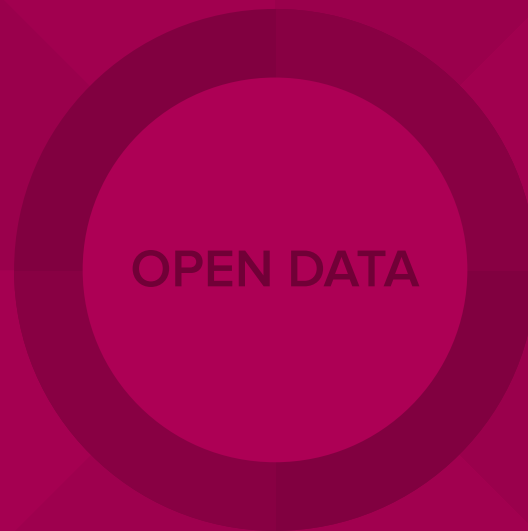


OPEN DATA'S IMPACT

COELIAC UK AND BRANDBANK: A VIEW FROM THE OTHER SIDE OF OPEN



by Becky Hogge

January 2016

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Summary

Gluten-Free on the Move is an award-winning app designed to help coeliac sufferers adhere to the strict gluten-free diet that is the only treatment for their condition. It is the result of a data-sharing agreement between Coeliac UK—a patient self-help society—and Brandbank—Europe’s largest provider of digital content for online retail portals. The Brandbank/Coeliac UK

partnership shares several features of other cases in this report, but exhibits one important difference: The data is not open data, Brandbank licenses it to Coeliac UK. The case is included in this report to underline the importance of considering the counterfactual when evaluating open data impact. Those examining open data impacts should be ready to ask the question: Are these impacts only happening because data is open? What else about this dataset is contributing to these impacts?

Key Takeaways

- Coeliac UK has transformed Brandbank’s data: It now serves a market Brandbank would probably never reach on its own, with important social and health impacts.
- Brandbank operates in a highly standardised and regulated environment. Barcodes¹ were the backbone to this project’s success.

Barcodes enabled Coeliac UK to bring its information on gluten-free foods to a whole new platform—smartphones—and transformed the way coeliacs could shop for food.

- Coeliac UK found Brandbank, asked for access to the data, and got it. Open data policy played no role. Those examining open data impact should be prepared to ask the question: Would impact still have

¹ Specifically, the GTIN barcode data standard, maintained by GS1 (GS1 n.d.)

occurred if the data in question was not open data?

- Moving to an open data approach might benefit Brandbank's business: The suppliers and brands who pay to

be part of the Brandbank database do so to achieve "high visibility" for their products on online retail platform and other third parties.w

The case in numbers

- Number of people in the UK diagnosed with coeliac disease: >160,000
- Percentage of a sample of coeliacs who report being glutened in a six month period: 54%
- Members of Coeliac UK: 60,000
- Number of downloads of Gluten-Free on the Move: 70,500
- Increase in products listed thanks to data-sharing partnership: +50% (~5,000 products)

Quote

"Love using the scanner on my new Coeliac UK app it's genius! Thank you for making gluten-free life simpler"

Gluten-Free on the Move user

Background

Coeliac disease is an auto-immune disease caused by intolerance to gluten. Complications associated with untreated coeliac disease include osteoporosis, small bowel cancer, and non-Hodgkin's lymphoma. Around 1 in 100 people are thought to suffer from coeliac disease in the UK, although only a quarter of them are diagnosed. Coeliac disease is caused by a reaction of the immune system to gluten—a protein found in wheat, barley, and rye. When someone with coeliac disease eats gluten, their immune system reacts by damaging the lining of the gut.

Coeliac disease has no cure, and the only treatment for coeliac disease is a strict gluten-free diet for life¹. Maintaining this regime is tough, since many staples of the Western diet include gluten (e.g., bread, pasta), processed foods, soups, and sauces can contain hidden gluten, and foods intended to be gluten free can easily become contaminated in kitchens where gluten is present (e.g., through cooking equipment, especially toasters and deep fat fryers).

