ELFIN - AN ONTOLOGY-BASED HEALTH RECORD FOR THE FRACTURE LIAISON SERVICE

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ABSTRACT

This paper describes the implementation of an ontology-based Electronic Health Record for clinical management and reporting in a Fracture Liaison Service. The system, called Elfin, was first implemented in live practice at the Nuffield Orthopaedic Centre, Oxford, in 2014. Elfin uses the model-driven cityEHR open source health record system and was originally developed using an agile methodology (iterative and user-centered). It was then iteratively refined in response to user feedback on the live implementation. In 2021, a second version of the system was developed (Elfin2) using a new specification of the underlying clinical information model and incorporating feedback and lessons learned from the first implementation. Elfin2 has never been introduced into live operation but the original Elfin has continued in live use and was more formally evaluated in 2025, in preparation for the development of Elfin3 which includes the additional design goal of creating a system that can be used in any international setting.

KEYWORDS

Fracture Liaison Service, ISO 13606, Ontology, HL7 CDA. Agile Scrum Methodology, Model-Driven Development

1. INTRODUCTION

Weakening of the bones (loss of bone density) increases the risk of fragility fracture – a fracture following a low-energy trauma such as a fall from standing. Bone density can be measured using a dual-energy X-ray absorptiometry (DXA) scan, and osteoporosis is diagnosed in patients whose bone mineral density (BMD) at the hip falls lower than 2.5 standard deviations from the mean, as measured in a population of healthy young adults of the same sex (Kanis, 2002). The risk of fracture can be calculated using the FRAX assessment tool (McCloskey, et al, 2022) which takes into account the BMD and other factors such as age, family history and lifestyle

The Fracture Liaison Service (FLS) was pioneered as a clinical service in Glasgow, Scotland, starting in 1999 (McLellan, et al, 2003). An FLS identifies patients after a fragility fracture, assesses their risk of suffering further fractures, makes treatment recommendations to reduce the risk and monitors compliance to the treatment.

Elfin is an Electronic Health Record (EHR) designed to support the clinical and administrative practice of the FLS at the Nuffield Orthopaedic Centre in Oxford, England. The system was developed following a

public procurement for development of a prototype to investigate and address the needs for an information system to support secondary fracture prevention in the South Central region of the National Health Service (NHS) in England, where considerable variations in care could be observed (Drew,. Et al, 2014). The procurement started in January 2012 and resulted in a contract to deliver a Vision Document and working prototype, which were developed using an iterative process from July to December 2012.

The Elfin prototype was an EHR that used a clinical information model for the FLS supporting the basic care pathway shown in Figure 1, including the generation of letters (clinical correspondence) for communication between the FLS, the patient and their primary care physician. The prototype was refined in response to further user feedback during the first half of 2013 and in the second half of that year was loaded with live data for existing patients that had previously been held in a Microsoft Access database running on a local PC within the FLS.

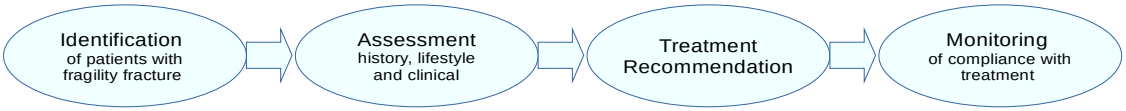

Figure 1. Basic Care Pathway supported by Elfin

A pilot of the system went live in early 2014 with two users and the first Elfin system was live with the full group of users (approximately eight) in the first quarter of 2015. A second version of the system, Elfin2, was developed in 2021, but was not introduced into live service. The original Elfin remains in live operation through 2026, with over 30,000 patients in its database and an archive of a further 8,000.

The remaining sections of this paper describe the iterative development and evaluation of the first Elfin prototype, further refinement of the live system in response to user feedback and new requirements for national-level reporting, the development of Elfin2 in preparation for international deployment, and the new features of Elfin3 that are being developed using feedback from a more formal user evaluation.

2. METHOD

2.1 Iterative Model-Driven Development

Elfin was developed using the open source, model-driven cityEHR platform (Chelsom et al, 2013) which follows the design principles of the ISO 13606 standard for structured health records and the associated openEHR initiative (Kalra, et al, 2006). The clinical information architecture of cityEHR is realized as an ontology, represented in OWL/XML (Hitzler, et al, 2009) and incorporating the basic structure of a generic health record using the components defined by ISO 13606.

The information architecture of cityEHR is used to build clinical information models, which are also held as OWL/XML ontologies but are developed using spreadsheets that are transformed to the ontology representation. The patient records are stored as XML using the HL7 CDA standard, which is closely aligned with the structure of ISO 13606 (Schloeffel, et al, 2006) meaning that HL7 CDA templates can be generated directly from the ISO 13606 ontology model.

