

Improving Pathways for Managing Coeliac Disease

The YouTube generation – enabling faster access to dietetic care and empowering patients to self-manage their condition

“What I hear, I forget; What I see, I remember; What I do, I understand.” Chinese proverb



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NICE guideline 20, Coeliac UK and the British Society of Gastroenterology all detail the value of specialist dietetic intervention to support the management of coeliac disease and improve long-term adherence to a gluten-free diet. However, it is also acknowledged that access to specialist dietitians is limited in many parts of the UK and that dietetics is under-resourced for managing coeliac disease.^{1, 2, 3}

At Cardiff and Vale University Health Board, audits have identified variations in the length of time patients diagnosed with coeliac disease were waiting to receive education on a gluten-free diet from a registered dietitian.

Our service standard has previously been to deliver dietetic advice within 14 days of receiving a referral, on average we were taking 23 days. Further variation and delays were identified in the time taken from biopsy result to a referral reaching the dietetic department. By undertaking a review of the pathway and taking an innovative approach, it was felt we could improve. Patients (and their carers) who have been diagnosed with coeliac disease are busy with school, work and life. Taking time off to attend the hospital for appointments is not always easy. Quality, well structured advice with a registered dietitian requires a lengthy consultation. As healthcare professionals we know that when individuals are provided with verbal information they will not retain all of it, typically retaining the first and last things they are told. In a consultation that focuses a gluten-free diet, this could well mean that core information is not well recalled

by patients once at home. Whilst we provide written literature for patients to take away, the complexity of the diet and volume of information often causes patients to misunderstand and, consequently, struggle with adherence. Evidence suggests that after three days, a user retains only 10-20% of written or spoken information, but almost 65% of visual information.⁴ Both comprehension and adherence have been shown to be improved by the use of a visual reference (pictogram) in addition to explanatory text.⁵ Visual content plays a role in everyday life; it is now possible through faster broadband and cellular networks to utilise this for the purpose of healthcare education. We hypothesised that by producing an educational video, containing quality information and hosting it via our Health Board's 'YouTube' channel, we could improve the patient experience in the following ways:

1. Dietetic advice almost immediately following diagnosis resulting in faster resolution of symptoms
2. Highlighting to patients the importance of adherence – a greater emphasis placed on the speed at which advice is provided may result in a perceived greater importance by patients with the potential to positively influence adherence
3. When patients attend for their 1:1 consultation with the registered dietitian, they will have had experience of the diet making the 1:1 more meaningful and individualised
4. Patient empowerment to manage their condition from the very beginning of the therapeutic relationship
5. Ability to review the information contained in the educational video as many times as necessary and with as many friends/family/carers as is required to support their adherence to dietary treatment
6. Signpost patients to other reliable sources of information to support diagnosis and treatment.

Additional advantages for our organisation and service included having a transparent Health Board wide treatment pathway to reduce waste, harm and variation, and under resourced dietetic time could be utilised to provide greater support to clients with more complex coeliac disease or those needing greater support.

Funding

In mid-September 2015 we applied for the inaugural 'Dr Schär Institute Gastroenterology Project Award' to win a project-funding grant of £5000. This was a quick and simple application process requiring an outline of the project, including



who the project would benefit, what it involved, where it would take place, and how positive clinical outcomes would be demonstrated. We were also required to include a budget for how the money would be spent. By the end of September, we were notified we had been shortlisted for the award, and by mid-October we were notified that we had won!

Development

Having been notified that we were successful in winning the Dr Schär Award, we collected the award at the British Dietetic Association Gastroenterology Specialist Group study day in November 2015, with a brief presentation of the idea to the study day attendees, and then the hard work began. The gastroenterology dietitians within our Health Board met in November 2015. This included

representatives from both adult and paediatric services. The initial meeting was to discuss and define the content of the video. At this stage we had a standard educational video in mind, with basic images and a presenter, or voice over narrator, providing the information. We sought advice from Cardiff and Vale Media Resources Team about the running time of the video. It was suggested that around 12-13 minutes would be optimum and we should avoid exceeding 15 minutes. It was agreed that we would produce the information in chapters, so that if anything required amending or editing in the future it would be a simpler process. This also meant patients could watch the whole video or break it into 'bite size chunks'. At this time, we discovered that we had a patient in our paediatric service whose mum was an actor, script writer and voice over artist, and that she would be more than happy to meet with us and give us some advice.

