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# A Step Towards the Standardisation of HIV Care Practices

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**Abstract:** Recent improvements to HIV care at the NHS Lothian Board have concentrated on a re-mapping of the processes involved in their existing Integrated Care Pathway (ICP), in order to incorporate improvements identified during the ICP implementation and consider new advances in care. Our work aims to extend and enhance this mapping by formalising care workflows using our logic-based tool WorkflowFM. This paper presents our progress to date in terms of methodology and initial findings concerning actors, resources and workflows involved in the first 3 months of HIV care for the Chalmers Sexual Health Centre. We argue that the resulting models and analysis could address some of the difficulties faced by units providing HIV outpatient care.

## 1 INTRODUCTION

HIV infection is a major global concern. In 2015, 36.7 million people were living with HIV, and it was the cause of 1.1 million deaths worldwide (UNAIDS, 2016). HIV care is complex and lifelong, which makes the efficient collaboration of multidisciplinary teams at local, regional and national levels important (HIS, 2011). In Scotland, a recognition of the inconsistency of existing HIV services has led in 2011 to the consideration of Integrated Care Pathways (ICPs) as a key priority area within HIV standards (Standard 9 (HIS, 2011)). ICPs are recognised as valuable in the long term management of HIV as a chronic disease, but the particular complexity of the first 3 months of care following diagnosis resulted in a prioritisation of support for developing ICPs for the first 3 months of HIV care across the NHS Boards (HIS, 2013).

An ICP is defined as “a structured chronological, multidisciplinary clinical record, developed by local development groups, to suit a local situation” (SPA, 2016) and NHS Scotland uses the one proposed by the Scottish Pathways Association (SPA). The SPA also points out that an ICP could contain a chronological plan of a patient’s care or treatment, usage protocols, information on guidelines or instructions, sign off sections for allocating responsibilities for entries and variance tracking sections for recording cases when the patient does not follow the usual pathway.

The NHS Lothian Board has been using an ICP

for the first 3 months of HIV care since April 2012 (Wielding et al., 2013). The ICP acts as a map of the patient’s journey through care and was devised through a development process following a recognised methodology (ICPUS, 2007) that involved multidisciplinary HIV care teams – consultants, nurses, pharmacists, other health professionals – and patient representatives. Its creation proceeded mainly through an adhoc identification of the various activities involved in the provision of care and resulted in documents intended to capture a multidisciplinary, chronological and structured case-record for each patient. The developed ICP pathway documents were first used in paper, and since 2014, electronic form.

The development and use of the NHS Lothian HIV ICP helped not only improve and maintain a consistent standard of care amongst patients, but also identify a range of potential improvements to care delivery. These included, for example, routinely checking vaccination status prior to clinic visits, checking results prior to patient attendance, cutting down on redundant documentation and instigating some self-completion of social and mental health status information. Implementing such changes requires an ongoing re-thinking and recording of the flow of processes. This is not uncommon, as ICPs are regarded by the research community as continuous care process improvement interventions (Vanhaecht et al., 2010).

As part of the continuous improvement process, we started a detailed, post-hoc mapping of the work-

flows<sup>1</sup> involved in the ICP in collaboration with the NHS Lothian HIV ICP Development Group. We aim to create and document an unambiguous model of care that is shareable among the HIV team and across NHS boards and can be modified as new policies, guidelines and systems are introduced in HIV care. Ultimately, this model could be the precursor to the systematic design of an adaptable IT system that facilitates documentation, integrates the existing medical record systems, tracks each patient's journey, flags up the tasks that need to be done, and routinely records outputs such as completion rates, timescales etc.

