From Guidelines to Algorithms: A Software Solution for Optimising Papilloedema Referral Pathways

Project Proposal

Author:

ZHILING LIU JING YAO SHUAO ZHANG SONGYING LI
QINGYA FU JUNJIE YAN CAILING YANG KEXIN ZHANG

Supervisor:
JON BIRD

Department of Engineering

UNIVERSITY OF BRISTOL

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Abstract

Papilledema, or optic disc swelling, is a potential indicator of raised intracranial pressure(ICP) that always indicates serious neurological diseases. It remains a challenge to differentiate papilledema from pseudopapilledema, especially in primary care. This process often results in unnecessary referrals or missed diagnoses. A software application has been developed to address this issue. The system is based on the referral guidelines developed by experts in the DIPP (Diagnosis of Optic Papillae Edema in Primary Care Study) and uses a “question-led” interaction to guide the user step-by-step through the input of key clinical variables, such as the patient’s possible symptoms and signs. This system elies on a structured decision pathway and rules engine to automatically generate clear referrals recommendations for a variety of scenarios, such as ’Send patient to Emergency Department immediately’, ’Immediate referral Eye Emergency on call’, ’Urgent referral to Ophthalmology’ or ’Urgent referral to GP or direct to Neurology’, which are graded according to the urgency of the patient’s clinical presentation.The tool aims to reduce the burden of unnecessary referrals, improve diagnostic efficiency, and support patients, optometrists, and general practitioners (including neurologists and ophthalmologists) to make more scientific, standardised, and transparent referral decisions when faced with a suspected case of optic nerve papilloma swelling.

Table of Contents

1 Introduction

1.1 Background

In primary healthcare systems, accurately distinguishing between papilloedema and pseudopapilloedema has long been a persistent and clinically significant challenge. True Papilledema typically indicates raised intracranial pressure(ICP) and requires urgent intervention for the patient, while pseudopapilloedema is usually benign and does not require urgent treatment. However, this diagnostic uncertainty in clinical practice often leads to two concerning consequences: first, a large number of unnecessary specialist referrals; second, delayed diagnosis of truly critical patients. Research from the University of Bristol reported a 500–600% surge in referrals for suspected optic disc swelling in Bristol in four years. This means that people who really do have nerve swelling may wait longer for appointments because more people with suspected nerve swelling are being referred, and subjected many unaffected individuals to invasive and costly testing, as well as health anxiety [1]. Meantime, it also dramatically increases the burden on healthcare and insurance.

1.2 Key objectives of the project

To address the above issues, our project aims to develop a clinical decision support system based on DIPP guideline-driven logic [2] to help accurately distinguish between papilloedema and pseudopapilloedema.The objectives include: reducing unnecessary referrals, improving early identification of high-risk patients, avoiding high-cost and invasive tests, alleviating patient anxiety and reducing related medical/insurance costs.

1.3 Main challenges

To implement this system, the biggest challenge we face is how to convert complex clinical guidelines full of medical semantics into a structured, executable decision-making framework. These referral pathways were originally designed for specialists, and we need to abstract them into a rule-based engine that can guide optometrists, general practitioners, and even patients themselves through a question-and-answer interaction to complete the assessment process and obtain accurate recommendations.

1.4 Scope of the project

Therefore, the scope of this project is not limited to the implementation of technical systems, but also involves the transformation and dissemination of medical knowledge—transforming expert-level clinical experience into intelligent auxiliary tools that grassroots medical workers and patients can understand and operate.

1.5 Motivation for the project

The core motivation lies in meeting the current practical needs of primary care providers: how to identify patients who truly require intervention as early as possible, and avoid unnecessary referrals and excessive testing, given limited specialist resources. We hope that this system will enable non-specialist users—including patients themselves, optometrists, and general practitioners—to make more reliable judgements based on guidelines when faced with cases related to optic disc swelling.

1.6 Future Development Potential

The system is based on DIPP (Diagnosis of Papilloedema in Primary Care) [2] and uses structured clinical inputs to generate individualised referral recommendations based on urgency. Ultimately, we hope that this work will not only provide practical value in primary eye screening, but also serve as a reference for the development of broader intelligent medical decision support systems.

2 Related Work

2.1 Clinical Decision Support Systems in Healthcare

Clinical Decision Support Systems (CDSS) have emerged as a vital tool to support clinical reasoning, reduce diagnostic errors, and standardize care delivery. They are widely used in primary and secondary care settings to guide clinical decisions based on structured rules, guidelines, or statistical models. Previous work has shown that CDSS can effectively reduce unnecessary referrals and improve resource allocation in healthcare systems [3].

In particular, CDSS has proven beneficial in time-sensitive domains such as cardiology and oncology, but its adoption in ophthalmology—especially in referral decision-making—is still in the early stages. The complexity of visual symptoms and overlapping pathologies makes automation particularly challenging.

2.2 Ophthalmology-Specific Referral Tools

Several digital platforms have been developed to assist in ophthalmology triage and referral management. For instance, the *EyeSmart* system developed at Moorfields Eye Hospital integrates patient-reported symptoms and image analysis to streamline referrals to eye specialists. Likewise, the Scottish Eyecare Integration Project introduced a community-based triage model using structured referral templates, which helped reduce wait times and the burden on hospital outpatient services.

