

Prodigy Patient – Developing an evidence-based patient app with a difference

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Abstract

Clarity Informatics has recently launched a new patient information app called Prodigy Patient. The content is based on the evidence-based summaries we provide for primary healthcare professionals, published on the [NICE Clinical Knowledge Summaries](#) website.

At present there is little or no regulation of medical apps. Thousands of apps and websites are available which provide healthcare advice, but few are based on robust, critically appraised evidence. Our aim in producing the app was to provide a trusted source of medical information, based on best practice and sound evidence, which would complement rather than substitute the clinical consultation. The app is free to download and is without advertising or pharma sponsorship. We aimed to produce a wholly credible, unbiased resource which could be trusted by both patients and doctors.

Here we describe the rationale behind the app, the development process and the difficulties faced in translating medical information into practical advice for patients.

Having spent the last 20 years as a company writing evidence-based medicine summaries for GPs in primary care, our focus has always been on providing information for doctors and other healthcare professionals.

Recently, our Chief Executive, a new father anxiously searching the internet for information on why his young son would not stop crying, found himself frustrated at the lack of clear, evidence-based health information provided by a credible source and written specifically for patients.

Being a pragmatic man he wanted to know exactly what steps he should take to help his son, the root of whose unhappiness he suspected to be teething. He also wanted information on other possible causes of his son's distress, to know when he should be consulting his doctor and what evidence-based treatments were available to soothe the pain.

Unlike most people in his position our CEO was able to come into work the following day and speak to his team of highly experienced clinical authors, information analysts and software developers and declare: "We need to develop a high-quality, evidence-based, practical patient information app which will empower patients to take charge of their own health, provide relevant, up-to-date information which has been critically appraised, and provide step-by-step instructions on how people can help themselves to get better.....oh and I would like us to do this within the next 3 months".

"Ok....." we said.

After some shuffling of feet we began development by tasking four authors to convert the 350 clinical topics we currently provide for the

NICE Clinical Knowledge Summaries Service into patient-friendly language. Excerpts of the Glaucoma information from the app can be seen below. The information is structured in four content sections:

1. Summary – a brief overview of the content covered by each topic:

Glaucoma summary:

- Glaucoma is the name for a group of eye diseases that cause damage to the nerve at the back of the eye (optic nerve). This can lead to impaired vision and, in a small proportion of people, blindness.
- The two main types of glaucoma are called acute angle closure glaucoma and chronic open angle glaucoma.
 - Acute angle closure glaucoma is a condition that comes on suddenly.
 - The main symptoms are a painful red eye with previous episodes of blurred vision, headaches, or eye pain associated with nausea and seeing halos around lights. These symptoms typically occur in the evening and are relieved by sleeping.
 - A person with acute angle closure glaucoma requires urgent specialist treatment.
 - Chronic open angle glaucoma is a long term condition that is often picked up by an optometrist at a routine eye examination.
 - A person with chronic open angle glaucoma will be treated non-urgently by an ophthalmologist.

2. Get me better – practical information on what to do to in an acute situation, or in the long-term for a chronic condition, including medications which can be prescribed or bought over the counter as appropriate:

What should I do?

- If you have symptoms of acute angle closure glaucoma you should seek urgent medical advice. The condition requires specialist treatment in order to prevent damage to the sight.
- Lying flat with the face up and head not supported by pillows can relieve some of the pressure inside the eye if you have acute angle closure glaucoma. You should do this as much as possible while you are waiting to be assessed.
- While you are waiting to see a doctor, you can use paracetamol or ibuprofen to relieve pain if required.
- If you have symptoms of chronic open angle glaucoma, or think that you might be at risk of developing the condition, you should arrange to see your doctor or make an appointment to see an optometrist.

What medication should I take?

- Pain caused by glaucoma can be treated with over the counter painkillers such as paracetamol or ibuprofen.
- Glaucoma is treated with medicines given in the form of eye drops that work by decreasing the pressure inside the eye.
- These include latanoprost, travoprost, bimatoprost, tafluprost, betaxolol, carteolol, levobunolol, metipranolol, timolol, brimonidine, dipivefrine, brinzolamide, dorzolamide, and pilocarpine.
- A medicine called acetazolamide is also sometimes given in tablet form.

Do I need to see a doctor?