The process of mapping the care processes in the initial ICP in Lothian was iterative and relatively informal: using a map of the pathway and asking multidisciplinary team members to add detail individually or in groups, then reviewing and revising the map and the resulting ICP document over multiple cycles. The aim of the current work is to extend and improve these mapping activities with the use of the process modelling framework WorkflowFM (Papapanagiotou and Fleuriot, 2014). This provides a diagrammatic interface to build process workflows in a formal, systematic way, similar in some respects to other common process modelling languages such as BPMN (Object Management Group, 2011). In addition, though, its logical core helps reduce design errors by providing mathematical guarantees of correctness, systematic accounting of resources and freedom from deadlocks. The resulting workflows clearly depict the modelled practices using a simple graphical notation, can be easily modified to reflect policy changes and can be executed to simulate patient journeys.

The capabilities of WorkflowFM fit well with the process mapping needs of the HIV ICP Development group, as it not only allows a structured, shareable representation of their deployed ICP, but can also help analyse and evaluate potential changes in the ICP before they are applied in practice. We note, in passing (due to space limitations), WorkflowFM's growing track record in the analysis of various healthcare processes. For a more in-depth look, we refer the interested reader to our work on collaboration patterns in healthcare (Papapanagiotou and Fleuriot, 2014) and intra-hospital patient transfers (Manataki et al., 2016).

This paper presents our methodology and progress so far for the Chalmers Sexual Health Centre, one of the largest HIV care providers in Scotland.

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<sup>1</sup>In this paper, we define a workflow as a set of well-defined processes, sequential or concurrent, which take a work task from initiation to completion. Processes can be seen at different levels of abstraction – from single steps, to aggregates of several steps, to even a whole workflow.

## 2 METHODOLOGY

In our approach, we adopt a 3-stage methodology:

1. **Gain an in-depth understanding of HIV care in the organisation** by consulting available documentation, shadowing and interviewing the different involved stakeholders, including clinicians, nurses, administrators and patients.
2. **Use the results of the first step to formally specify the workflows for the existing Lothian ICP, suggest improvements** (e.g. with respect to efficiency or new approaches to patient care) **and propose new formalised ICPs for areas not covered by the current one** using WorkflowFM.
3. **Evaluate the formal ICPs** by re-approaching the participants from Step 1 with a questionnaire about the key processes, exceptions, resources and information used in the workflow diagrams.

At the end of the project, we will thus have a set of validated formal ICPs that can be shared with different HIV care providers to help them re-think their workflows and agree on an improved, up-to-date ICP.

## 3 DATA COLLECTION

The data for this work was collected by going through the existing documentation, consisting of preliminary flowcharts, checklists and tables devised by the NHS Lothian's HIV ICP Development Group, chaired by D. Clutterbuck, a Consultant in Genitourinary and HIV medicine and one of the authors of this article.

In order to gain a range of perspectives on the care processes at play, we interviewed a variety of stakeholders including (other) consultants, nurses, pharmacists and coders. We focused on breaking down the resources (paper or electronic) used, the flow of information, how these depend on the patient and time in their care, and whether the performed activities actually fit the existing records. Interviews were semi-structured for one hour. With the participants' approval in a consent form, interviews were audio recorded, and notes were taken. Once the interviews were transcribed, the data was analysed qualitatively.

## 4 INITIAL RESULTS

### 4.1 The Actors Involved in HIV Care

The main actors involved in HIV care in the Chalmers Sexual Health Centre are nurses, consultants, phar-

