

A Thesis Submitted for the Degree of PhD at the University of Warwick

Permanent WRAP URL:

<http://wrap.warwick.ac.uk/103497>

Copyright and reuse:

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it.

Our policy information is available from the repository home page.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk

**Coeliac Disease:
Chronic Illness and Self-Care in the Digital Age**

by

Sam Martin, BA, M.Sc.

Ph.D. candidate 2013-2017

Student no: 1358557

Thesis

Submitted to the University of Warwick

for the degree of

Doctor of Philosophy

Centre for Interdisciplinary Methodologies

and

Department of Sociology

September 2017

Table of Contents

Figures	4
Tables	6
Acknowledgements	7
Declaration	8
Doctoral Training Undertaken	9
Publication Mentions	10
Conference Publications	11
Abstract	13
Glossary	14
Chapter 1: Introduction	16
Statement of Gap in Literature	17
Chapter Summaries	20
Chapter 2: Literature Review	23
Biographical Disruption.....	24
Illness narratives.....	29
Technologies of the Self	33
Risk Coeliac-tivism on Social Media.....	38
Gamification.....	45
Visualising Self Care	54
Visualising the Self in Photos.....	60
Conclusion.....	61
Chapter 3: Methodology	62
Selecting Social Media Data Samples	62
Crossing platforms.....	76
Hashtag Analysis.....	82
Analysing Facebook comments	85
Using Instagram and reading images	87
Ethical Considerations.....	93
Conclusion.....	95
Chapter 4: Symptoms, Subjectivity and Selfhood	97
Symptoms in context.....	97
Behavioural adjustments to the GFD	100
Visualising the GFD.....	102
Instagram and shared Coeliac symptoms.....	109
Sharing Subjectivity and Stigma via social media	114
Food as Medicine	122
Conclusion.....	127
Chapter 5: Risk Communication and Activism on Social Media ..	129
Food risk and social media as strategic communication tool.....	130
The case(s) of the Genius Foods recall	132
The case of the Cheerios (General Mills) recall.....	135

Coeliac-tivists and the Cheerios Recall.....	140
Coeliac-tivism, Risk and Technologies of Self.....	143
Conclusion.....	154
Chapter 6: Coeliacs, Social Media and Gamification	159
Turning User Data on Social Media into Gamified Learning Tools....	160
Gluten Fighters.....	160
Coeliac Sam: Learning Basic Gluten Free Diet Concepts with Games	163
Conclusion.....	170
Chapter 7: Visualising CD and Comorbidity on Social Media	173
Visualising CD.....	178
Gamifying the Mundane: Coeliacs and the Gluten free Diet	178
Coeliacs and the #Spoonie hashtag	183
Digital Photovoice: Visualisation of Coeliac comorbidity	186
Visualisation of Embedded, Sensory experience of chronic illness ..	189
Illustrative Study: Spoonie Living App	190
Visualising Comorbid practices of Self care.....	194
Visualising the Invisible: Hidden Chronic Illness and Visibility of Self in Photos.....	201
Live Methods & Call-and-Response	209
Gender usage	215
User Feedback.....	216
Private vs Public Visualisation: User Experience.....	220
Conclusion.....	224
Chapter 8: Conclusion	227
Chapter Summaries	228
Limitations of the Research.....	239
Policy Implications	240
Appendix I	245
Appendix II.....	246
Ethics Review Form	246
Bibliography	255

Figures

Figure 1. Comparison and testing of Streaming and Gnip metadata.	74
Figure 2. Skewed trending tweet rates in Streaming API vs Firehose tweet rates	75
Figure 5. Example of Coeliac Tweet sharing medical details.....	79
Figure 6. Word cloud showing strength of conversation re. diagnostic blood tests and CD symptoms.	79
Figure 7. Word-pair analysis of blood test conversations.....	80
Figure 8. Spoonie Living app: CD and comorbid illnesses.	91
Figure 9. Twitter: Call-and-response sticker collaboration.....	92
Figure 10. Symptoms from deliberate ingestion of gluten.....	101
Figure 11. Instagram: visualising symptoms and remedies	103
Figure 12. Instagram: Remedy for accidental glutening.....	105
Figure 13. #cleaneating photos of users without CD, show majority body/gym shots.....	107
Figure 14. Coeliac posts with #cleaneating = 40% more food images ..	108
Figure 15. Top 10 words co-occurring with symptoms of CD.....	110
Figure 16. Co-occurring words: cause of symptoms.....	111
Figure 17. Symptoms, and co-occurring 'pain' words.....	112
Figure 18. "Stomach" and co-occurring words	112
Figure 19. Being "Sick: co-occurring words.....	113
Figure 20. #NoCureNoChoice network (Instagram).....	121
Figure 21. UK Gluten Free Prescription Map (CoeliacUK.org 2017).....	125
Figure 22. Coeliac-tivist questions mechanical sorting process of oats claimed as gluten free (October 2015)	136
Figure 23. Coeliac-tivist questions mechanical sorting process of oats claimed as gluten free (November 2015).....	137
Figure 24. Mapped: Coeliacs made sick from Gluten Free Cheerios by 21st Sept 2015 (Perry, 2015b).....	139
Figure 25. Cheerios Recall: Consumer Facebook Sentiment: July 2015 - March 2016.....	140
Figure 26. First Tweet conversation mentioning the term "Coeliacivist" (2012)	143
Figure 27. Instagram post, with comments referencing the Cheerios recall and Gluten Free WatchDog analysis	149

