Visualising patient pathways and identifying data repositories in a UK neurosciences centre

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Abstract

Background: Health and clinical activity data are a vital resource for research, improving patient care and service efficiency. Healthcare data is inherently complex, and its acquisition, storage, retrieval, and subsequent analysis require a thorough understanding of the clinical pathways underpinning such data. Better use of healthcare data could lead to improvements in patient care and service delivery. However, this depends on the identification of relevant datasets.

Objective: We aim to demonstrate the application of Business Process Modelling Notation to represent clinical pathways at a UK neurosciences centre and map clinical activity to corresponding data flows into electronic health records and other non-standard data repositories.

Methods: We used Business Process Modelling Notation (BPMN) to map and visualise a patient journey and the subsequent movement and storage of patient data. After identifying several datasets which were being held outside of the approved applications. We collected information about these datasets using a questionnaire.

Results: We identified 13 approved applications where neurology clinical activity was captured as part of the patient's electronic health record including applications and databases for managing referrals, outpatient activity, laboratory data, imaging, and clinic letters. We also identified 22 distinct datasets that were not approved by the hospital and were created and managed within the neurosciences department, either by individuals or teams. These were being used to deliver direct patient care and include datasets for tracking patient blood results, recording home visits, and tracking triage status.

Conclusions: Mapping patient data flows and repositories allowed us to identify areas in which the current EHR is not fulfilling the needs of day-to-day patient care. Data that is being stored outside of approved applications represents a potential duplication in effort and risks being overlooked. Future work should identify unmet data needs to inform correct data capture and centralisation within appropriate data architectures. Clinical Trial: Not Applicable

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Keywords: Health data; NHS; Neurology; Business Process Modelling Notation (BPMN).

Introduction

In the UK the National Health Service (NHS) is the largest healthcare provider and as such it holds a large amount of complex and sensitive data. A recent paper mapped NHS data flows at a national level, highlighting its scale and complexity, with a lack of transparency, duplication of datasets and failures to follow best practices for data safety, as well as the need to ensure the capability for electronic health record data extraction [1]. Key reports released in the last few of years have identified that better use of routine NHS data could lead to improvements in patient care, service delivery, research and innovation, but that the NHS faces a number of challenges including a lack of suitable data infrastructure [2,3]. One proposal arising from these papers was the development of national and subnational secure data environments (SDEs). The development of SDEs is ongoing and they will allow previously separate datasets to be accessed as one database. However, the utility of SDEs relies on the data uploaded to them, which is dependent upon engagement of stakeholders and the availability of appropriate infrastructure [1].

In this paper we use Business Process Modelling Notation (BPMN) to map data flows and data repositories within neurology services at a regional neurosciences centre. BPMN is a visual modelling language, primarily used in business analysis, which follows a standardised grammar for depicting workflows. There are two stages to BPMN, the creation of a visual workflow and the execution of that workflow as an automated process. Here we focus on the first stage of creating visual process diagrams using the BPMN grammar to understand how patient data is used, stored, and disseminated. We aim to highlight the complexity of these processes, to identify any data repositories which are kept outside of the centralised EHR and allow for future improvements in data capture by identifying where unnecessary effort is being made. The benefits of using BPMN over other flowchart systems include that fact that is it easily understandable, standardised, and flexible [4]. Within a healthcare setting BPMN has been used to model clinical processes, patient trajectories and hospital protocols, and there have also been attempts to create healthcare specific extensions to the BPMN grammar [5].

Methods

The study was conducted at Lancashire Teaching Hospitals NHS Foundation Trust, a large NHS Trust in the northwest of England providing secondary and tertiary services to a population of 1.5M in Lancashire and South Cumbria, including the regional neurosciences centre.

We formed a multidisciplinary team consisting of a lead clinician (HE – a consultant neurologist), a data scientist (FB) and a patient pathway coordinator. The initial goal of this team was to identify patient pathways and the data flows and storage associated with them. Three potential pathways were explored, including an outpatient pathway with a patient referred on a standard NHS 18-week timeline, an outpatient pathway where a patient was referred directly to diagnostic scanning as the referring clinician needed to exclude cancer, and an inpatient pathway. Initial flowcharts were drafted by this team which allowed the identification of areas in which more information was required. These informal diagrams were then translated into BPMN diagrams using the formalised grammar and notation.