¹ Coeliac UK. (n.d.). *History of Coeliac UK*. Retrieved September 30, 2015, from Coeliac UK: <https://www.coeliac.org.uk/about-us/our-organisation/history-of-coeliac-uk/>

Coeliac UK was founded in 1968 by Peter Benenson, the founder of Amnesty International and himself a coeliac sufferer, and Elizabeth Segall, mother to a coeliac child². It is “probably one of the best national coeliac societies in the world” and was one of the first patient self-help societies to be established in the UK³. Today, it has over 60,000 members, who pay a membership fee of between £12 and £30 per year depending on their circumstances. The charity receives no funding from government, and supplements its membership income with fundraising activities. The charity’s work includes supporting its members in maintaining their gluten-free diet through various information sources and local groups, campaigning on policies that affect its membership such as food labelling and prescription of gluten-free foods, and funding research into the condition.

Brandbank was established in 1998 and is based in Norwich. It describes itself as a “world leader in providing rich digital content” and its core business is in supplying detailed product data and images of food and pharmaceutical products to online retailers. Its retail clients include Boots, Tesco, and Waitrose and it currently holds details of 250,000 products from over 6,000 different suppliers in its database. In January 2015 Brandbank was acquired by global information and measurement company Nielsen Holdings in a multi-million dollar deal⁴.

In June 2014, Coeliac UK launched its *Gluten-Free on the Move* app, allowing users to scan food product barcodes to ascertain whether they were safe for coeliacs to consume⁵. The app contains details of around 15,000 branded and supermarket own-brand products, and is powered in part by Brandbank data.

The data

Brandbank captures “full back-of-pack data as well as high resolution images of each product”⁶. The company’s preferred method is to capture data from a physical sample of the product. Suppliers send Brandbank a sample of the product, and Brandbank then photograph it in a professional studio to provide all the images of the product that consumers will later see on e-retail platforms such as Amazon.

While these images are in post-production, data entry teams capture the detailed nutritional and allergen information online suppliers and retailers are bound by law to communicate to consumers, so that consumers buying the product online can make as informed a choice as if they were holding the package in front of them in a shop. The backbone of this data capture is the product barcode standard GTIN, maintained by GS1, which sets set rigorous standards around, for example, when changes to products necessitate new barcodes.

2 Wikipedia. (n.d.). *Coeliac UK*. Retrieved September 30, 2015, from Wikipedia: https://en.wikipedia.org/wiki/Coeliac_UK

3 Howdle, P. (2010). *Your Guide to Coeliac Disease*. UK: Hodder Arnold.

4 Brandbank. (2015, January 22). *Nielsen acquires Brandbank*. Retrieved from Brandbank: <https://www.brandbank.com/blog/brandbank-news/nielsen-acquires-brandbank/>; Mills & Reeve. (2015, February 09). *Mills & Reeve advise on multi-million dollar sale*. Retrieved from Mills & Reeve: <http://www.mills-reeve.com/mills-reeve-advise-on-multi-million-dollar-sale-02-09-2015/>

5 Coeliac UK. (2014, June 27). *Coeliac UK's smartphone app available on iPhone and Android devices now*. Retrieved from Coeliac UK: <https://www.coeliac.org.uk/about-us/news/coeliac-uks-smartphone-app-available-on-iphone-and-android/>

6 Interview, Beau Archer, Technical Pre-Sales Consultant, Brandbank

Once the supplier has approved the images and data captured by Brandbank, it goes live on Brandbank's database of over 250,000 products. Online retailers then access the data to populate their retail platforms, using a number of approaches including Brandbank's own API.

The Brandbank dataset is not open data. Brandbank owns the intellectual property in the images and data it captures, and it licenses this data to the retailers that use it. Agreements with the retail platforms who partner with Brandbank are subject to commercial confidentiality. When asked to elaborate on the Brandbank business model, and specifically whether Brandbank charges retailers for access to their database, Beau Archer, Technical Pre Sales Consultant at Brandbank, responded:

*Giving retailers access to our product content is core to the **Brandbank** business. Ecommerce is becoming a more important revenue engine for Brands, and [they] therefore want to ensure that the consumer has visibility of their products. Visibility of products comes through the retailer and 3rd parties.⁷*

Brandbank was unwilling to go into further detail on their business model, but this statement could be taken to read that suppliers pay to be in the database, and retailers are given access for free. Indeed, the Brandbank website indicates suppliers pay Brandbank an annual subscription⁸.