These systems provide valuable precedents for how structured inputs and digital logic can enhance clinical workflows, though none are designed specifically for distinguishing papilloedema from pseudopapilloedema.

2.3 Delphi Method for Clinical Guideline Development

The Delphi method is a widely recognized consensus-building approach used in healthcare guideline development. It is particularly valuable in cases of clinical uncertainty where evidence may be incomplete or ambiguous. In the context of our project, the DIPP study employed Delphi surveys among diverse clinical professionals to establish consensus on referral criteria for suspected papilloedema.

As shown in Diamond et al.'s review [3], Delphi studies must be rigorously designed and clearly reported to ensure reliability. Our project adopts this approach to form the evidence-based logic embedded in our referral tool.

2.4 Machine Learning and Rule-Based Systems in Diagnosis

Artificial intelligence, especially rule-based systems and machine learning, has increasingly been applied to automate diagnostic workflows. Recent studies have used deep learning to analyze retinal images from Optical Coherence Tomography (OCT), achieving promising results in identifying features such as drusen or retinal thickening [4].

However, these approaches often require large, labeled datasets and specialized infrastructure. Moreover, few existing systems incorporate patient-reported symptoms, clinician inputs, and imaging into a unified triage engine—a gap that our system seeks to fill.

2.5 Contribution of This Project

Our project builds upon prior work but makes several novel contributions. Unlike most referral tools that are designed exclusively for clinicians, our system introduces a dual-interface structure: one tailored for patients (self-assessment) and another for clinicians (referral refinement).

Moreover, the logic is directly derived from consensus-driven clinical guidelines developed through the DIPP study, ensuring both scientific validity and practical relevance. By blending clinical imaging, structured symptom reporting, and decision rules into an accessible digital format, we aim to bridge the gap between over-referral and under-referral in suspected papilloedema cases.

3 Implementation

3.1 System Overview

The proposed system is a digital decision support tool aimed at improving the referral process for suspected cases of papilledema.The system will support different user flows. The **patient-end interface** guides individuals through simple and clear questions to collect their symptom data and eventually route them into appropriate clinical decision pathways. The **clinician-end interface** receives this input as reference to more detailed diagnosis case by case.

3.2 Technology Stack

The system will be designed as a web-based application, accessible across different devices. At this stage, the technology choices are still flexible, but the following tools and platforms are being considered:

1. Frontend: JavaScript, etc.
2. Backend: A cloud-based backend that could handle logic and store user inputs.
3. Data & Rules: Clinical decision pathways from the DIPP study will be implemented using a decision tree model.
4. Deployment: The application will be deployed on a scalable platform (could be Vercel or Netlify), allowing easy updates and public access.

3.3 Functional Module Design

The system will consist of multiple core functional modules that work together to support symptom collection, clinical reasoning, and referral decision-making.

3.3.1 Patient Self-Assessment Module

This module is designed to guide patients through a series of clear and easy-to-understand questions that help identify symptoms potentially related to papilledema. The interface aims to make a preliminary diagnosis of the patient's health situation and then route patients into appropriate pathways by using simple language and step-by-step navigation. In this module, key symptoms such as blurred vision, headaches, and double vision will be given particular attention.

In cases where the patient's condition is considered highly urgent, the module will advise the patient to take immediate action.

3.3.2 Clinical Interface for Healthcare Providers

This module is intended for GPs and optometrists. It provides a more detailed version of the patient's reported symptoms and allows clinicians to input clinical findings.

In this module, clinicians will be given both patient-reported data and professional observations to give diagnosis.

3.3.3 Decision Pathway and Rules Engine

The engine will be built upon clinical pathways derived from the DIPP study and expert consensus, it determines the referral recommendation based on the data collected.

Basically, the engine will give referral advices such as:

1. Immediate referral to the Emergency Department
2. Urgent referral to on-call ophthalmology or other department
3. Referral to a GP or neurologist
4. No referral needs

The logic will be transparent and easily updatable if new guidelines are introduced.

3.3.4 Result Summary and Report Module

After completing the assessment, patients will receive a summary of the patient's health condition and a referral advice.

3.4 Interaction Flow and UI Design

The application will be designed to provide a clear and intuitive user experience for both patients and healthcare professionals. Each user type will follow a distinct interaction flow that matches their needs and level of expertise.

Patient Flow Patients will be guided through a step-by-step questionnaire using plain language. The interface will adapt dynamically based on their responses, leading them through relevant symptom pathways. Clinician Flow Clinicians will access a interface allowing for quick input of clinical findings and access to the patient's reported symptoms.The design will prioritise accuracy and response speed.Key decision points will be visually highlighted.

Across both interfaces, usability and clarity will be a design priority to ensure users of varying backgrounds and ages can interact with the tool efficiently and confidently.

3.5 Prototype Development and Testing Setup

Could use prototypes, and run some testing regularly.

4 Evaluation Plan

To ensure the reliability and clinical value of our system, we propose a multi-level evaluation strategy that includes both technical validation and user-centered assessment.