We then consulted with staff from different departments to identify the details of the patient pathway and the relevant data flows and storage. We identified three key areas of discussion – how data was received by the department, how the department used and stored data when treating patients, and how data was disseminated to other departments or to the patient/GP. The departments consulted included neurology subspecialties such as neurophysiology, and specialist nurse teams for motor neurone disease (MND), Parkinson's disease and epilepsy, as well as departments outside of direct neurology care including radiology and phlebotomy as neurology patients are often sent to these services for diagnostic testing. Following on from these discussions the BPMN diagrams were updated to include the detail of the movement of data to, from and between departments.

As well as identifying the movement of data relating to neurology patient care, we also identified where this data was being stored. There are several approved applications used by the hospital including an EHR as well as specialised systems for the collection and dissemination of complex data such as imaging results. We tracked the usage of these applications in the BPMN diagrams, but we also collected information about data storage outside of these approved systems. We were able to identify several separate spreadsheet and text files and other electronic data which were being used to directly enable patient care.

The final step after completing the BPMN diagrams and identifying data repositories was to collect information on the data being stored outside of the approved applications. For this we used a simple questionnaire to request information from departments on the location of the dataset, the individual data fields collected, the purpose of the data, and how and where it is stored (See Appendix).

Results

BPMN was successfully used to visualise the patient pathway and the movement and storage of data. A simplified example of a diagram created for neurology outpatients can be seen in Figure 1. The original, more complex, diagrams can be found in the multimedia appendix. A description of BPMN terminology and how to read the diagrams can be found in Textbox 1. We used subprocess within the BPMN diagram to simplify the presentation, and these are denoted by a plus symbol within the task box. An example of the subprocess created for ordering tests from imagery is shown in Figure 2. For completeness all process diagrams that were created as part of this project are available for viewing in the Multimedia Appendix.

Figure 1: A simplified BPMN diagram showing the patient journey through neurology services, and the corresponding points of data transfer and storage.