Beau Archer states that Brandbank generally "[does] not control how retailers use [its] content"⁹. The exact terms under which Brandbank licenses its data to retailers are also subject to commercial confidentiality. But Brandbank has developed its own browser extension for consumer use, Shopper Goggles, which may shed some light on the priorities of the company when licensing its data. The free tool allows users to layer Brandbank data over retail platforms not partnered with the company, and contains (among others) the following licensing conditions:

You are permitted to download Shopper Goggles solely for your own personal and private use. You must not:

- reverse compile, disassemble, reverse engineer, decompile, copy, duplicate, modify or adapt any software or other code or scripts forming part of Shopper Goggles; or
- publish, distribute, sub-license or sell Shopper Goggles to anyone else; or
- use Shopper Goggles in contravention of any applicable law.¹⁰

Even if large retailers do access Brandbank data for free, this may not be the case for all of its data re-users. Brandbank differentiates between 3rd party users of its data:

7 Interview, Beau Archer, Technical Pre-Sales Consultant, Brandbank

8 Brandbank. (n.d.). *FAQs*. Retrieved September 30, 2015, from Brandbank: <https://www.brandbank.com/about/faqs/>

9 Interview, Beau Archer, Technical Pre-Sales Consultant, Brandbank

10 Shopper Goggles. (n.d.). *Terms & Conditions and Legal Stuff*. Retrieved September 30, 2015, from Shopper Goggles: <http://shoppergoggles.com/terms-conditions-legal-stuff/>

As a supplier has a focus on high visibility of its products, Brandbank wants to ensure that we are appealing to all ranges and types of 3rd parties. This includes the large retailers, however there are other types of businesses that may require this data such as an eRetailer, nutritional apps etc., which we would call syndication.¹¹

Users

Coeliac UK began producing lists of foods suitable for coeliacs in 1968¹². One of the key benefits of becoming a member of Coeliac UK today is receiving a copy of their annual **Food and Drink Directory**, which lists thousands of brands and supermarket own-brand products that are suitable for coeliacs to eat. As well as detailing foods available on prescription and those certified gluten-free, the directory focuses on the hard-to-judge products that could contain hidden gluten, such as ready-meals, breakfast cereals, soups, and sauces. In this section of the directory, Coeliac UK list foods that have no gluten-containing ingredients, and that are produced in environments where sufficient care is taken to avoid cross-contamination with gluten. Throughout the year, Coeliac UK posts updates to the directory, where food products have changed in some identifying detail (e.g., name/weight) but are still safe, or where Coeliac UK has received information that food products are no longer safe.

For many years, Coeliac UK liaised directly with suppliers and food manufacturers to ascertain which products could be listed in its directory. The directory is also available electronically, in the members area of the Coeliac UK website. But although a smartphone app associated with the data was an obvious next step for Coeliac UK, it was held back by how hard it was to match products to the most obvious input for such an app: their GTIN barcode identifiers. Kathryn Miller, Food Policy Lead at Coeliac UK, says the department at the supplier organisation who dealt with product barcodes was always different from the one they were dealing with to ascertain ingredients and manufacturing processes, making matching data hard.

Coeliac UK's relationship with Brandbank began in 2013. One of Brandbank's directors is a coeliac and Beau Archer says the initial approach from Coeliac UK represented "a perfect fit to work together"¹³, since Brandbank captures all data that appears on product packaging, including allergens such as gluten. Crucially for Coeliac UK, Brandbank's database is built around the GTIN barcode standard, so an app based on their data would allow users to scan barcodes of products in-store, and find out immediately whether the product was listed in the directory as suitable for them to eat.

