NETIMIS

# CASE STUDY

## The National Standard for Giant Cell Arteritis Diagnosis and Management

Client: The TARGET Consortium

# Overview

This case study has been completed as part of a University of Leeds undergraduate project in collaboration with The MRC TARGET Consortium and X-Lab Ltd. X-Lab's simulation software, NETIMIS, has been used to simulate and model the Giant Cell Arteritis (GCA) patient care pathway from clinical suspicion through to clinical diagnosis. The TARGET (Treatment According to Response in Giant Cell Arteritis) Consortium is a partnership primarily aimed at reducing steroid toxicity and improving outcomes for patients with GCA. They mean to achieve this through implementing a more effective pathway for delivering patient care, particularly in the early diagnostic pathway, as part of routine clinical practice using the NETIMIS tool. NETIMIS is a web-based simulation software tool, designed and developed by X-Lab, that enables the user to create process models. It is based on the concept of Unified Modelling Language (UML) diagrams, and uses nodes, edges, and diamonds for decision points to visually represent pathway flow within any given organisation.

# About the Project

The aim of this case study is to showcase a series of models that were created to represent the flow of patients with suspected GCA. By understanding the challenges involved with the current pathway, potential improvements can be sought out to create hypothetical future pathways that deliver more effective diagnoses. In order to further validate the work conducted, an investigation into the national pathways within the UK for GCA diagnosis and management took place and the outcomes of this investigation have been included in this case study.

# Challenges

Presently, there is no independent diagnosis for GCA meaning that this process relies on the ability of the healthcare provider to identify whether the symptoms described by the patient are those of GCA. This decision will lead to the patient undergoing a series of examinations before a firm diagnosis of positive or negative for GCA.

# The National Guidelines for GCA

The pathways described in this document have been based on the guidelines provided by the National Institute for Health and Care Excellence (NICE). NICE delivers guidance in delivering effective patient care to improve outcomes for those using the NHS and other public health and social care services. These measures, stated in the Clinical Knowledge Summaries (CKS) described by NICE, aim to identify patients with suspected GCA and to make referrals for temporal biopsies appropriately and in a timely manner. The patients' symptoms should be controlled, frequently monitored and the risks of complications, like vision loss, should be mitigated. Long-term steroid treatment has many risks and side effects that should be monitored and minimised where possible. In doing so, the patients' independence, quality of life and mobility can be maintained.

The steps described below have been broken down into:

- Suspicion of GCA
- Diagnosis
- Initial management
- On-going management.

# How NETIMIS Helped

NETIMIS has been used to draw out the NICE pathways to allow for the visualisation of the current GCA pathway. Although the processes described by NICE are clear to follow, creating models in NETIMIS that represented the pathways helped improve comprehension of patient flow. These models can be used those working with GCA and can be populated with real data to enhance the accuracy of the projected flow and enable analysis on the outcomes produced. This will allow individual hospitals to simulate personalised models to determine locally which are the most efficient and cost effective.

[1] The information presented on the next page has been gathered from NICE, (2014), Clinical Knowledge Summaries – Giant Cell Arteritis. Available online at: *https://cks.nice.org.uk/giant-cell-arteritis#!diagnosissub:1 [Last Accessed: 14/04/2018]*

# The Steps: Steps when GCA is Suspected

1. GCA can be suspected if the patient is over 50 years old and displays the following symptoms:
   a. Headache in the temple area
   b. Abnormality in the temporal artery and these could be tenderness and thickness. This symptom is present in 45%-75% of patients who have confirmed GCA (Nice, 2014). The patients skin around this area is red and their pulse is reduced or not present.
2. Other symptoms that could lead to suspected GCA include:
   a. Systemic symptoms such as fatigue, fever, weight loss, eating disorders and depression. These symptoms affect the majority of patients with GCA.
   b. Symptoms linked to polymyalgia rheumatic, as patients with this feature may also develop GCA.
   c. Tenderness of the scalp, specifically around the temples. (approximately 50% of patients with GCA have this symptom (NICE, 2014))
   d. Jaw pain, affecting 50% of patients and this will lead to them feeling pain when chewing and may also affect their tongue, muscles used for swallowing and occasionally their arms and shoulders.
   e. Visual impairment, this could be partial or complete vision loss in one, or both eyes. This symptom effects 20% of patients. The effects of visual loss are permanent and cannot be reversed.
   f. Neurological features affecting approximately 30% of patients.
   g. Peripheral arthritis and swelling in the hands, wrists, feet and ankles and these symptoms affect approximately 25% of patients with GCA
   h. Respiratory features such as coughs and sore throats and this affects 10% of patients with GCA