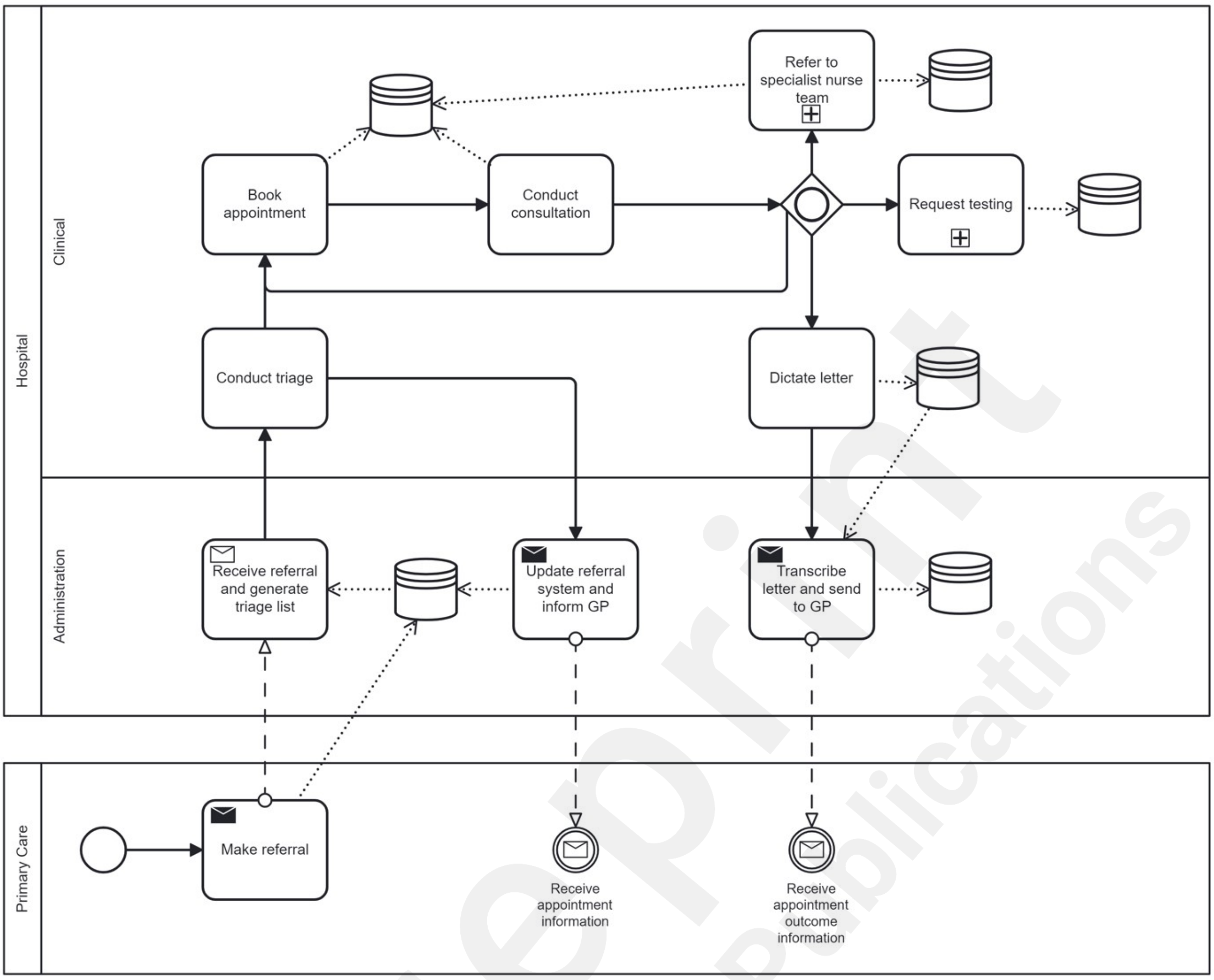
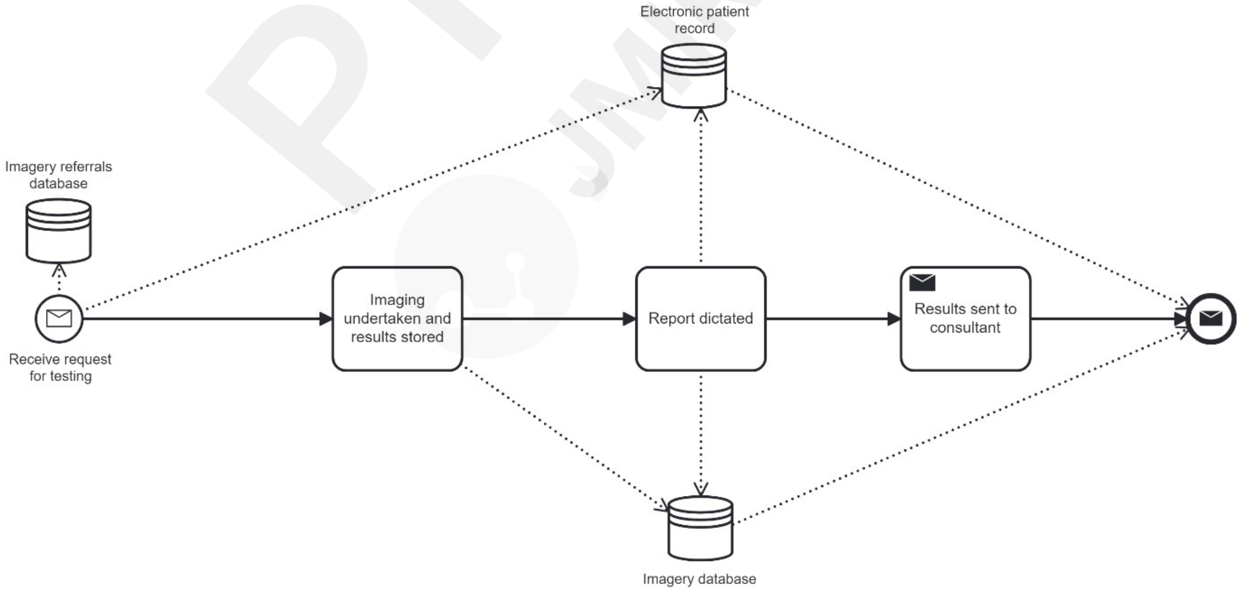


Figure 2. A BPMN diagram showing a subprocess. This subprocess represents the flow of data to, through and from diagnostic imaging services.



Textbox 1. A brief guide to BPMN terminology.

BPMN symbols:

- Rectangles represent tasks.
- Rectangles containing a plus sign represent subprocesses which contain behind them their own process diagrams (see subprocesses below)
- Cylinder icons represent data storage.
- Envelope icons represent messages and data being sent or received.
- Diamond icons represent decisions or ‘gateways’.

For more information on the BPMN protocols please refer to the BPMN 2.0 symbol reference guide by Camunda [6].

