HIV-MSS: A User-Friendly Management Support System for Better Planning of HIV Care Services

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Abstract

The advent of antiretroviral therapy (ART) has transformed HIV infection from a deadly disease to a manageable chronic condition. The life expectancy of people living with HIV has been prolonged dramatically. Therefore, health systems are now confronted with new challenges, with ever-increasing number of newly diagnosed cases, fuelling the pool of existing patients, with many comorbidities and requiring hospital admissions. Are health systems prepared to handle large and increasing numbers of people with HIV? We developed a HIV-Management Support System (MSS) to support service evaluation and management using simulation by capturing individual patient's pathways within HIV services in the UK. Two scenarios were tested, 1) the impact of increasing the number of diagnosed cases in steps of 5% on human resources, and 2) the impact of treating all patients with ART on hospital admissions. A 5% increase in newly diagnosed HIV cases increases human resource requirements between 4% and 8%, whereas the impact of treating all HIV patients with ART on hospital admissions is far greater. HIV services are under intense pressure and managing patient and service needs are far more important than ever, hence the development of our HIV MSS is timely, to support better planning of services. Note that the HIV simulation model presented in this study is the first of its kind.

Keywords

HIV, Patient pathway modelling, Discrete Event Simulation, Management Support System

1. Introduction

In 2019, there are 101,600 people currently living with HIV in the United Kingdom (UK) of which 7,800 are undiagnosed (7.7% of all cases) [1]. This translates to approximately 1.7 per 1,000 people of all ages [2], where 4,453 new patients diagnosed each year [3]. Based on targets set by the Joint United Nations Programme on HIV/AIDS (UNAIDS), UK has an outstanding record of achievement in the treatment and prevention of HIV [4]. The UNAIDS (90-90-90) target aims to diagnose 90% of all HIV positive people, provide antiretroviral therapy (ART) for 90% of those diagnosed and achieve viral suppression for 90% of those treated, by 2020. Some countries like the UK has already achieved this target, as a result UNAIDS has revised this to 95-95-95.

But today, HIV services in the UK and other parts of the world are at a transition point. Effective treatment coupled with early diagnosis of new infections, permit HIV patients to live longer with a normal life expectancy [5].

This has resulted in increase in the number of older people living for long periods with HIV, with a significant proportion of them having co-morbidities, such as hepatitis, and other age-related disorders, e.g. diabetes, hypertension and osteoporosis. These conditions are exacerbated by HIV and its treatment and findings indicate that for persons 50 years and older with HIV, additional chronic health problems are expected [6]. Almost a third of those currently living with HIV are aged 50 or over [7], whereas by 2028 this is forecasted to be more than 50% [8]. As a result, there is a rapid increase in the number of people visiting HIV healthcare providers for a wide range of services, including diagnosis, treatment, monitoring, psychological support, and added to this are issues surrounding co-morbidities.

The global efforts in transforming HIV from a deadly disease into a chronic, manageable condition has succeeded. However, this success and achievement have produced new challenges, not so much on patients, but those responsible for the management and treatment of HIV and those responsible for the management of HIV services, payers, donors and decision-makers. For instance, are services prepared for larger numbers of people with HIV, with needs that are different from those in the past? How are HIV services managing this complex arrangement? Can they keep pace with changes to HIV services that will be needed in the future, and with new technologies and interventions?

Our research aimed at answering these types of crucial questions, with the intention of helping those responsible at local, national and global levels for planning and delivering optimal HIV services. We developed a patient pathway simulation of HIV services in the UK, capturing individual “footsteps” of patients from initial contact until discharge, including all the processes and resource consumption in between. The simulation model is then transformed into an easy-to-use management support toolkit, so that key decision-makers can easily engage with the complex model and run scenarios for better service planning. The quantifiable impact of changes (or re-design) in HIV services has never been studied before. For instance, it is not well known how a change in one area of the service will impact on resources in another, including activity, resource utilisation and financial implications.