In January of 2016, we met with our volunteer actress/script writer/voice over artist and informed her of our thoughts. Straight away she steered us in another direction suggesting that the video should be a patient's journey as seen from their perspective. This would be visually more interesting, and 'speak' to the patients more directly. Our dietetic team needed little convincing and so the script writing began. Channelling our inner 'script writer' was challenging. This was less of dietitians translating nutrition science into practical advice and more of dietitians channelling dramatic flair and truly attempting to step into a patient's shoes!



Peer review and patient engagement

Once we had a script that we had voice rehearsed and timed to ensure it fitted within our time parameters (draft number 10), we were ready to seek peer review and patient's views. The judging panel for the award had agreed to peer review the script. We also asked Coeliac UK to do the same. All feedback was incorporated into the script. We held patient panels where discovery interviews were undertaken to explore experiences of diagnosis. We were keen to ensure that the pathway and concept was perceived as beneficial and empowering from the patient's perspective, and that we had addressed the core concerns that these patients had experienced at the time of their diagnosis. Brutal honesty about the video content and tone was encouraged and the feedback was indispensable.

Learning points

Alongside the peer review and patient engagement, we were exploring how to find and employ actors or voice over artists. This is not a standard NHS procurement process! We also scouted locations and agreed each screen frame with our helpful cameraman. There were many barriers in obtaining authorisation for filming in supermarkets, or even for a supermarket's customer services to advise us who would be able to authorise such a thing. Time was spent attempting to understand the complexities of royalties, copyright and long-term costs of hosting a video in different media formats for the digital age. Describing this experience as a steep learning curve would be an understatement!

The fundamental learning points have been:

- Patient engagement is crucial and their perspective is possibly the most valuable
- Stepping outside of your comfort zone can indeed feel uncomfortable, but is ultimately rewarding and incredibly exciting
- There is huge enthusiasm and support available for novel ideas and projects.

Use all of the offers of support to make your project the best it can be

- The various steps and stages possibly all took longer than expected, so do not set a short deadline for completing this type of project and allow flexibility to make sure time pressures don't inhibit the process
- There are many people involved and co-ordinating a project of this nature takes good time management and leadership skills
- The script is the crux of the project, getting this right helps everything else to fall into place and determines the success of the entire project. Taking as much time as needed on this aspect of the project is invaluable. In the end it was possibly script number 25 that was filmed.

The future

The video is not yet finished, filming has been completed and the editing is underway. Evaluation of the new pathway will be through several methods:

1. Discovery interviews for patients who follow the new pathway
2. Auditing compliance to the pathway
3. Number of patients unable to comply to pathway, i.e. no DVD/internet access, visual or hearing impairment, requiring an interpreter
4. Time to receiving treatment, i.e. biopsy results to patients receiving access to the video
5. Establishing number of patients who have started a gluten-free diet at initial face-to-face dietetic review.

If the video is positively received by patients, and well evaluated, then we would be keen to share the resource UK wide. We have ensured that whilst the video has been produced to meet our local population in Wales within the context of gluten-free prescribing, there is an alternate ending available to ensure it can be applied to the UK population more widely.

Lastly, I fully expect to be able to add a few additional learning points to my list before the project is fully completed.

Declaration: This article was commissioned by The Dr Schär Institute. The opinions expressed within the article are those of the author alone.

References: **1.** National Institute for Clinical Excellence (2015). Coeliac disease: recognition, assessment and management. NICE guideline [NG20]. Accessed online: www.nice.org.uk/guidance/ng20?unlid=732265044201673144654 (Sept 2016). **2.** Ludvigsson JF, et al. (2014). Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology. Gut; 0: 1-20. **3.** Coeliac UK (2016). Factors affecting adherence. Accessed online: www.coeliac.org.uk/healthcare-professionals/management/ (Sept 2016). **4.** Dale E (1969). Cone of experience, in *Educational Media: Theory into Practice*. Wiman RV (ed). Charles Merrill: Columbus, Ohio. **5.** Katz MG, Kripalani S & Weiss BD (2006). Use of pictorial aids in medication instructions: A review of the literature. Am J Health-Syst Pharm.; 63(1): 2391-2397.

The Dr Schär Institute (DSI) Nutrition Project Award

At the time of publication, judging for the 2nd DSI Nutrition Project Award (formally known as the DSI Gastroenterology Project Award) will be well underway, with winners to be announced by the end of 2016. The Award hopes to encourage quality and innovation in patient care by providing small-scale service development funding for projects or initiatives specifically designed to improve the nutritional/dietetic care of patients with a gastroenterological condition. If you, or your department, have an innovative project idea to enhance the services you offer to your patients, look out for first announcements of the 2017 DSI Nutrition Project Award early next year...it could be you!