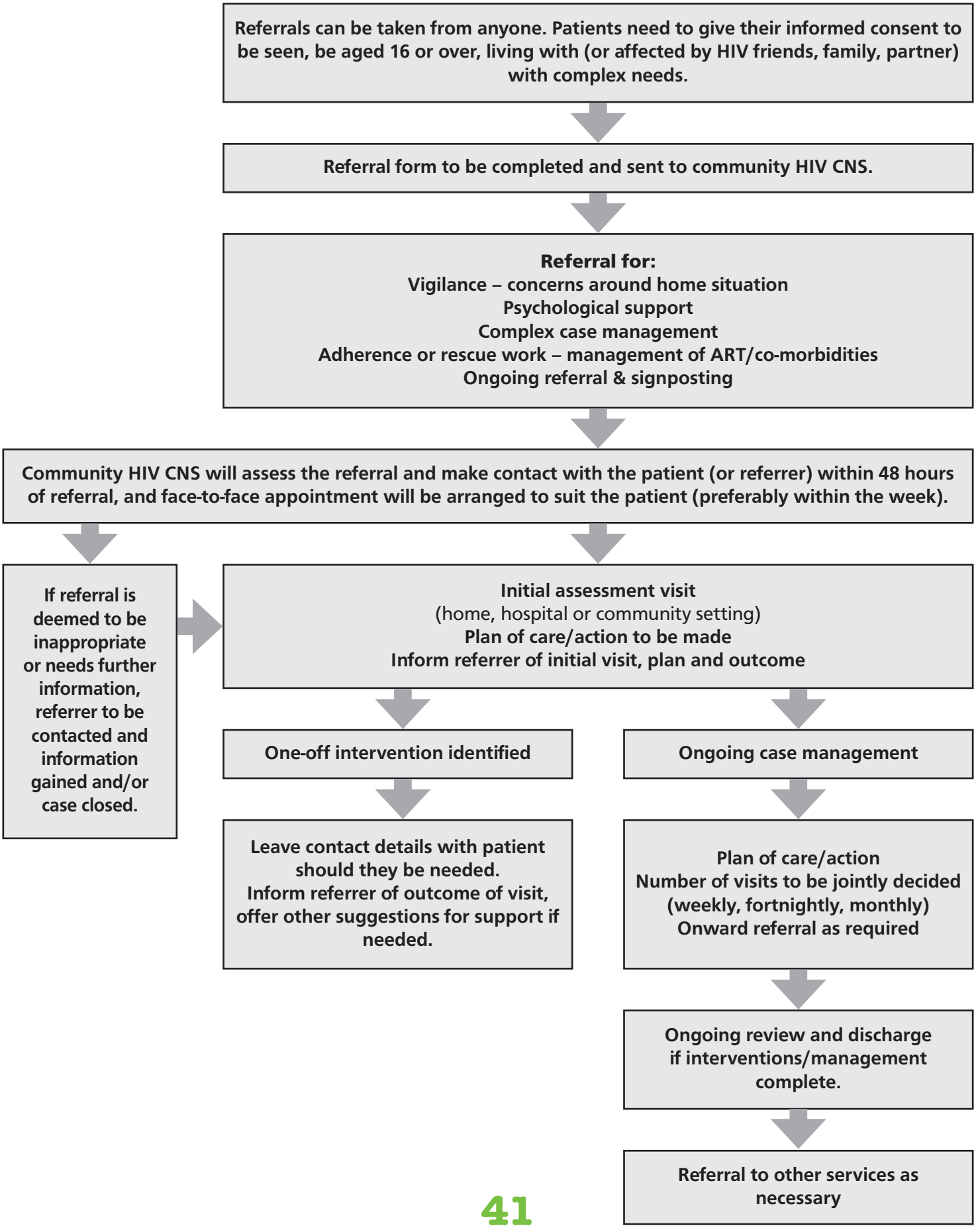
Appendix 5

Pathway example – West Sussex, Brighton & Hove



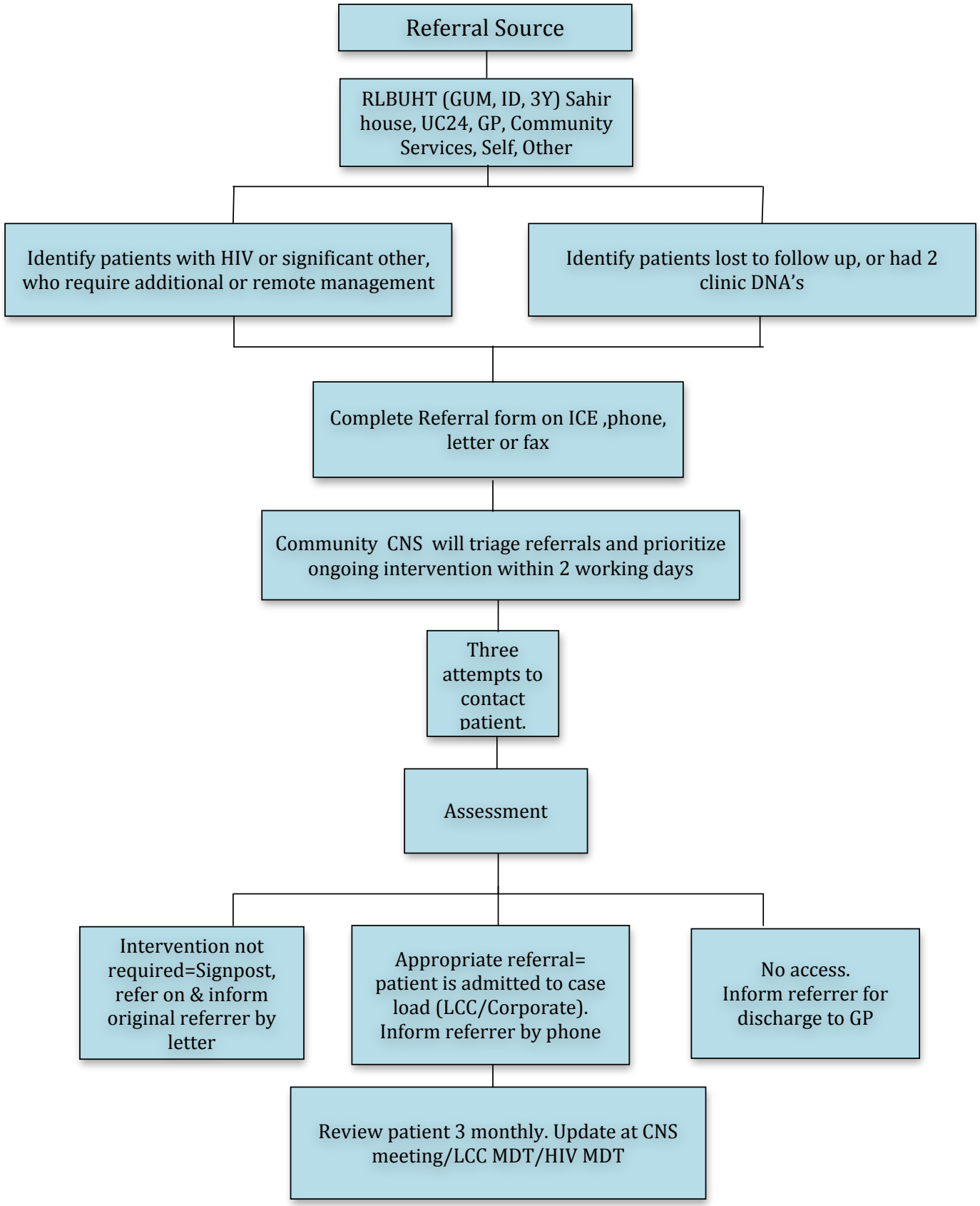
Appendix 6

Community HIV CNS referral pathway
(London boroughs of Westminster, Hammersmith and Fulham)



Liverpool Community HIV CNS Referral Pathway

(Patient must reside within Liverpool or be registered with a Liverpool GP)



Appendix 7

Elements of Liverpool Community Clinic (LCC)