Figure 28. Class Action Lawsuit as a result of FDA action from Coeliac- tivist lobbying.....	151
Figure 29. Gluten Fighters game and achievement interface	161
Figure 30. 'Gluten Monsters' (#Glutenmonster) mentioned in Coeliac Twitter corpus.....	165
Figure 31. Coeliac Sam app: Gameplay.....	165
Figure 32. Hashtag analysis of Coeliac Symptoms	166
Figure 33. Coeliac Sam: Super Fruit power-ups: remedies for being glutened.....	166
Figure 34. Coeliac Sam: Game Over - 'Glutened'	166
Figure 35. Coeliac Sam Review/Feedback	167
Figure 36. Spoonie Living app Stickers: Symptoms + identities of CD + comorbidity.....	174
Figure 37. The mundane tasks that a spoon of energy might represent. (Kathleen Hoffman, 2014).....	176
Figure 38. Coeliac photo diaries on Instagram.....	181
Figure 39. Coeliac Meme Poetry: Gamifying the mundane on Instagram	181
Figure 40. #50ShadesofCoeliac - gamifying the mundane with popular film culture	182
Figure 41. Instagram Hashtags co-occurring with #Celiac AND #Spoonie.	184
Figure 42. Coeliac Image Memes: Visual expression of being Glutened	188
Figure 43. Informed consent message and form - wording based on Mappiness study (MacKerron & Mourato, 2013:p.994)	191
Figure 44. Spoonie Living App Stickers + Quantified Tachycardic Symptoms of POTs.....	195
Figure 45. Spoonie visualising identity with CD, IBS and Chronic Pain.	197
Figure 46. Listing diagnosed and undiagnosed comorbid illnesses	198
Figure 47. Varying degrees of visual co-presence in #spoonie photographs	203
Figure 48. No co-presence: Internet Meme with plus app stickers.....	204
Figure 49. #Spoonie visualisation of comorbid chronic pain on both Twitter (less words) and Instagram (more text description)	205
Figure 50. Photo using no visual-co presence.....	207
Figure 51. Spoonie photos tagged with positive Coeliac stickers.....	207

Figure 52. Reminiscing on self prior to biographical disruption of chronic illness.....	208
Figure 53. Previous image to reveal hidden nature of comorbid chronic illnesses.....	208
Figure 54. Work in progress tweets during call-and-response sticker collaboration.....	211
Figure 55. Increase in app user sessions per app update (Apr-July 2016).	212
Figure 56. App Territory downloads (Apr-July 2016).....	213
Figure 57. Tumblr adoption of Spoonie Living App (May 2016)	214
Figure 58. Live Methods + Call-and-Response: Fixing app bugs on live Twitter stream.....	220

Tables

Table 1. Social media data and tools used in thesis	68
------------------------------------------------------------------	-----------

Acknowledgements

I would like to take this opportunity to express my gratitude to the people who have been invaluable during this PhD journey. I thank my supervisors, Dr. Emma Uprichard and Prof. Simon J Williams, for their advice, support and guidance. Thank-you for helping with my development as a researcher, and for the valued sharing of your time, knowledge and expertise. Thank-you also for allowing me to craft my own path, and for asking all the right questions, and placing confidence in my abilities.

Thank-you also to Coeliac UK, the co-sponsors of my research – most specifically Sara Sleet and Heidi Urwin for their belief in my vision and the opportunities they have encouraged. I hope that this research will benefit your much valued and needed work for a long time to come.

Thank-you to every person who has inspired, motivated and encouraged me to complete this thesis and through this challenging journey, including my family, friends and peers. To Magdalena for your much-cherished support and wise advice, that this PhD journey was a marathon, and not a race. Your love, support and many sacrifices, with all that you have done to make this possible, will never be forgotten. I am eternally grateful for everything you have been to me, and the person you continue to be now and in the future. And to Tavian, my brother from another mother, you have been my constant companion through so many things, and have kept me smiling and in hugs throughout, thank-you.

Finally, my deepest and most heartfelt thanks goes to my mother, Theresa. You have been, and will continue to be my life-long inspiration, my rock, and my champion, and without your hard work, support, wisdom, unquestioning love and patience, I would not be here today. I owe you everything and love you eternally.

Declaration

I hereby declare that all of the work presented in this thesis is original material and analysis conducted by myself during the duration of this PhD. None of the material has been published in another thesis, a peer reviewed journal or book.

This Thesis is protected by original copyright.