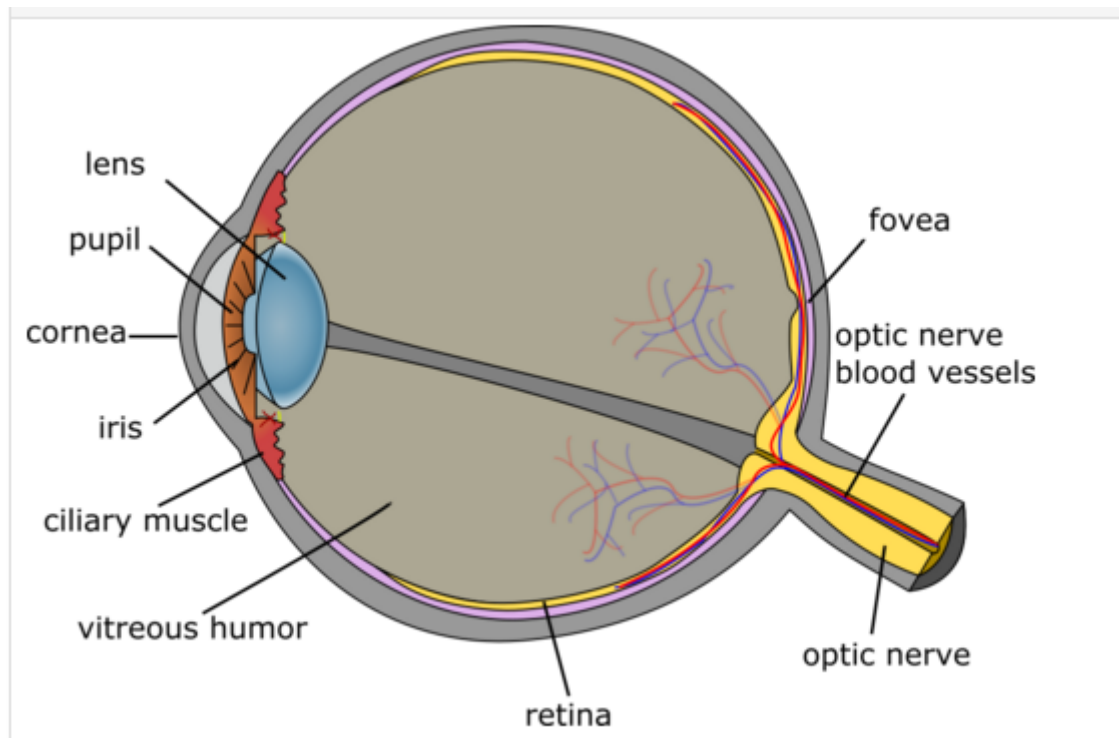
- Yes. Glaucoma can permanently damage the eyesight. Acute angle closure glaucoma requires urgent medical treatment, and chronic open angle glaucoma is treated on a long-term basis.

3. What else could it be – links to possible differential diagnoses and a section for other topics which may also be of interest.

4. Learn more –detailed information on the condition including prevalence, causes, complications, treatments and practicalities:

What is glaucoma?

- Glaucoma is a group of eye diseases in which damage to the nerve at the back of the eye (the optic nerve) leads, over time, to impaired vision and, in a small proportion of people, blindness.
- Glaucoma is characterized by areas of lost vision in one or both eyes.
- The optic nerve can be damaged when:
 - The pressure inside the eye is abnormally high — this is the most common cause of damage.
 - The blood supply to the optic nerve is reduced.
 - There is a weakness in the optic nerve structure.



How do I know I have glaucoma?

- The main symptom of **acute angle closure glaucoma** is a painful red eye that has come on suddenly. Other symptoms include:
 - Headache, nausea, and vomiting caused by the painful eye.
 - Lights that are seen surrounded by halos
 - Visual problems.
 - An affected person might have had previous episodes of blurred vision, headaches, or eye pain associated with nausea and seeing halos around lights. These symptoms typically occur in the evening and are relieved by sleeping.
- **Chronic open angle glaucoma** is most commonly detected by an optometrist during a routine eye examination.
- Occasionally, a person with chronic open angle glaucoma will visit their GP because they have an area of reduced or lost vision in one or both eyes with no other symptoms.