Subprocesses:
Behind each subprocess is at least one separate process diagram. For example, the task box ‘request for testing’ has several subprocesses linked to it including separate process diagrams for requesting imaging, bloods, genetic testing lumbar puncture and so on.

Reading the diagram:
The process outlined in Figure 1 starts with a circle in bottom left with the patient’s decision to seek healthcare. The process can then be followed by the direction of the arrows. The first decision point (diamond symbol) comes from the GP, and there are three possible outcome of this decision – to refer to the hospital via electronic referral, to refer to the hospital via a direct to scan referral (a separate subprocess as denoted by the plus symbol within the task box), or a decision not to refer. If the GP decides not to refer the patient the process ends with a bold outlined circle.

We identified 13 approved applications where neurology clinical activity was captured as part of the patient's electronic health record, and these were backed by independent, vendor-provided databases with minimal integration with the core electronic patient record software. These included separate applications (and databases) for managing referrals, outpatient activity, laboratory data, imaging and other diagnostics, prescribing and pharmacy and clinic letters. We also identified 22 distinct datasets that were not approved by the hospital and were created and managed within the neurosciences department, either by individuals or teams. The majority of these were stored as Excel spreadsheets with a few Word documents. There was no consistent or agreed structure to these datasets. They are being used by individuals or teams to enable them to deliver direct patient care, and include datasets for tracking patient blood results, recording which patients are enrolled in trials, recording home visits, monitoring patients with certain conditions or who are on particular medications, and tracking triage status. Table 1 shows the types of data category contained in these datasets and the frequency with which those categories are stored. The table shows all data categories that appear in more than one dataset. Other categories that appear in only one dataset include patient telephone number, next of kin, triage decisions and other miscellaneous information. Most of the datasets are stored as excel spreadsheets with one patient represented per line, however, some of the data is stored in other ways, for example in separate word files for each patient, or in excel but with a separate tab for each patient.

Table 1. The categories of data that were found in the datasets stored outside of approved applications.

Data Category Recorded	**Number of datasets in which it appears**
Patient Name	22
NHS number	17

Medication	12
Diagnosis	11
Hospital Number	9
Outcome of patient contact/appointment	8
Address and/or postcode	7
Date of patient contact/appointment	7
Responsible consultant(s)	7
Planned follow up interval or date	7
Relevant Medical History	5
Date of Birth	5
Date of death	4
GP	3
Gender	3
Referral to other services	3
Planned interval or date for testing	3
Test results	3
Date referral received	3
Intervention start and end dates	3
Date of diagnosis	3
Co-morbidities	2
Patient referral source	2

Discussion

BPMN has been previously used to model clinical pathways, and we have used a similar approach in this paper to model and understand the data flows and storage that arise alongside the patient pathway. One of the first appearances in the literature of BPMN related to healthcare was a 2008 conference paper demonstrating how to apply BPMN to a pathology process [7]. The authors conclude that using BPMN allowed easy communication of the process, early detection of errors and could lead to future improvements in the process. Since this early adoption many other have gone on to apply BPMN to healthcare. For example, comparing BPMN with accepted standards for depicting hazardous drug workflows [8], using BPMN for modelling national healthcare guidelines [9], translating FHIR plans into BPMN diagrams [10], and modelling cross-sector healthcare quality indicators [11].

We used BPMN to visualise the patient pathway and identify data flows and repositories, highlighting the volume and complexity of the data generated by and used within neurology services. This study has shown that there are numerous datasets being stored outside of the hospital's approved applications which raises concerns about duplication of effort and the need to ensure that this data is being captured by central systems and therefore included in any data uploaded to a Secure Data Environment. This study gives us an understanding of where datasets are stored, how the approved applications are being used, and an insight into why data may not always be stored in those systems.

We found that the further a patient is removed from inpatient services, the less well the EHR and other approved applications worked for recording their care. EHRs and related systems are often designed around inpatient episodes. However, outpatient care is structured differently, clinician interaction with the EHR is also time pressured, and the EHR doesn't necessarily do the things that are required for patient care, such as tracking which patients are still waiting for test results. This leads to individual clinicians creating their own records and spreadsheets, which are necessary for patient care, but are potentially duplicating data and are stored in decentralised repositories disconnected from the EHR. This is particularly noticeable within the teams who treat patients in the community, and who find it necessary to create their own data repositories for activities such as tracking home visits, and equipment ordering.