The Elfin prototype was developed using the agile Scrum methodology (Takeuchi and Nonaka, 1986), with six, one month 'sprints'. Sprint review/planning meetings were held with a full range of stakeholders, including nurses, administrators, rheumatologists and general practitioners. The primary objective was to develop the clinical information model for the FLS, but early iterations also led to updates of the ontology architecture and underlying cityEHR framework, when requirements were elicited that could not readily be implemented using the architecture and framework as they existed at the start. By the time the system was fully live, the underlying information architecture had been fixed, so that later iterations resulted only in changes to the information model, as shown in Figure 2. An advantage of the model-driven approach is that small iterative changes to the model can continue even once a system has entered live operation, subject to a robust process of quality assurance, release and versioning.

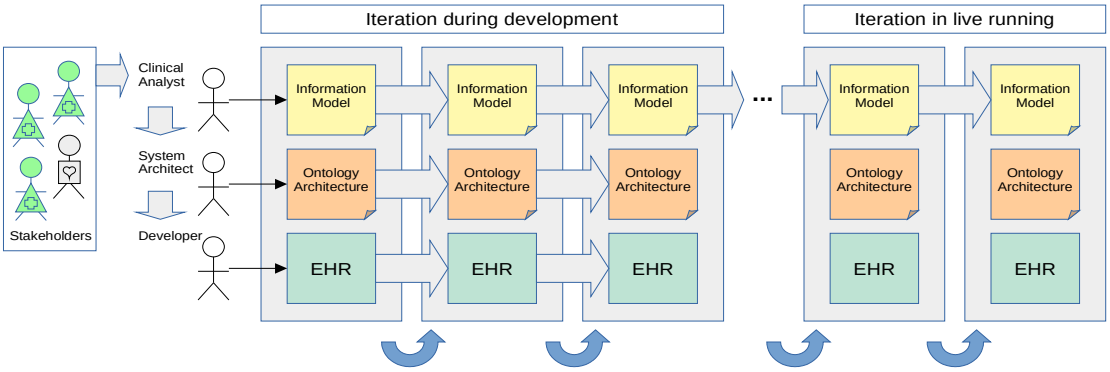

Figure 2. Iterative Development of the Elfin Prototype and Live System

2.2 Refinement in Response to User Feedback and Changing Requirements

Once Elfin had been fully rolled out, two major enhancements were made in response to feedback from users and to a new requirement for national level reporting.

Users reported that the registration of new patients was unnecessarily time consuming because all patient demographics and details of their general practitioner (primary care physician) needed to be entered manually. In response to this feedback a new feature was added to cityEHR whereby any entry in the information model can be designated for lookup in a directory, based on the value entered for a single key data value, rather than being entered manually. The directory look-up can then be configured to search a directory of entries loaded to the cityEHR database itself or to submit the search to an external web service which returns matched entries in HL7 CDA format. For Elfin, the look-up of patient demographics is made from a web service that accesses the main hospital health records (which in turn access demographics on the national-level Patient Demographics Service); look-up of details for the general practitioner is made from an internal directory that is imported from the national NHS register.

The second major enhancement was made after a national reporting service, the Fracture Liaison Service Database (FLS-DB), was introduced to the NHS in 2016 to audit and report on the performance of participating services and to provide an information source for clinical studies (Javaid, et al, 2022). To meet this requirement, new reporting features were added to cityEHR and configured to generate FLS-DB reports, as shown in Figure 3. Data entry is constrained by Elfin's clinical information model, as is the formulation of cohort searches which can use any combination of data to define the phenotype of a cohort, for example patients suffering particular types of fracture in a specified time period.