macists and clinical coders. The responsibilities of **nurses** vary from doing basic clinical tasks such as taking bloods or doing urine analysis (Band 2, also known as clinical support workers), to giving prescribed vaccines and treatments (Band 5), deciding on treatment and seeing patients independently (Band 6, the majority in Chalmers) and having all of the previous responsibilities but also a leadership role in the management of HIV care (Band 7). **Senior nurses** (Bands 6 and 7) are usually the first point of contact for new patients. They also have **health advisor** roles within their team, and thus can discuss partner notification with patients. Additionally, during the first 3 months of care they act as **ICP Leads**, making sure that the ICP documents are completed within this time. Senior nurses have their own appointments with patients for completing the required elements of care and filling in the ICP documents. **Consultants** are specialist HIV clinicians who see patients for a medical review and decide on their treatment. They work during Monday or Thursday afternoon clinics to see their own patients (6-8 appointments). They may also be contacted about them outside of these clinics. On a rotational basis, they occupy the role of **senior genitourinary medicine (GUM) consultants** covering the clinic throughout the day, which involves being available for consultation with the senior nurses, seeing patients in person for urgent cases (e.g. a patient being unwell), or liaising with the pharmacist regarding emergency medication requests. **Pharmacists** are responsible for medicine reconciliation (i.e. checking what other medication patients are already on, what drug allergies they have and checking for interaction with their ARV regimen), advising patients on treatment options and dispensing drugs. Clinical pharmacists also take part in formal and informal meetings with doctors and senior nurses to decide on HIV treatment initiation and treatment changes, providing expertise on appropriate drug choices, interactions and suitability. During the first 3 months of HIV care, the **clinical coders** are responsible for keeping the computer records up-to-date and consistent and moving information on blood results from electronic form to a paper care plan for pharmacists for weekly meetings.

## 4.2 Resources used

Chalmers currently use two main computer systems to support HIV care: an **Access database**, initially developed for infectious diseases in the Western General Regional Infectious Disease Unit (RIDU), which now also contains forms for the ICP checklists, and the **National Sexual Health System (NaSH)**, a comprehensive patient management system for sexual and

reproductive health which was introduced for clinical care in the Lothian Sexual and Reproductive Health Service in 2011 and adopted for use in HIV care in 2014. Both of the systems are important for HIV care in Chalmers. NaSH is used in all clinics in Scotland for sexual and reproductive health care and facilitates communication with other sexual health clinics, replacing paper records. The HIV database facilitates prescribing and helps ensure that all of the necessary steps for the first 3 months of care have been performed. However, the two systems are not integrated and they contain numerous common fields, thus leading to a lot of duplication. Keeping information up-to-date and consistent between them is time consuming and an ongoing concern. Common fields are often in different formats. Moreover, each of the systems has additional fields and functionality, making information very scattered and requiring clinicians to frequently move between the two systems. To speed this up at regular meetings discussing the management of each patient who is to be seen that week, workarounds have evolved. **Standard patient letters** developed on NaSH have been introduced, containing an overview of the patient's health status, medication, immune status and serology and highlighting any issues or outstanding tasks and gaps in the ICP documentation. These are updated by clinicians after each patient appointment with the primary purpose of forwarding them to the general practitioners (GPs) or using as transfer letters, but also serving as a concise summary of the ICP and its completion during meetings. After each appointment, consultants and nurses also write **clinical note summaries on NaSH**, which are also used in meetings. Moreover, pharmacists use a **paper care plan** when discussing prescriptions, which is pre-populated with blood results and clinical issues from the two systems.

HIV clinicians may sometimes need to consult other computer systems that do not currently communicate with NaSH or the HIV database: **Trak** for demographics, lab results, ordering other tests including imaging, and for onward referral to other specialities (Trak is the main patient management system for hospital services in Lothian, so patients will have a record there if they are seen for other conditions), **Apex** for lab results and **SCCR** for cervical smear test results.

## 4.3 First 3 Months of HIV Care

A patient may enter the HIV care pathway through different means: he/she may be newly diagnosed with HIV – either in Chalmers or in one of the numerous Outreach clinics doing point of care testing in Lothian – or transferred from another HIV health centre, or re-

ferred from their GP. Once he/she enters the pathway, the **ideal workflow** involves the following processes:

1. No matter how he/she entered the pathway, the patient is seen for a **one hour first visit by one of the senior nurses**. Patients who were recently diagnosed in Chalmers are given their diagnosis during this visit. Moreover, all patients have a confirmatory HIV antibody test and other baseline investigations (depending on whether they have done some of them previously) and have an initial discussion with the senior nurse which varies very much case-by-case, but usually is about how they feel, what HIV means to them and how they are going to cope. Very importantly, during the first visit with a patient the senior nurse fills in as much as possible of his/her NaSH record, registers the patient on the database and fills in as much as possible of the ICP checklist from the database together with the patient. The senior nurse must also discuss with the patient about his/her availability and preference for a certain consultant (e.g. some patients may wish to be seen by the same consultant as their partners). This, together with the availability of the consultants and the day of the patient's first visit, will inform the senior nurse's decision regarding the team (Monday or Thursday) and consultant to whom to allocate the patient. A diagrammatic representation of the workflow for the first visit for new patients after they have received their diagnosis is presented in Fig. 1, and will be discussed in subsection 4.4. After the first visit, the senior nurse books an appointment for the patient with his/her consultant (the medical review visit) within the following 2 weeks, when investigation results are back.
2. The patient attends the **first medical review visit**, during which the consultant usually discusses with him/her presenting issues, past medical history, medications, sometimes family history, and decides on a management plan. Depending on the patient, antiretroviral treatment options may also be discussed at this time. The consultant ideally fills in medical fields on NaSH and the database during this discussion. After the visit, the consultant summarizes the discussion in a NaSH clinical note and fills in the standard patient letter from NaSH which, with the patient's approval, is forwarded to his/her GP.
3. If an antiretroviral treatment regimen has been decided, the consultant contacts the pharmacists about the treatment decision or proposed options. One of them will meet with the patient (**pharmacist visit**) within the same clinic to collect information on medications and drug aller-

gies and make a decision on medicine reconciliation. The pharmacist may discuss treatment options with the patient, help him/her make a decision and provide the drugs.

4. For most patients, the baseline assessment and ICP are completed within 3 months of entering the pathway. Appointment frequency then decreases once patients become more stable and their viral load is undetectable (usually within 6 months). For patients who have an undetectable viral load on therapy and do not have significant psychological or social problems or other physical comorbidities, visits then occur every 6 months as part of the organised programme of routine care.

These processes seem mostly sequential and quite straightforward. However, we have marked them as ideal because they only apply to patients who do not require a lot of support, who are at a stage in their disease when things can progress at a normal pace, not needing an urgent medical review, and for cases where emergencies never occur. Moreover, they rely on the availability of staff and patients, and in particular limited numbers of staff and increasing numbers of patients in Chalmers are an issue. In reality, the ideal workflow occurs rarely. More often than not the workflow has variances such as exceptions, optional processes, repeated processes, or processes happening in any order, making it very complex. Such variances are due to the patients' state, need for support and how this evolves over time:

1. Sometimes a senior nurse must make a decision to bypass a patient's first visit in order to have him/her see a consultant sooner. In such situations, the items from the first visit usually need to be deferred to later, one or more, regular (30 minute) appointments with the senior nurse. The most important cases are the following:
  - If a new transferred in or referred patient is found during an initial prioritization before the first visit (by checking the transfer/referral letter or calling the patient on the phone) to be unwell or already taking antiretrovirals and not having enough medication left, the senior nurse will set up an early medical review appointment for him/her with an available consultant.
  - When a patient seems unwell and needs an urgent review when coming in for his/her first visit, the senior nurse contacts the senior GUM consultant to see him/her immediately.
2. Especially if newly diagnosed, a patient may feel distressed and need additional support, and so the senior nurse may need to meet with him/her repeatedly (regular nurse 30-minute visits) after the