Within the NETIMIS model, the patient demographics, their route of entry into the care pathway and their symptoms have been categorised like below:

# The National Guidelines for GCA

1. Refer all patients with suspected GCA to undergo a temporal artery biopsy. Positive results will confirm diagnosis, but a negative result does not rule out diagnosis
   a. If patient displays visual loss, then refer to ophthalmologist for same day urgent assessment
   b. If patient does not display visual loss, then refer for urgent same day specialist assessment, usually rheumatology

2. Start oral steroids immediately whilst waiting for patient to undergo biopsy. Dosage will be dependent on patient's symptoms and will vary amongst patients.

3. If patient's response to oral steroids is not positive (after 48hrs) then consider alternative conditions. If appropriate, arrange examinations to exclude other conditions.

4. Arrange the following tests and examinations, for a firm diagnosis alongside the biopsy results:
   a. Erythrocyte Sedimentation Rate (ESR), to establish if it is above 50mm/hr and approximately 20% of patients will display an elevated rate.
   b. C-Reactive Protein (CRP) will be elevated amongst patients with GCA
   c. Full blood count as patients with GCA will have an elevated platelet count
   d. Liver function tests as approximately 33.3% of patients will have elevated liver function


Model available from:

*https://www.netimis.co.uk/shared/5ad5fe6f7775761d4c5fd5ec*

# Initial Management

1. Record patients' symptoms (both before and after treatment to determine patient's response to treatment)

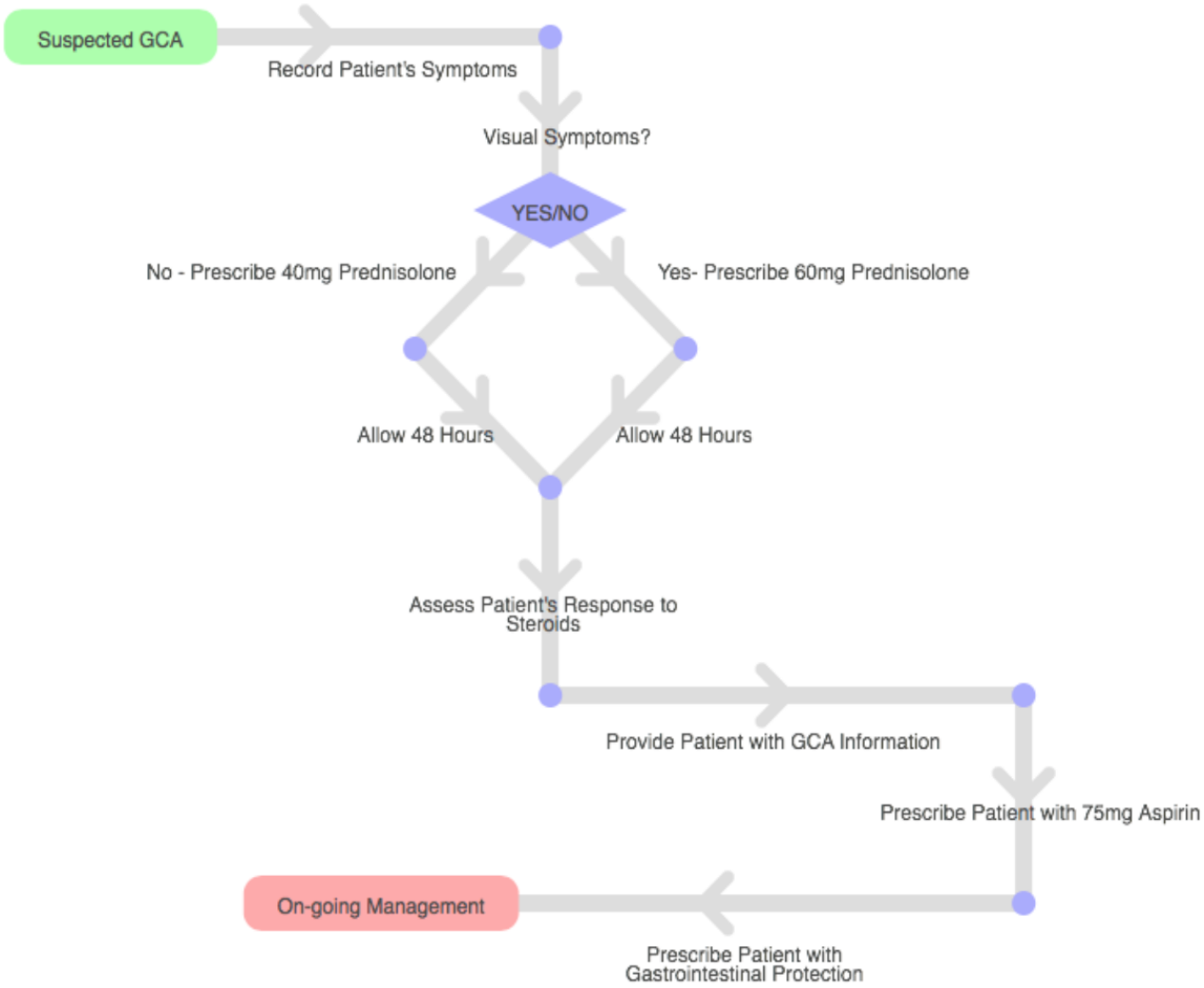
2. Prescribe oral steroids
   a. If patient displays visual impairment symptoms, then refer to ophthalmologist and prescribe one-off dosage of 60mg Prednisolone
   b. If patient does not display visual symptoms, then prescribe between 40-60mg Prednisolone

3. Assess the patient's response to steroid treatment within 48 hours

4. Ensure patient is provided with relevant information and advise them to:
   a. Seek immediate urgent care attention if any visual impairment symptoms emerge
   2. In the case of a positive diagnosis, steroid treatment will continue for 1-2 years, and a lower dosage may be required after the 2 years
   3. Relapses may occur when dosage of steroids are reduced
   4. Regular follow-ups are necessary for monitoring patients' wellbeing and response to treatment

5. 75mg of Aspirin should be prescribed and taken daily by the patient. This is recommended for side effects of steroid treatment