The need to use datasets outside of the approved applications for data capture and patient tracking has arisen from the evolution of data practices from previous paper-based systems and the essential need to facilitate the delivery of clinical care. Often the EHR and other systems commissioned by the hospital do not work for all situations, and clinicians are left in a position where they need to implement their own system in order to provide the care the patient needs. To improve the design and architecture of future EHRs, and ensure the correct data is captured by SDEs, it is essential to understand why the EHRs are currently not providing the capability required, and what steps need to be taken to ensure that future platforms are fit for purpose. This paper has taken a first step in this direction, but more work needs to be done to ensure that data systems are functional, and that data is being properly captured.

In this study we found that data was being kept outside of the approved applications, but we were not able to explore or quantify how much data is being stored in this way. It is possible that the data being held in spreadsheets and text files is a duplicate of data already held in the EHR, in which case this represents an inefficiency in the system. However, it is also possible that the data represents information which is not being captured in the EHR, in which case it is important to capture this to ensure that all patient data is available for patient care and for transfer to SDEs. If data is being captured in more than one place this also raises questions about what happens if the data differs between different systems, for example if a patient record in the EHR shows one date of birth and a record within a clinician spreadsheet shows a different date, which should be trusted? Having multiple sources of data storage increases the likelihood of there being such discrepancies.

With regard to the specific needs of the neurology department within this hospital, this paper has highlighted areas where there are commonalities in processes within different parts of the neurology pathways. This knowledge could lead to improved understanding of where efficiencies can be achieved. For example, we noted that the six specialist nurse teams all have different ways of capturing data, but the way in which patient data is communicated to them could be standardised. This would allow for a more streamlined and efficient approach.

Although this paper focuses on one specialty in one hospital the work presented here may be of value to other departments and regions. We have demonstrated that BPMN can be of use in visualising data pathways as well as clinical processes and, although the specific insights generated from this work may not be generalisable to other areas, the methodology is. It would be of great interest to extend this work into other specialties within the hospital to discover whether the same need to create bespoke datasets applies in other areas where patient care is removed from the inpatient setting. It would also be of value to extend this work to other hospitals and other geographical areas to see whether the insights remain the same, or whether other neurology departments face different data challenges.

Future work should focus on understanding why staff have developed datasets outside of the approved applications. It is essential to understand what functionality the current systems are not providing and how can we design better systems so that data is captured correctly. The failure to capture data correctly at local levels will only be magnified once data is drawn into national and subnational SDEs. Another area of future work needs to focus on discovering whether the data kept outside of the approved applications is a duplicate of that being kept within the EHR, or whether these datasets represent a source of information that is not being officially recorded. Where data is being duplicated and the same information is being kept in several sources it will be important to understand not only why it is being kept that way, but also whether the data differs, and if so which source of data should be considered the ‘single source of truth’.

Conclusion

We have used BPMN to visualise patient pathways and the data flow and storage that arise alongside it within a neurology department in a large NHS hospital. We have highlighted the complexity of data flow and the existence of data repositories outside of the approved applications. Explicitly identifying these datasets has allowed us to identify areas in which the current EHR is not fulfilling the needs of day-to-day patient care. Future work needs to be done to identify the specific data needs that are not being met to ensure that any future data architectures are able to meet this need and ensure that data is correctly captured and centralised. This is especially pertinent as the NHS moves towards the use of SDEs, in order for the SDEs to be of most value, we need to ensure that the correct data is being captured at a local level.

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Author Contributions

FB: Conceptualisation, methodology, interpretation, writing – original draft, visualisation. JK: Conceptualisation, interpretation, writing – review and editing, funding acquisition. HE: Conceptualisation, methodology, interpretation, writing – review and editing, funding acquisition. VC: Conceptualisation, methodology, interpretation, writing – review and editing, funding acquisition. All authors approved the final manuscript.

Ethics

This study did not access any individual patient data and was undertaken under a Service Evaluation agreement with Lancashire Teaching Hospitals NHS Foundation Trust (Service Evaluation Ref: 427).

Conflicts of interest

None declared.