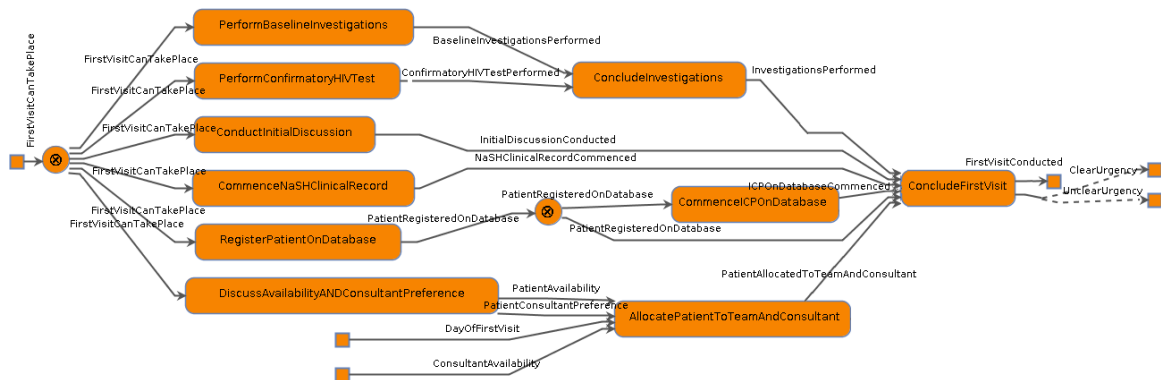


Figure 1: Workflow for the first visit after diagnosis for new patients

first visit. The nurse will usually try to fit such subsequent appointments in the same day with the patient’s medical review visit with the consultant, but this is not always possible.

3. Following a senior GUM consultant visit, or the first visit with the senior nurse, depending on his/her state a patient may require an early review appointment (occurring earlier than the default 2 weeks) to be booked with a consultant.
4. Following a medical review visit, a consultant may decide that early follow-up appointments are necessary, e.g. if the patient has abnormal results, medical issues, mental issues, is vulnerable, has comorbidities that affect his/her immune status or will require an STI screen or vaccination.

Another important exception is given by the fact that senior nurses often do not manage to finish filling in all of the relevant parts of the NaSH and ICP checklists from the database during first visits. In this case, they need to, sometimes repeatedly, book additional routine nurse appointments with the patients.

The steps required for filling in information on the systems are, actually, often performed in an order which depends on the patient’s state and needs, and earlier or later within the actual visits, which makes them optional at different times. Although there is an expectation for consultants to fill in some information on the systems, we have found that this is not done consistently, as they prioritise patient care. Some have expressed their concern about the unclear sharing of responsibility for filling in the ICP checklists, and the lack of time to do this during an appointment.

Another less frequent exception is given by the case of patients whose level of urgency for being seen for a medical review is not completely clear to the senior nurse after their first visit. In such circumstance, the senior nurse first discusses with a consultant before booking subsequent appointments for the patient.

Apart from the work directly involving patients, there is also important background work happening in Chalmers during the first 3 months of care. In particular, the two Chalmers HIV teams, the Monday and the Thursday team, meet every week to discuss the management of the patients who are scheduled in clinic that week, and to check progress with the ICP. Patients are discussed in turn, using the NaSH summary page (projected onto a screen from the system), the pharmacists’ care plan with pre-filled bloods and clinical details and their printed provisional prescriptions. If a patient’s status is not clear or more up to date information is needed, the team may also browse through clinical notes or other pages from NaSH, the HIV database and even other systems such as Apex. Once a week, clinical coders move any additional information from NaSH onto the ICP checklists from the database. The ICP leads (senior nurses) check progress with the ICP checklists on the database for each patient and flag up missing information before the meeting during their admin time. They may use clinical notes to remind consultants to fill it in. Once information of a form is complete, they sign it off.

#### 4.4 Rigorous Workflow Modelling

As mentioned previously, we model and compose the workflows involved in the first 3 months ICP using WorkflowFM, a graphical tool built on top of logical foundations. Processes in WorkflowFM are represented visually as rectangles, and their inputs and outputs as edges. An example diagram of the workflow for the first visit for new patients after they have received their diagnosis is provided in Fig. 1.