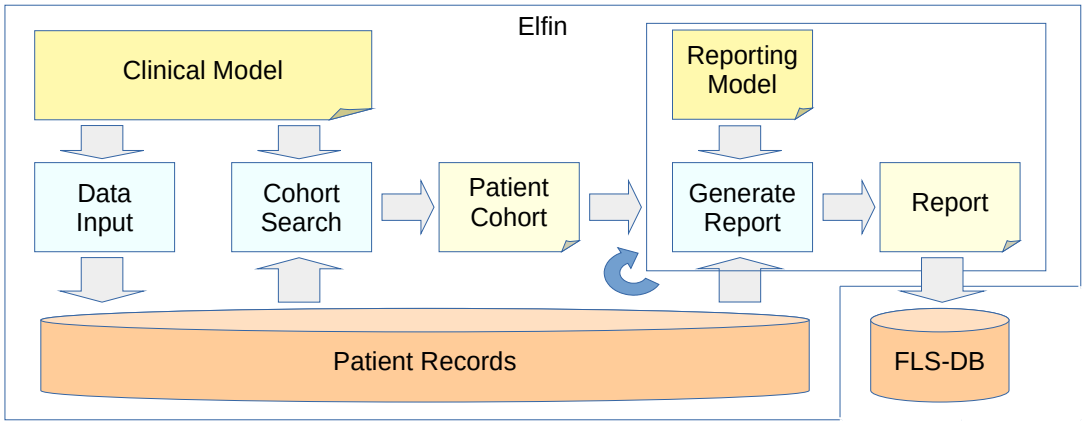

Figure 3. Generation of reports for upload to the FLS-DB

Reports are generated using a different information model which specifies how each data value in the report for an individual patient is derived from combinations of data in the clinical model. Iterating through the cohort, the report for each patient is loaded, the data are calculated and the results are exported cumulatively to build the complete report as a spreadsheet of over 50 fields that is required by the FLS-DB. A typical quarterly report contains records for 300 to 400 patients and the spreadsheet is uploaded manually to the FLS-DB web site (FLS-DB, 2025).

By using this approach, the original clinical model remained largely unchanged, and the report calculations were confined to the reporting model. However, the process of iterating through hundreds of patients, performing multiple calculations to generate the report for each one and then aggregating the results to produce the complete report requires intense processing and means that report generation is quite slow.

2.3 Development of Elfin2

A second version of the system, Elfin2, was developed primarily to support a new clinical information model that had been created to streamline the capture of FLS data in a wider variety of services, including in international locations. This model reduced information that was not essential to the basic operation of the FLS and more directly represented information that was to be reported to the FLS-DB, so that the generation of reports was based more on data that were directly recorded, and less on data that were calculated or derived. Any calculations that were still necessary for reporting were performed at the time the original clinical data were entered and then stored in the patient record. The reports could then be generated more quickly, since additional calculations were no longer required. This new model also opened the possibility of generating reports using a simple database query, since all the required data were already available in the stored record.

In preparation for potential international deployment, Elfin2 was built using a new version of cityEHR which added support for language variants of the base clinical information model, meaning that the same structure of clinical information could be gathered using variants of the model presented in the local language and following local adaptations of the care pathway (Chelsom, et al. 2024).

2.4 Formal Evaluation of Elfin

The Elfin2 system was not deployed in live operation, but the original Elfin system continues to be used in the Oxford FLS and underwent a more formal evaluation in 2025 as part of a wider user survey conducted to discover the existing practices and requirements for information systems in an FLS, as perceived by end users. A survey was designed with 15 top level questions and 135 unique responses, and was sent to a total of 85 FLS system users in the UK and other countries.

The FLS systems ranged from simple spreadsheets through to more sophisticated health record systems, such as Elfin. Although not specifically developed as an evaluation of Elfin, six Elfin users participated in the survey and analysis of their responses to three key questions provided useful insight into the development of a third iteration of the system, Elfin3:

- agree or disagree (on a six-point scale) with 20 statements regarding the acceptance and use of the existing FLS information system;
- state whether the existing FLS information system supports ('yes', 'no' or 'to some extent') a list of 57 possible features;
- grade the importance of 20 possible features in an 'ideal' FLS information system, on a scale of 1 (not important) to 6 (very important).

3. RESULTS

Survey responses from the Oxford FLS team are indicative of a service operating across a fragmented digital landscape. When reporting on current system capabilities, the following were reported as missing features:

1. Automated monitoring reminders
2. Integration of data from other systems (DXA, lab results)
3. Advanced reporting and dashboard functionality
4. Automated uploads to FLS-DB

Interestingly, the first of these 'missing features', automated monitoring reminders, is actually available in the system, which indicates a lack of adequate user training, rather than a deficiency in the Elfin system itself.

Evaluation of current system capabilities shows that several key functions (including integration of DXA and lab results, automated monitoring reminders, custom reporting, and streamlined FLS-DB uploads) are only partially functional or absent, yet these same features were rated among the most important for an ideal system. The clear conclusion is that the service is clinically robust but digitally constrained, with staff effectively acting as the integration layer between systems, representing a significant opportunity for efficiency gains through targeted interoperability and workflow automation. However, the lack of some features, particularly integration with other systems, is not due to inherent lack of capability in Elfin, but due to lack of budget available for the services work required to implement such integration.