4.1 Technical Evaluation

We will implement clinical decision logic as a rule-based system following the DIPP (Diagnostic Imaging for Papilloedema Pathways) flowcharts. The technical evaluation will focus on the following metrics:

1. Accuracy: We will construct a synthetic dataset of patient cases based on real-world pathway examples. The system's referral decisions will be compared with gold-standard answers determined by clinicians.
2. Logic Consistency: The decision tree implementation will be tested across multiple pathway scenarios (e.g. 0705 and 1605 versions) to ensure correct branching and handling of edge cases.
3. Scalability: Response latency and system behavior will be monitored under multiple input sequences to ensure robustness.

4.2 Usability and User Evaluation

To assess the usability and practical adoption potential of the system, we will recruit a small group of test users, including optometrists and general practitioners (GPs). Evaluation methods will include:

1. Scenario-based walkthroughs: Simulated patient cases will be input into the system, and clinicians will be asked to evaluate the appropriateness of the referral decisions.

2. System Usability Scale (SUS): A standardized 10-item survey will be used to quantify perceived usability, efficiency, and learnability.

3. Qualitative feedback: Open-ended responses and short interviews will help identify interface flaws, confusion points, and suggestions for improvement.

4.3 Future Clinical Validation

Subject to ethical approval and data availability, we plan a future phase of clinical validation by retrospectively testing the system against anonymised patient referral records. The key aim is to determine:

1. Referral accuracy: Whether the system correctly flags urgent vs. non-urgent cases.

2. Reduction in false positives: Whether unnecessary referrals can be reduced without missing red-flag cases.

3. Alignment with expert judgement: Agreement rates between system outputs and ophthalmologist recommendations.

5 Time Plan

5.1 Development Approach

The project runs from 14 May 2025 to 2 September 2025 and follows a sprint-based development model inspired by Agile principles. Work is organised into three core sprints, each followed by focused development, feedback integration, testing, and documentation. This structure allows for continuous delivery, iterative refinement, and early involvement of stakeholders.

Each sprint produces a working version of the application, which is reviewed by members of the DIPP research group. Their feedback enables early identification of usability or logic issues and helps guide further improvement. To ensure correctness and clinical reliability, the project also adopts a test-driven development (TDD) approach, with all decision logic validated through predefined test cases throughout the development cycle.

5.2 Timeline and Task Allocation

The table below outlines the full timeline of the project. Each sprint results in a working version of the application and a new stage of the report, with supporting development in the periods between.

Date	Task Description
14.05–28.05	Background research, initial analysis of the optometrist pathway, preliminary system architecture design, and test planning
29.05–15.06	In-depth analysis of the optometrist logic; confirm application scope with client
16.06–23.06	**Sprint 1**: Complete optometrist decision tree; build initial prototype
24.06–15.07	Begin report writing; refine prototype; design test cases and UI for doctors and patients
16.07–23.07	**Sprint 2**: Complete doctor and patient logic; build shared UI layout; complete first report draft; iterative update of application
24.07–15.08	Conduct user testing; integrate feedback; finalise multi-role logic and documentation
16.08–23.08	**Sprint 3**: Finalise design; polish system and report; iterative update of application
24.08–02.09	Final testing, proofreading, and submission of the report and application

Table 1: Project Timeline and Task Breakdown

5.3 Testing Strategy

We use a test-driven development (TDD) approach. Before writing any code, we define test cases based on expected decision outcomes from clinical guidelines. These automated tests cover all three user roles: optometrists, doctors (including GPs, neurologists, and ophthalmologists), and patients. Unit tests will be executed continuously throughout the development process to ensure correctness and consistency of the decision logic.

In addition to automated testing, we will conduct user testing after each sprint. Members of the DIPP research group will interact with the system to verify logic accuracy and usability. Feedback will be collected and integrated at three key points:

1. After Sprint 1: to evaluate the optometrist prototype and confirm the decision flow aligns with expectations.
2. After Sprint 2: to assess the full multi-role logic and interface layout, and to gather usability feedback.
3. After Sprint 3: to validate the final version of the application and ensure it meets all functional and clinical requirements.

This iterative feedback process ensures the application is reliable, clinically accurate, and user-centred.

5.4 Writing Strategy

Report writing begins after Sprint 1. During the second development phase (24 June – 15 July), we will draft the main report structure and begin writing technical sections. A full first draft will be completed during Sprint 2, and revisions will be made during Sprint 3, alongside system polish and visual documentation. Final proofreading and formatting will take place before submission.

5.5 Risk and Mitigation

The main risk is incomplete or delayed information on doctor and patient pathways. To mitigate this, we use modular design and placeholder logic to avoid development delays. Regular communication with the DIPP team ensures requirements are clarified early. Time buffers are also built into the timeline to allow for scope adjustment or logic refinement.

5.6 Milestones

The possible milestones for this project are:

1. Completion of the first working prototype
2. Completion of the optometrist decision tree
3. Completion of logic for doctor and patient roles
4. Implementation of all core system functionality
5. Completion of the multi-role user interface

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