We demonstrate our management support system by examining two key concerns as highlighted above, 1) to evaluate the impact of increased use of services due to rising levels of diagnosed HIV cases on human resources, and 2) to assess the impact of early initiation of antiretroviral therapy (ART) on HIV related hospital inpatient admissions. Note that these are high-intensive users, where multiple comorbidities lead to hospital admissions and readmissions.

Note that other methods, apart from simulation modelling exists, e.g. multi-state models for HIV disease progression to study of demographic and clinical characteristics' effects on the entire disease progression pathway [9]. These types of models are not as flexible as simulation models.

2. Method: Simulation for Better Decisions

Decision-making process for a complex situation in a complex environment can be daunting. For instance, a patient's initial admission/assessment until discharge, including all the processes that takes place in between (and use of a wide range of resources) means that healthcare systems are complex.

While decisions are usually a guess about the future, there are ways of minimising risk, where informed decisions are only possible with the help of tools for thinking [10]. There are many activities carried out for each patient during their visit to a hospital, including diagnostic testing, treatment, medication, regular follow-ups (or checks), and at each stage of this process numerous human and non-human resources are consumed. The level of resource needs of each patient is unique depending on the severity of their condition.

We can only minimise the risk of wrong decision making if the full spectrum of a patient's pathway within the healthcare setting is considered. For example, how do you assess the impact of a new screening policy for HIV patients? This will have an impact on every single aspect of day to day operations. What about evaluating the introduction of a new HIV clinic in the community? Again, decision-makers need to better understand the likely impact on every component of the system, e.g. utilisation of resources (doctors, nurses, clinic rooms), treatment outcomes, disease progression and financial implications as a result of change. We cannot assess one aspect of the system and leave out others when making decisions.

No mathematical, statistical or health economics approaches can capture this level of detail, whereas simulation, particularly Discrete Event Simulation (DES), is one of the most widely used tools to develop very complex situations within a computer simulation environment. DES is recognised by the community for its suitability, adoptability, and scalability in healthcare challenges [11].

Simulation is a method used to mimic a system to observe its behaviour and state changes in time, on a computer. A system such as HIV patients' treatment can be represented with a simulation model. Any representation on a computer is a simplification of the reality and therefore relies on routine healthcare data obtained from a system. There are two types of data; first, the system itself and how it works, the HIV patients' treatment in our case, and second, historical data obtained from the system. Understanding the treatment for HIV patients requires domain expertise and a detailed view of patient types, possible pathways, human resources, facility, and machine resources, and how all these interact. Historical data is analysed to create inferences which a simulation model requires.

We have developed a DES to analyse the impact of alternative scenarios and interventions of HIV treatment. Our model has a simple user interface and a complex structure. The designed interface illustrates a simplistic flow of HIV patients in the treatment course, however in the background the flow is far more complex. The complex part, which does not appeal to users, is made not visible to “ordinary” users as decision-makers are not interested in bits and bolts of a model. Users usually refrain from using complicated, not easy to use, support systems.

Therefore, the HIV-MSS is designed and implemented with key decision-makers in mind, including service managers, nurses and physicians, without the need for a technical intermediary. As a result, the front interface and the simulation controls are simple, concise and fit for purpose. Users can make necessary changes in the input parameters. The input parameters are in an Excel spreadsheet for ease of use. The user of the model can customize the input values for costing, treatment, and patient routing. In this sense, our model is a generic model which can be tailored for specific healthcare providers.

2.1. Patient Pathway for HIV

The model simulates the entire pathway starting from initial referral to a healthcare provider (or clinic), with all the diagnostic and treatment procedures carried out throughout a patient’s journey. Figure 1 shows the typical pathway for HIV patients in the UK. The pathway mapping consisted of structured interviews with HIV specialist nurses and consultants. At each stage of the interview, the pathway was updated in real-time according to the expert’s opinion, to ensure every aspect and detail of the pathway is captured.