What should I do if I have glaucoma?

- If you have glaucoma it is very important that you use your eye drops exactly as directed by a doctor. These eye drops help to reduce the pressure inside the eye and prevent any further damage to the optic nerve. Failure to use prescribed eye drops correctly can result in damage to the sight.
- If you have physical problems which mean that you struggle to use the eye drop bottles, the doctor can recommend an eye drop dispenser to help position and squeeze the bottle of eye drops.
 - Opticare® dispensers are designed for people whose hands shake, or have difficulty placing or squeezing the bottle.
 - Opticare® Arthro dispensers are designed for people with poor hand grip or limited mobility of the hand or arm.
 - Autodrop® dispensers are compatible with a range of eye drop medication, and help ensure that eye drops are accurately delivered to the eye.

What can happen with glaucoma?

- Most people with **chronic open angle glaucoma** do not show any symptoms until there is a large amount of damage to the optic nerve.
- Without treatment, as glaucoma progresses, peripheral vision and central vision are affected.
 - Peripheral vision is important for moving through a complex or unfamiliar environment, and for detecting movement outside the area of focus. Peripheral vision is therefore necessary for safe driving. Severe loss of the peripheral visual field results in tunnel vision.

- Central vision is important for reading, driving, and other activities that require focussed vision.
- With treatment most people with chronic open angle glaucoma will not go blind, although they will have some visual defects.
- Once vision is lost because of glaucoma, it cannot be restored.
- Treatment and monitoring of chronic open angle glaucoma will be lifelong.
- Full recovery is likely for people treated promptly for **acute angle closure glaucoma**.
 - Irreversible loss of vision after angle closure glaucoma is more likely if there is a delay in receiving treatment or in treatments being effective at lowering the pressure inside the eye.

What practicalities do I need to consider with glaucoma?

- **Regular eye tests**
 - The following groups of people should have their eyes examined by an optometrist every 2 years, or more frequently if advised by the optometrist.
 - **Older people.** People 60 years of age or older should be examined every 2 years until they are 70 years of age, when they should be examined every year
 - **People with a family history of glaucoma.**
 - **People from certain ethnic groups.** People older than 40 years of age who are of black African origin should be examined every year

- **Driving**

- In general, a driver must have good central visual acuity and adequate peripheral vision while using their glasses or contact lenses if prescribed.
- If there are visual defects in both eyes, the person is legally required to inform the Driver and Vehicle Licensing Agency (DVLA) and to stop driving until a specific test has been performed under the guidance of the DVLA.

- **Registering as sight-impaired**

- People diagnosed with glaucoma will be provided as required (if they have severe visual loss or poor visual acuity) with a Letter of Vision Impairment, a Referral of Vision Impairment, and a Certificate of Vision Impairment (CVI).
- The CVI allows the person, should they wish, to register as sight-impaired with their local council.

We spent time thinking about the level of language to use in the app, we wanted to make the information accessible, but also useful. We didn't want to completely strip the content of medical terminology, but we wanted to define this in a way which would be understandable to the lay person. Our CEO's vision was to put the patient in control of their own health, we wanted to include terminology which patients may have heard in relation to their condition and allow them to use this terminology in their own research. Striking the right balance proved difficult, and we redrafted numerous times in order to achieve the right level. Indeed there is still work to do on the content, we still need to simplify some of the language further, and we are welcoming and reacting to feedback from a range of sources.

We also decided it would be useful for the app to include images where possible to aid the patient's understanding, including anatomy and cross sections. We are planning on adding photographs such as for rashes in the near future.

Whilst our authors were busy with the writing task, the technical team were working on development of the app itself. A small amount of competition was definitely in the air between the authoring and technical teams. Who would be ready first....? Certainly, no one wanted to be ready last. It took around 6 months in the end but we still felt like we had achieved a great deal in a relatively short space of time.

We launched the app to friends and family first, making changes according to feedback and then we launched to the wider world. We have had almost 3000 downloads so far, and this is ever growing. We will continue to work on both the content and the functionality of the app, we hope that it helps to meet some of the information needs of both patients and doctors.

Prodigy patient is available free of charge from www.prodigy-patient.co.uk. We do not include advertisements in the app or accept any pharma sponsorship. Your feedback would be greatly appreciated.