The full results of the user survey will be published at a later date, but analysis of the responses from Elfin users, and comparison with the responses from users of other systems, provided useful input to the formulation of design goals for Elfin3. This third iteration is being developed with a revised information model specified and published by the Oxford FLS and the latest version of the cityEHR platform, which incorporates some new features developed as a direct response to the feedback from the user evaluation:

- the information architecture supports orders, appointments and prescriptions
- extended support for graphical data entry
- letter templates developed and configured locally, by system administrators
- enhanced tools for internationalization
- built in, context sensitive help
- local configuration of help and explanation of the clinical information model
- scheduling of automated report generation
- enhanced import and export, including scheduling of automated import/export

4. CONCLUSION

The use of a model driven, standards-based, EHR platform (cityEHR) facilitated the iterative development of the first Elfin prototype and enabled iterative enhancements to the system over several years, based on continuous informal feedback from users and other stakeholders. Although such evolution of a model-driven system is possible, the need to retain backwards compatibility of the model imposes a limit on the extent of evolution; eventually it becomes necessary to create a new, refactored, model and to migrate the existing data to that model.

Similarly, the onward development of the underlying cityEHR platform has required additions to the information architecture underpinning the models. This means that support for new features in the most recent releases would also require migration of the historic data currently stored in Elfin. Whilst it would be technically feasible to do this, there is not a budget to fund the services work required. This could be viewed as a wider issue for open source EHR systems; they provide a cost effective software solution, but still require funding of the services work for development and deployment, particularly to implement interfaces with other digital systems.

Elfin2 was developed on the basis of informal feedback and evaluation of the original system. A more formal evaluation with Elfin users, and a comparison with responses from users of other FLS information systems, provided the input to the design goals of Elfin3, which is aimed at deployment in different international settings. Although the experience with Elfin at the Nuffield Orthopaedic Centre has been invaluable in the development of Elfin2 and Elfin3, budget constraints mean they are more likely to be deployed at other, green field, sites than to replace the original Elfin system in Oxford.

REFERENCES

Beale, T., 2002, November. Archetypes: Constraint-based domain models for future-proof information systems. In OOPSLA 2002 workshop on behavioural semantics (Vol. 105, pp. 1-69).

Chelsom, J., et al, 2013. Clinician-led development of electronic health records systems. In Enabling Health and Healthcare through ICT (pp. 3-8). IOS Press.

Chelsom, J., et al, 2024. An Ontology-Based Architecture to Support Language Variants of Model-Driven Electronic Health Records. Studies in health technology and informatics, 310, pp.139-143.

Chesser, T.J., et al, 2022. Overview of fracture liaison services in the UK and Europe: standards, model of care, funding, and challenges. OTA International, 5(3S), p.e198.

Conlon, B., et al, 2025. The development and implementation of a digital platform in a fracture liaison service. Archives of Osteoporosis, 20(1), pp.1-5.

Dockery, F., et al, 2022. Fracture liaison services in Ireland—how do we compare to international standards?. Osteoporosis International, 33(5), pp.1089-1096.

Drew, S., et al, 2014. Describing variation in the delivery of secondary fracture prevention after hip fracture: an overview of 11 hospitals within one regional area in England. Osteoporosis international, 25, pp.2427-2433.

FLS-DB, 2025. The Fracture Liaison Service Database (FLS-DB). Accessible at: https://www.rcp.ac.uk/improving-care/national-clinical-audits/falls-and-fragility-fracture-audit-programme-fffap/fracture-liaison-service-database-fls-db/

Javaid, M.K., et al, 2022. Subsequent hip fractures in patients identified by a Fracture Liaison Service (FLS) in England and Wales–linkage of the national FLS and Hip Fracture databases. medRxiv, pp.2022-01.

Kalra, D. and Ingram, D., 2006. Electronic health records. In Information technology solutions for healthcare (pp. 135-181). Springer, London.

Kanis JA, 2022. Diagnosis of osteoporosis and assessment of fracture risk. The Lancet. 2002 Jun 1;359(9321):1929-36.

McCloskey EV, et al, 2002. Fracture risk assessment by the FRAX model. Climacteric. 2022 Jan 2;25(1):22-8.

McLellan AR, et al, 2003. The fracture liaison service: success of a program for the evaluation and management of patients with osteoporotic fracture. Osteoporosis international. 2003 Dec;14:1028-34.

Mitchell, P.J., 2022. Fracture liaison: a crucial tool in the fight against fragility fracture. Maturitas, 165, pp.26-32.

Paccou, J., et al, 2023. Effectiveness of fracture liaison services in osteoporosis. Joint Bone Spine, 90(5), p.105574.

Schloeffel, P., et al, 2006. The relationship between CEN 13606, HL7, and openEHR. HIC 2006 and HINZ 2006: Proceedings, 24.

Takeuchi, H. and Nonaka, I., 1986. The new new product development game. Harvard business review, 64(1), pp.137-146.

Walters, S., et al, 2017. Fracture liaison services: improving outcomes for patients with osteoporosis. Clinical interventions in aging, pp.117-127.