Patient’s start their journey with HIV diagnosis (Referral), where most are carried out at a genitourinary (GU) clinic. After an initial assessment phase, a series of tests (e.g. blood test) is carried out, and where necessary, psychological support is started with pre-test counselling. At the initial phase of diagnosis, if a patient is found to be HIV positive, they are required to have multiple appointments with the multidisciplinary team (MDT), made up of doctors, nurses, psychologists, pharmacists, health counsellor and administration staff. There are 2 types of patients, HIV-1, most widespread, around 90% in the world and HIV-2 least prevalent, 10% of cases.

The HIV outpatient services in the NHS is designed pathway for two groups of patients: Naive patients are those that have been newly diagnosed in the UK or have newly started antiretroviral therapy (ART). A new patient will be in this group for about one year, after which they will then automatically be known as Treatment Experienced (Tx Experienced). Amongst the Tx Experienced, a small percentage can be critically ill patient group, needing more care and close monitoring, or being highly dependent patients. Some of the complexities include current tuberculosis (TB) co-infection on anti-tuberculosis treatment; on treatment for chronic viral liver disease and receiving oncological treatment [12, 13].

Regardless of Naïve or Tx Experienced, patients have regular monitoring visits made up of tests, routine clinic visits, and investigations carried out throughout the year, e.g., Naïve can be seen by a physician around 3 times per year for 20 minutes at each visit, whereas a more complex Tx Experienced patient is seen 6 times in a year. Around 5% of patients disengage from treatment, some transfer to a different HIV service provider and a very small percentage discharge by death.

2.2. Input Parameters

A total of 260 input parameters were established using the national hospital episodes statistics (HES) dataset, the literature, online resources (mainly NHS sites), local data and where necessary expert opinion (HIV specialist nurses and physicians). HES is a database containing details of all admissions, accident and emergency (A&E) attendances and outpatient appointments at NHS hospitals in England [14]. These input parameters were identified as essential in collaboration with key stakeholders (i.e. HIV specialists and nurses) not just to power the model, but to capture reality to a certain extent within a simulation environment. A balance had to be made between complexity (i.e. the real system) and the needs of the model to answer key concerns raised by the stakeholders.

The input parameters include all information on individual patients' pathway with the required resources for treatment, e.g., demand (number of new and existing HIV patients per year), route of admission, initial assessment activities, pharmacological treatment, percentage of patients falling into each category (new, stable and complex), human resource utilisation, human resource capacity, hourly cost of staff and disease progression.

Table 1, accounting for 42% of the input parameters (110 out of 260), shows the list of staffs involved for the treatment and management of HIV patients in NHS Outpatient services, including the number of visits per year and the amount of time required by each staff. A patient can be seen by several staff at each visit, e.g. a doctor, a specialist nurse, and by a pharmacist (if on ART). Not all patients require a visit to a dietician, clinical psychologist, occupational therapist and HIV health advisor (also known as task shifting), i.e., 6%, 3% and 7% of new, stable and complex patients are given psychological support by a clinical psychologist, respectively. The average hourly cost of staff is also provided in Table 1 using pay scales based on bands, e.g., the highest pay scale is for physicians (band 8 and 9), ranging from £22.82/hour to £53.12/hour (depending on the number of years of experience), whereas a band 7 HIV specialist nurse would cost the NHS on average of £20.07/hour [15].

Using statistical programme R, distributions were established to capture uncertainty within the pathway. Instead of relying on average estimates or fixed figures as stated in Table 1, observed frequency distributions are determined using real data. The problem with using averages is that it may lead to incorrect predictions, known as the 'error of averages' [16]. It is important to be accurate as HIV clinics deals with 100's of patients costing millions of pounds (GBP). For instance, according to HES, the average length of stay (LoS) for TB-HIV co-infection patients who are admitted to hospital in England due to complications is 11.3 days (based on 7,818 admitted cases). Assuming that all patients stay for 11.3 days could be misleading. LoS is exponentially distributed for these patients, and each time a patient is admitted to hospital for TB-HIV co-infection on TB treatment, the simulation randomly assigns a LoS using the distribution. Reality is captured via the observed distributions, as opposed to averages, thus avoiding the flaws of averages. The same is applied to the number of times a patient visits the clinic or the amount of time staff spend with patients. For instance, does a HIV specialist nurse always spend 30 minutes or a pharmacist 15 minutes?