6. Patients should also be given gastrointestinal protection

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# On-going Management

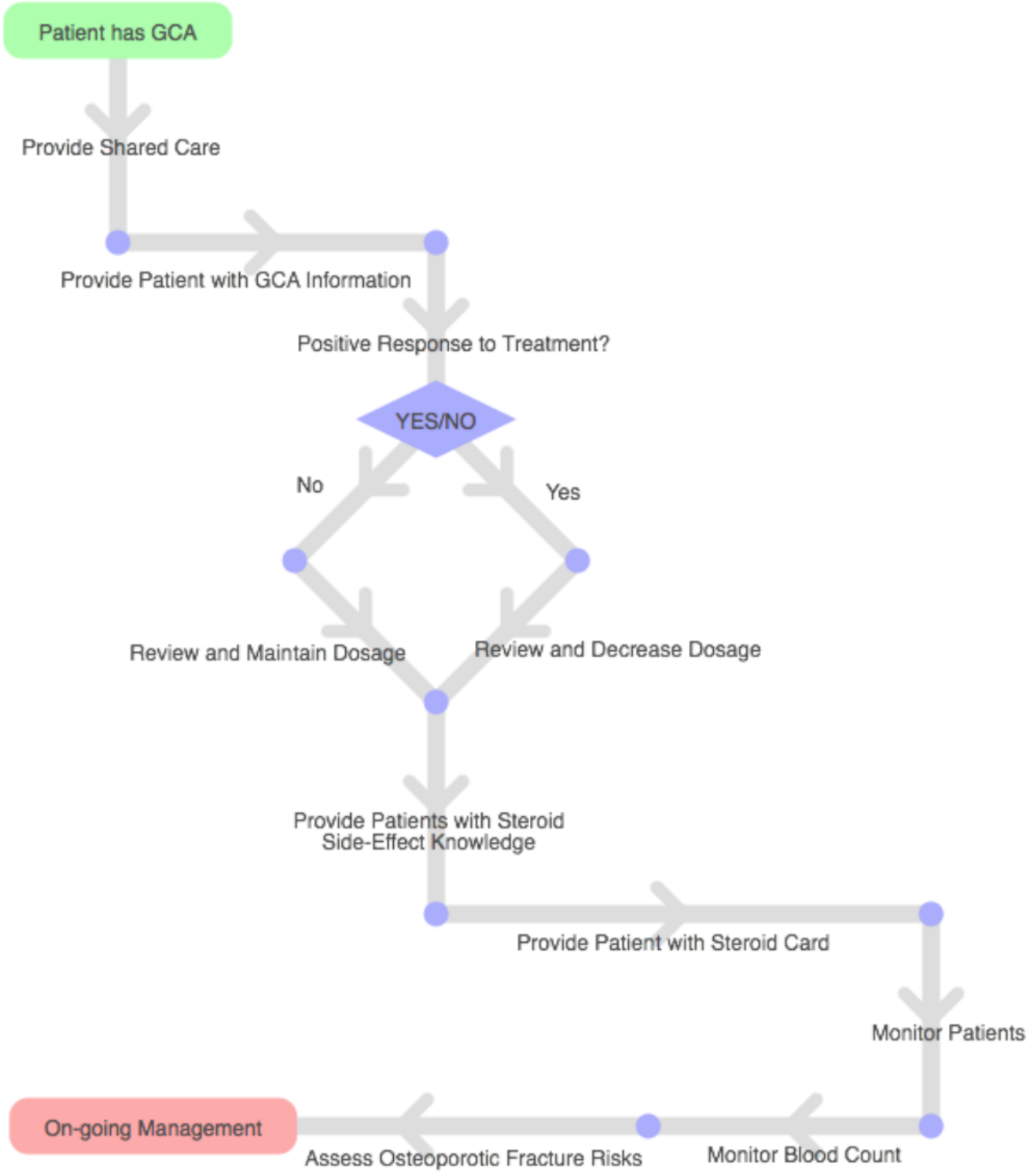
1. Provide shared care, between primary care, i.e. GP, and a specialist, i.e. rheumatologist.

2. Patient should be provided with information on GCA, such as booklets, and be advised to join a GCA support group.

3. If patient's response to steroid treatment is positive, and their symptoms are controlled, then the dosage of steroids can be decreased. This should be done on a patient by patient basis, and the dosage should be tailored to each individual based on their diagnosis.

4. Each patient should be provided with a blue steroids card and they should be informed on the side effects they may experience as a result of taking them. However, they should also be advised not to stop taking their medication unless directed to do so by a specialist. Patients should also avoid contact with people who may have shingles, chicken pox or measles as they would be prone to being contaminated with diseases such as these.

5. Patients should be monitored frequently –
    a. Within the first year of diagnosis, weekly follow-ups may be required whilst the patient is on a high dosage of steroids. If steroid intake is reduced within this time a routine check should be carried out 1 week after dosage change, and this should be done every 3 months
    b. After the first year of treatment, each patient should be seen every 3-6 months, but more frequently should they have a relapse
6. Every 3 months the patients' bloods should be checked, and their ESR/CRP counts should be assessed.
7. Each patient's osteoporotic fracture risks should be assessed and managed throughout treatment.

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