After gaining access to the Brandbank database, Coeliac UK hired a data company to help them work out a set of rules they could apply to the data to identify candidate products for the app. Once these rules are applied to the data, Coeliac UK performs extensive manual checking based on its in-depth sector knowledge. This both ensures the products identified are suitable

¹¹ Interview, Beau Archer, Technical Pre-Sales Consultant, Brandbank

¹² Coeliac UK. (n.d.). *History of Coeliac UK*. Retrieved September 30, 2015, from Coeliac UK: <https://www.coeliac.org.uk/about-us/our-organisation/history-of-coeliac-uk/>

¹³ Interview, Beau Archer, Technical Pre-Sales Consultant, Brandbank

for coeliacs, and checks that no products have been excluded by the filter that are suitable. The resulting app, *Gluten-Free on the Move*, also includes details of cafes, restaurants, and other venues accredited by Coeliac UK as catering well for coeliacs. It launched for iOS and Android platforms in June 2014.

Outcomes

In the month of its launch, *Gluten Free on the Move* won “Best Audience Migration to Mobile Technology” at the 2014 UK Mobile & App Design Awards. In September of the same year, Kathryn Miller won TalkTalk’s Healthy Living Digital Hero Award¹⁴.

Coeliac UK reports that so far, the app has been downloaded 70,500 times¹⁵, indicating it may be reaching considerably beyond Coeliac UK’s member base. The app provides free services including food label guides, a gluten-free checklist and eating out tips, but only Coeliac UK members can access the food directory and venue guide elements. Coeliac UK reports that the app is typically used on 5,000 devices each week, and that it is used in excess of 2,000 times a day resulting in more than 200 food products a day being matched and 100 venues being looked at.

Coeliac UK is yet to develop the app for other platforms such as Windows mobile, to the ire of some of its members¹⁶. In August 2015 Coeliac UK announced a new feature letting users download the full dataset to their phone, so they can refer to it in the absence of a network connection.

Impact

A study¹⁷ published in 2013 involving 287 coeliac sufferers in North East England found that 54% had inadvertently consumed gluten in the past 6 months, even though 84.7% of respondents reported that they intended to keep to the very strict gluten-free diet that is the only treatment for their condition. Only 15.7% of respondents reported never having inadvertently consumed gluten since diagnosis.

Clearly, even with the best intentions, sticking to the strict gluten-free diet required to treat coeliac disease is hard. The same study found that perceptions of difficulty—often reinforced by the frequency with which sufferers make mistakes and get glutened—can feed into negative self-efficacy that in turn discourages some sufferers from maintaining their treatment.

14 TalkTalk Digital Heroes. (n.d.). *2014 Winners*. Retrieved September 30, 2015, from TalkTalk: <http://digitalheroes.talktalk.co.uk/past-winners/2014-winners/>

15 Private communication, Kathryn Miller, Food Policy Lead, Coeliac UK

16 Coeliac UK. (2014, September 29). *Post announcing launch of new version of Gluten Free on the Move*. Retrieved from Facebook: <https://www.facebook.com/CoeliacUK/posts/811396572214734>

17 Hall, N., Rubin, G., & Charnock, A. (2013). Intentional and inadvertent non-adherence in adult coeliac disease: a cross-sectional survey. *Appetite*, 68 (1), 56-62.

The study reports that:

When asked what would make sticking to the diet easier, the most frequently cited responses related to better quality, choice, cost and availability of gluten-free food, followed by improved awareness and understanding, clearer and universal product labelling and clearer information when eating out.¹⁸

The **Gluten Free on the Move** app contributes to several of these goals, not just in terms of information but in terms of non-specialist products the app helps coeliacs consume with confidence.

For the purpose of this report, Coeliac UK shared a number of tweets praising the app.

"Love using the scanner on my new @Coeliac_UK app it's genius! Thank you for making gluten-free life simpler"

"Impressed with @Coeliac_UK app for mobiles. Something to have a play with over next day or two. Thanks to all involved in its design."

"Whoa ho I have the long awaited @Coeliac_UK app. #makeslifeeasierforcoeliacs out and about. Yippee"

"Just downloaded the @Coeliac_UK app which is out today. Fantastic to have the gluten-free food & drink directory in electric on-the-go format"

"@Coeliac_UK the #gf (girlfriend) has already given it a go and is impressed. Will make #gf (glutenfree) life much easier! Great work, thanks"

"Great app will definitely help us getting our 5 year olds diet right @Coeliac_UK #glutenfree"

"@Coeliac_UK many thanks for info packed, easy to navigate app. Will certainly make my #glutenfree life much easier and safer. Great charity!"