In this, one can clearly identify processes that are independent and can therefore be performed concurrently, in any order. For example, once the patient attends for the first visit, the senior nurse can perform different investigations, have an initial discus-

sion with the patient, commence the NaSH clinical record, register him/her on the database or discuss his/her availability and consultant preference in any order. The priority of these steps is influenced by the patient's particular state and needs.

Other processes must be performed sequentially, as they are dependent on the ones preceding them. For example, only once the senior nurse registers the patient on the database can he/she commence the ICP on the database together with the patient. Also, the patient's availability and preference for a certain consultant partly influences the senior nurse's decision to allocate the patient to a certain team and consultant.

The final output of the workflow is the completion of the first visit and the evaluation of the level of urgency of the patient's state. The senior nurse may not be able to clearly determine this, in which case (marked as `UnclearUrgency`) he/she will need to discuss the case with a consultant before booking any other appointments (as described in subsection 4.3).

WorkflowFM allows an executable deployment of the developed models for both simulation and use in practice. Simulation enables further analysis of the workflows with respect to the available resources on site (including clinical workload), acceptable completion rates, costs, conflicts across multiple pathways, etc. The models can also be deployed to support the ICP through rigorous tracking of information and resources and automatically generated checklists for each step. This provides a skeleton for a larger system that can also integrate with the NaSH clinical record system, provide decision support, and send notifications and reminders to guide users through the ICP. We view this as a promising way of taking our work further once we conclude the evaluation of the ICPs (Step 3 of our methodology – see Section 2).

## 5 CONCLUSION

This paper described our progress towards formally re-mapping the integrated care pathways for the first 3 months of HIV care at the Chalmers Sexual Health Centre. Our study showed that the most important difficulty faced by HIV specialists is the requirement to continuously check and update information on several non integrated systems. This leads to inefficiency, frustration and burdens them with the need to ensure consistency in order to avoid errors. We believe the formal models we have developed using our logic-based tool WorkflowFM are not only a key first step towards addressing these core issues and optimizing current practices, but also offer a coherent, readily adaptable blueprint for designing and imple-

menting an effective IT support system for HIV care at Chalmers and beyond.

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## REFERENCES

- HIS (2011). Human immunodeficiency virus (HIV) services - standards. Technical report, Healthcare Improvement Scotland.
- HIS (2013). HIV implementation and improvement programme. [http://www.healthcareimprovementscotland.org/our\\_work/long\\_term\\_conditions/hiv\\_treatment\\_and\\_care/hiv\\_icp\\_implementation.aspx](http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/hiv_treatment_and_care/hiv_icp_implementation.aspx).
- ICPUS (2007). Integrated care pathway users in Scotland – A workbook for people starting to develop integrated care pathways. Technical report.
- Manataki, A., Fleuriot, J., and Papapanagiotou, P. (2016). A workflow-driven, formal methods approach to the generation of structured checklists for intra-hospital patient transfers. *Journal of Biomedical and Health Informatics*.
- Object Management Group (2011). Business Process Model and Notation (BPMN), version 2.0. <http://www.omg.org/spec/BPMN/2.0/PDF>.
- Papapanagiotou, P. and Fleuriot, J. D. (2014). Formal verification of collaboration patterns in healthcare. *Behaviour & Information Technology*, 33(12):1278–1293.
- SPA (2016). What is an integrated care pathway? Technical report, Scottish Pathways Association.
- UNAIDS (2016). AIDS update. Technical report, Joint United Nations Programme on HIV/AIDS.
- Vanhaecht, K., Panella, M., Van Zelm, R., and Sermeus, W. (2010). An overview on the history and concept of care pathways as complex interventions. *International Journal of Care Pathways*, 14(3):117–123.
- Wielding, S., Clutterbuck, D. J., Wilks, D., and Pantou, L. (2013). Development of an ICP for HIV outpatient care in Lothian, Scotland. In *European Care Pathways Conference Glasgow*.