Where no data is available, we assumed uniform or triangular distributions, e.g., the average hourly rate of band 8 or band 9 physician is £43.99, however band 8 and 9 hourly rates ranges from £22.82 to £53.12. So, how realistic is £43.99, when any physician within that range could be treating the patient. We therefore used the uniform distribution, where £22.82 is regarded as the lower bound and £53.12 the upper bound. This means that any amount within that range is randomly assigned (or selected) for each patient being treated by a band 8 or band 9 physician.

The power of simulation is the ability of using relevant statistical distributions, that account for the variability in the variable of interest, and where necessary attaching resources (e.g. a clinic room, a nurse, a bed) at each stage of a patient's treatment journey, which makes it far superior to any other modelling framework.

3. HIV-MSS: The HIV Management Support System

The simulation model is transformed into an easy to use management support system. The objective is to empower end-users, so that a wide range of scenarios can be tested without the need to consult developers. An easy to use front interface is designed, without providing the complex structure and visual logic codes of the simulation. Control buttons and graphical icons are designed for ease of use. Exhaustive set of outputs in the form of an Excel spreadsheet with numerical and graphical outputs are provided.

In addition to the user interface, there are questions for users to set up the simulation inputs. These questions enable users to assess their system against potential changes in the treatment pathway and cost. "Demand" and "Manage" control buttons are designed for this purpose. For example, "Please state the percentage of your patients on ART Treatment". Answers are entered through the model's input screen. Two scenarios are tested, scenario 1 (current practice) vs. scenario 2 (intervention).

Verification and validation (V&V) of a model is critical for accountability. V&V process goes together with the model building. Stakeholders are engaged in the project so that their feedback can help validate the model which also are known as white-box validation. Furthermore, black-box validation technique is used to compare simulated outputs with real outputs. Our simulation model benefited from both V&V techniques and stakeholders convinced that the model is fit for purpose.

4. Results

We run two sets of experiments, the first evaluates the impact of diagnosing all undiagnosed cases (in steps of 5%) on human resource needs at a clinical commissioning group (CCG) level, and the second assesses the impact of treating all patients with ART on hospital admissions and costing at the national level.

4.1. CCG level analysis: diagnosing all undiagnosed cases

The UK has met and exceeded the first and second 90s in the UNAIDs 90-90-90 targets for 2020, i.e., 91% of all HIV patients are diagnosed (target 90%), with 97% of those diagnosed on treatment (target 90%), where 87% are virally suppressed (slightly below target) [3]. The UK is not too far from a 100% diagnosis rate but at what cost. Do all service providers (e.g. GU clinics) have all the necessary resources in place, particularly human resources? It is a known fact that NHS services are stretched, and in most instances, they are at a breaking point, staff working at full capacity with financial difficulties [11]. Using our DES model, we assess the impact of diagnosing all patients in steps of 5% on key human resources at a CCG level. This will enable key decision makers (e.g. HIV clinic managers and commissioners) to assess their readiness in terms of human resource requirements to ensure effective delivery of care at the point of need.