Abbreviations

BPMN – Business Process Modelling Notation
EHR – Electronic Health Record
NHS – National Health Service
SDE – Secure Data Environment

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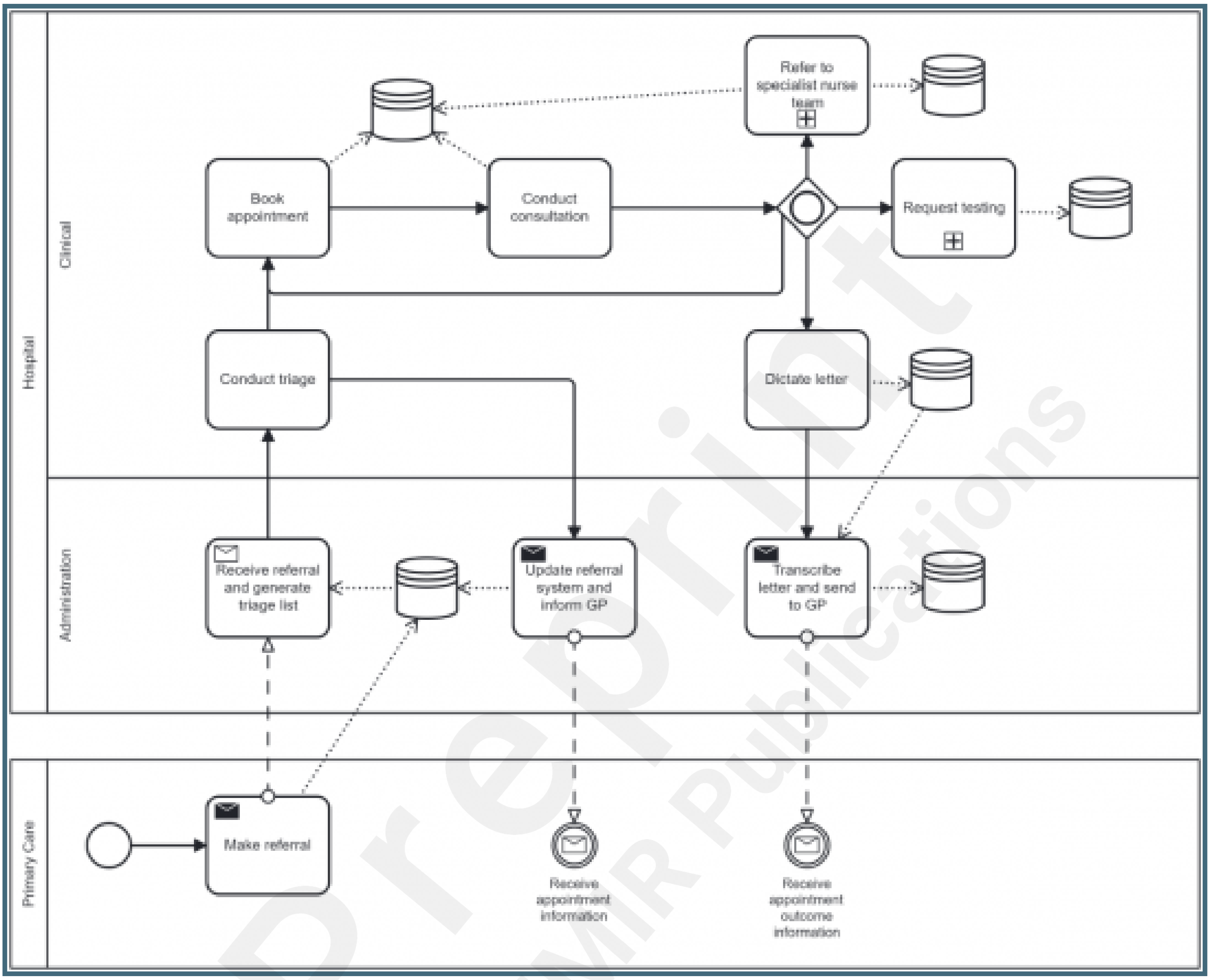
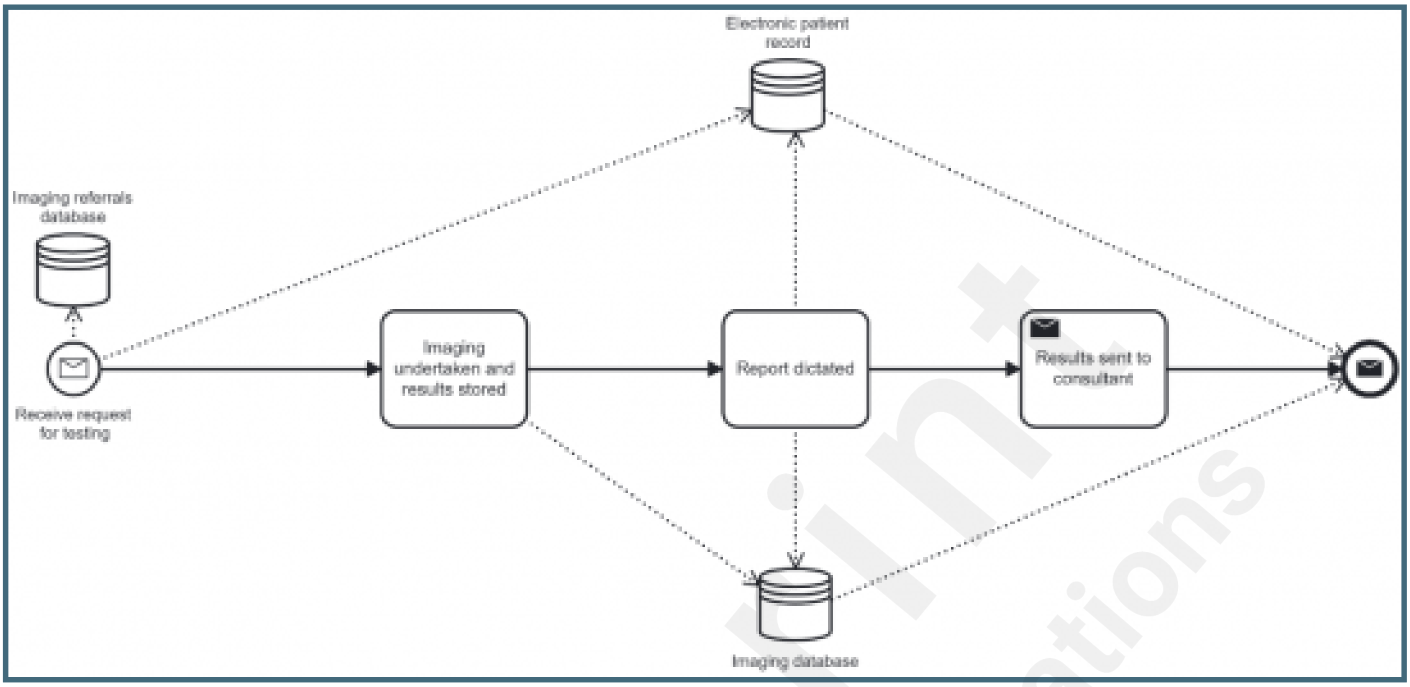
Supplementary Files