*"New @Coeliac_UK app is AWESOME! Venue map and barcode scan function are superb. Been practising already! *very happy face*"19*

18 Hall, N., Rubin, G., & Charnock, A. (2013). Intentional and inadvertent non-adherence in adult coeliac disease: a cross-sectional survey. *Appetite*, 68 (1), 56-62.

19 Private communication, Kathryn Miller, Food Policy Lead, Coeliac UK

Although some app users find it frustrating that more products are not listed by the app, the partnership with Brandbank has meant that Coeliac UK has already been able to increase the number of products listed as suitable from 10,000 to more than 15,000.

Kathryn Miller says an increase of this magnitude is probably a one-time thing, rather than a rate they can expect the directory to expand at year-on-year. Nonetheless, the aim of Coeliac UK is to use the Brandbank data to gradually continue the expansion of listed products. Right now, Coeliac UK is “just getting to grips with”²⁰ the possibilities using Brandbank data has for their mission. For example, monthly updates, which used to number between 10 and 50, now number in the hundreds. The vast majority of these are additions (new products that are suitable for coeliacs—overall the market for gluten-free foods is growing rapidly²¹) and amendments to existing products (weight, brand name, etc.), rather than deletions (foods no longer suitable for coeliacs that once were).

Discussion

The case of Brandbank and Coeliac UK has been included in this report as a signpost to those examining open data impact that they should consider the counterfactual. Are benefits being delivered by this or that open data project because the data is open? Or because the data is rich enough, real-time enough, or relevant enough to a particular community? Could impact have plausibly been delivered had the data remained closed, shared only with trusted third parties and under conditions set forth by the data owner?

The social, health, and economic impacts of the *Gluten Free on the Move* app may be hard to quantify, but they are impossible to deny. Like some of the other cases outlined in this report, this impact has been achieved thanks to a specific set of technical conditions—the proliferation among the general UK population of smartphones connected to a nearly always-on internet, and the existence of a highly standardised and rich dataset. Also like other cases, the data in question has been supplied by one entity, Brandbank, and transformed by another, Coeliac UK, such that it fulfils a purpose not envisaged by those who originally collected it.

And yet the data is not open data. Coeliac UK found Brandbank and asked their permission to use the data. That permission was granted, and the result is a relationship that after one year is already benefitting the lives of thousands of coeliacs.

I asked Beau Archer whether anyone at Brandbank was thinking about how open data approaches might play a role in their business moving forward, and he declined to answer. Beau Archer’s rather cryptic description of Brandbank’s business model, where brand visibility is achieved through giving access to the data to third parties, appears in many aspects to

²⁰ Interview, Kathryn Miller, Food Policy Lead, Coeliac UK

²¹ Booth, S. (2014, May 14). *The growth of gluten-free food: 10 of the best products*. Retrieved from The Guardian: <http://www.theguardian.com/lifeandstyle/2014/may/14/growth-gluten-free-10-best-products>

match what the Open Data Institute calls a “cross subsidy model” of open data business²². In a cross-subsidy model, data publishers derive value from opening up their data by reaching more customers, or providing enhanced services to existing customers, through wider sharing and use of the data. As such, the “cross-subsidy model” looks like a good fit for Brandbank.

Calls to action

For open data advocates

- Brandbank UK may be operating closer to an open data business model than they realise. Their data is rich and standardised and has the potential to benefit many more groups than just Coeliac UK. Governments are obvious targets for open data advocacy because of their public service mission and extensive data collecting activities. Private companies like Brandbank will require a different advocacy approach²³.

22 ODI. (n.d.). *How to make a business case for open data*. Retrieved September 30, 2015, from ODI: <https://theodi.org/guides/how-make-business-case-open-data>

23 The Open Data Institute has published the first in a series of research outputs on open data and business, see (Open Data Institute, 2015)