CCGs are responsible for planning and commissioning of health care services within their local area. As of April 2019, there are 191 CCGs in England with an average population of 226,000 [12]. Based on the prevalence rate of 1.7 per 1,000 people, we would expect an average CCG to be responsible for around 384 HIV patients. We run the simulation over a 12-month period and collect information each time a human (and non-human) resources are consumed by a patient. Based on the current diagnosed population (i.e. ~90%), approximately

365 existing patients (out of 384), with a further 23 new patient during the year (4,453/191), a CCG would expect 1,738 doctor visits in a year based on the stipulated regular and emergency hospital visits (see Table 2). This equates to around 634 hours of doctor's time treating patients, costing £27,904 (using hourly rates of £43.99). When all patients are diagnosed (100%), the number of doctor visits increases to 2012, meaning that 93 additional hours are required to treat patients.

Nurses are currently in shortage in England with about 40,000 vacancies waiting to be filled [11]. An increase from a current 90% diagnosis rate to 100%, means an additional 100 visits to HIV specialist nurses and 40 hours of treatment time added to the current 269 hours of treatment time. This is an additional burden to a single CCG in England, and when translated to the entire nation, it's approximately 19,100 extra visits to a specialist nurse with 7,640 additional hours of treatment time. The proposed NHS interim people plan which will be consolidated into a final people plan will benefit from HIV-MSS (see Figure 2 for impact of change on each staff). This plan which sets out approaches for improving the NHS working environment, strengthening the leadership culture, tackling nursing shortages and future-proofing the workforce. HIV-MSS is a tool that can help to ensure workforce strategies that reflect new ways of providing care for HIV patients, and that organisations are able to deploy staff in a way that best reflects the skills mix needed to provide effective and efficient services.

4.2. Treating all patients with ART: the impact on hospital admissions

Evidence suggests that immediate initiation of ART for adults with a CD4 count > 500 cells/mm3 provides greater clinical benefits over deferring ART initiation until after the CD4 count had declined to 350 cells/mm3 [17] [18]. Current practice is around World Health

Organizations “test and treat” model of care for HIV. Immediate ART reduced the risk of all-cause morbidity and mortality by 57% as compared to deferred ART initiation. We tested our model based on treating all HIV patients and its impact on hospital admissions associated with opportunistic infections and costing, i.e., two scenarios, a pessimistic scenario, whereby only 10% reduction in hospitalisation is noticed against an optimistic scenario, a 30% reduction. We examine at the national level as the number of inpatient admissions at CCG level broken down by ICD-10 codes is too small, e.g., 191 patients were admitted during the last 3 years for HIV diseases resulting for other viral infections. This would equate to around 1 admission per CCG, thus difficult to make a conclusive analysis of results.

During the data period, there were 14,678 HIV related hospital admissions (using ICD-10 B20-B24 as primary diagnosis). The analysis is broken down by elective and non-elective admissions and where Healthcare Resource Group (HRG) codes are provided. HRG codes are used to establish the exact cost of care provided by the provider. HRG’s are used to classify clinically similar treatments for costing purposes, e.g., let’s assume an HIV patient is admitted to hospital as non-elective (i.e. emergency) for chronic obstructive pulmonary disease (COPD), a non-HIV related admission. This admission has an HRG code DZ21A. The average cost for this HRG code is £475, meaning that all patients admitted for COPD will consume similar resources with an average cost of £475 [19].
Electives are those where an appointment is made prior to an admission, whereas non-electives are mostly emergency cases. According to Table 3, the highest number of admissions were for HIV diseases resulting in malignant neoplasms, where Kaposi’s sarcoma (B21.0) been the highest with 1,598 elective admissions, costing £6,964,084 (average cost of £4,358). Followed by other types of non-Hodgkin's lymphoma (B21.2), with 1,230 elective admissions costing £4,667,850. Amongst the non-electives, other infectious and parasitic

diseases (B20.8) were the main cause of admission (712), costing on average of £4,142 per admission.

We ran the model for a period of 3 years where all patients are initiated in ART after diagnosis. Even the pessimistic scenario leads to a significant reduction in the number of hospital admissions, i.e. 859 elective and 615 non-elective admissions (a total of 1,474), resulting in a net saving of £5,461,524 (see Figure 3 for a visual inspection of the impact of scenarios). These efficiencies release the pressures on the already stretched NHS services, thus allowing extra capacity for other areas.