Figures

A simplified BPMN diagram showing the patient journey through neurology services, and the corresponding points of data transfer and storage.



A BPMN diagram showing a subprocess. This subprocess represents the flow of data to, through and from diagnostic imaging services.



Multimedia Appendixes

Format of the Questionnaire.
URL: http://asset.jmir.pub/assets/26825af67abe1747f944f23b62d2ad2a.docx

A BPMN diagram showing the outpatient patient journey, and the corresponding points of data transfer and storage.
URL: http://asset.jmir.pub/assets/4b61846fa16e45535bea893a4bbf7fcb.png

A BPMN diagram showing the inpatient patient journey and the corresponding points of data transfer and storage.
URL: http://asset.jmir.pub/assets/74226d0254c145a10f133728c886d0d0.png

A BPMN diagram showing the patient journey and the corresponding points of data transfer and storage for patients referred 'direct to scan'.
URL: http://asset.jmir.pub/assets/3a486b7e90bfa4de4f2081b5671646ec.png

A BPMN diagram showing the subprocess for ordering blood tests.
URL: http://asset.jmir.pub/assets/c1c0ff129bfc5611ed7cb22641484b63.png

A BPMN diagram showing the subprocess for ordering genetic testing.
URL: http://asset.jmir.pub/assets/0e18f6919a8264d5e6fe959f540c5296.png

A BPMN diagram showing the subprocess for ordering lumbar puncture tests.
URL: http://asset.jmir.pub/assets/a14fc17e7db50e371f38beb7067abe0a.png

A BPMN diagram showing the subprocess for ordering neurophysiology tests.
URL: http://asset.jmir.pub/assets/3ae0a89b90cbe31b277e6e5b18a49971.png

A BPMN diagram showing the subprocess for referral to the specialist nurse teams.
URL: http://asset.jmir.pub/assets/e33790729eb2a824075e322b5be25ca9.png