5. Discussion

The HIV-MSS tool developed in this article is very timely at a period when services around the world are in intense pressure due to increasing rates of diagnosis and introduction of more effective therapies. Efforts to improve or refine treatment strategies must go together with efforts to managing patient needs, as health services now need to adapt to the very long-term nature of HIV care. This means that health services are not just confronted with the treatment of HIV, but other co-morbidities that arise due to ageing and/or chronic conditions complicated by HIV treatment. Therefore, adapting to the next stage of HIV means a better understanding of needs, now and in the future.

Our management support system is a new tool for planning to support decision making in HIV services. It allows users to predict the impact of a wide range of interventions in a validated computer simulation environment. According to HIV annual data tables [17], we noticed year on year increase in the diagnosed population and the number of people seen for HIV care in the UK (i.e. 5%). So, a scenario based on a 5% increase is tested, to establish the required human resources (known to be the costliest) to ensure effective and timely delivery of care at a CCG level. An increase from a current diagnosed population of 90% to 100%

means that staff needs are expected to increase between 5% and 8%, e.g. 6% pharmacist, 5% pharmacy technician, 8% nurse or phlebotomist, and 6% clinical psychologist. Given that staff shortages and financial pressures are phenomena in the NHS, senior managers would need to effectively plan well in advance. Even a 1% increase on workloads (directly related to treating patients) adds an additional burden on staff, such as filling in forms, taking notes, etc.

We also tested the impact of ART initiation at diagnosis on hospital admissions (for each ICD-10 codes B20-B24), which is also related to long term care of people living with multiple comorbidities. Clearly, a 10% reduction led to a significant number of reductions both in elective and non-elective admissions and net financial savings. The UK has fewer hospitals than most comparable countries with record number of patients waiting to be admitted for other conditions [20]. Reducing hospital admissions is welcomed by the Department of Health, so that capacity is released, thus minimising risks associated with prolonged waiting time for treatment and staff burnout. Note that the model is generic, such that it can be applied to other HIV services in the UK, as all the input parameters can be altered according to service needs.

The paradigm shift in healthcare management is from the provision of more resources, both human and financial, to the judicious use of the available one. This operational research has recognized the gap in our health facilities especially in respect to HIV care by creating a user-friendly model for the effective projection of the possible outcomes in the event of upscaling the currently available resources for HIV care in England.

This management support system would be extremely useful in planning and policy formulation while accessing the global impact of the UNAIDS goal of 95-95-95 by the year 2025, especially if replicated in countries with high burden of the disease and minimal resources.

No research is ever perfect, and our HIV simulation model is no exception. There are several enhancements that can be made, such as adding additional features around prevention, treatment and cost-benefit analysis. For instance, what happens if x% of patients at risk of HIV (e.g. men having sex with men) are on pre/post-exposure prophylaxis (or P(r)EP), and its impact on service utilisation, patient outcomes, future hospital admissions and disease progression. What if a combination of ART treatment regimen (as provided by database of drugs) is tested on patient outcomes, and its impact on disease progression and comparison of treatment? Health economic models (HEC) can be embedded in the simulation model to establish the most effective treatment plan for each patient (personalised medicine). On a similar note, HEC are needed to examine the overall impact of this decision support tool on overall healthcare costs, i.e., cost savings on the management of HIV patients might not necessarily improve overall healthcare costs.

HIV simulation modelling is in its infancy and the implementations of this tool will need a formal a randomized pragmatic trial to confirm its effectiveness in improving patient outcomes, health resource use, and healthcare costs.

Our HIV simulation model is first of its kind, in terms of completeness and complexity, and will enable key decision-makers (e.g. HIV specialists and nurses, service managers) to make informed decisions in terms of their readiness for future patient needs, both operationally and patient outcomes.

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