Doctoral Training Undertaken

- Core DTC Module: Practice of Social Research (Oct-Dec 2013)
- Core DTC Module: Philosophies of Social Science Research (Oct-Dec 2013)
- Mapping, Sampling and Visualising Big Social Data, CASA, UCL (Nov 2013)
- AQMeN: Fast Track Quantitative Methods using SPSS, Edinburgh University (Dec 2013)
- Core DTC Module: Qualitative Research Methods (Jan-Feb 2014)
- Guardian Master Class: Data visualisation (Jan 2014)
- TALISMAN Summer School: Agent Based Modelling & GIS, Leeds University (July, 2014)

Publication Mentions

1) The Lancet Gastroenterology & Hepatology:

Apps: solutions to sociological and health problems.

(Zajanckauskaite, 2017)

The “Fight the good fight” section of this paper reviews the two apps: Gluten Fighters (Martin, 2014d) and Coeliac Sam (Martin, 2014a), that I have developed and deployed to explore self-care and gamification of Coeliac Disease in Chapter 6 of this thesis.

2) British Library Case Studies:

Multimedia PhD Research and Non-text Theses Case Studies:

Sam Martin (Coral Manton, 2016)

The work I have undertaken in this thesis is discussed as part of this case study series, which explored the changing nature of the PhD thesis, and how researchers undertaking multimedia PhDs store and archive content in an accessible way for future researchers to build on.

3) The Happy Coeliac

An interview with Sam Martin, the creator of “Coeliac Sam” –

The Happy Coeliac (Samantha Stein, 2014)

An interview by Coeliac Blogger, Samantha Stein on the research behind the Coeliac Sam app, I have developed and deployed to explore self-care and gamification of Coeliac Disease in Chapter 6 of this thesis.

4) Spoonie Living App

Instagram for the Chronically Ill: #SpoonieLivingApp

(Grace Shockey, 2016)

An independent review of the Spoonie Living app, a research tool and app that I have developed and deployed to explore the visualisation of the self-care Coeliac Disease and comorbid illnesses in Chapter 7 of this thesis.

Conference Publications

- Conference Paper: *'The Digital Coeliac, Twitter and Coeliac Disease, Patterns and Sentiment'*.
Association of European Coeliac Societies (AOECS),
Amsterdam. Sep 7, 2013
- Conference Poster: *'The Digital Coeliac, Twitter and Coeliac Disease, Patterns and Sentiment'*.
Medical Humanities Conference, Warwick Medical School
(November 2013)
- Conference Presentation: *'Twitter, The City & The Gut: How Coeliacs Self-Manage Chronic Disease in the City'*.
Centre for Interdisciplinary Methodology, PhD Research Day,
Warwick (May 2014)
- Conference Poster: : *'Twitter, The City & The Gut: How Coeliacs Self-Manage Chronic Disease in the City'*.
Warwick Business School: Computational Social Science
Conference (June 2014)
- Conference Paper: *'Twitter, the City and the Gut How Coeliacs find food & re-write the city landscape with health-related knowledge'*.
BSA Conference. Ageing Society & the Body. British Library,
London (Dec 2014)
- Conference Paper: *'The Digital Patient: From New Expert to Digital Quantifier and Qualitative Image Diarist'*.
Conference: "25 Years of Public Health Criticism: Critique and Nostalgia in Public Health", London School of Hygiene and Tropical Medicine (Sept 2015)

- Conference Paper: *'Twitter, Instagram, the City and the Gut: Learning how to self-manage chronic illness through gamification'*.
 Medical Sociology Conference: British Sociological Association
 (University of York)
- Conference Paper: *'Spoonie Living App: Visualising The Experience and Self Care Of Coeliac Disease: a study in the use of apps to help with the self-care of coeliac disease'*.
 Quantified Self, Symposium on Pain, Singularity University,
 Mountain View, California, USA (Nov 2015)
- Conference Poster: *'Spoonie Living: Visualising The Experience and Self Care Of Coeliac Disease' (Winner of the Poster prize for Most Commended Academic Research Abstract)*.
 Coeliac UK Research Conference, 2016. Royal College of Physicians, London (March 2016)
- Conference Paper: *"Case study: Coeliac 'Millennials' and the Twitter generation"*.
 Food Matters Live Conference, Free-from, Allergy and Intolerance stream. London, (Nov 2016)

Abstract

This doctoral research contributes to three main fields: the Sociology of Health and Illness (SHI), specifically in the way it speaks to Coeliac Disease; and the field of Big Social Data and Health in general. Research in SHI, has typically focussed on the effects of diagnosis on self-identity, and illness narratives used in adapting to life with chronic disease. While there have been recent studies looking at how general food cultures, obesity and diabetes are visualised on social media, there have been no studies about the visualisation of self-care and identity in relation to Coeliac Disease specifically. Current social research in Coeliac Disease is mainly focused on the psychological impact of being diagnosed with Coeliac Disease and the challenge the gluten free diet can put on individuals. There is little in the literature about how individuals self-manage Coeliac Disease or share identity across social media platforms, or how they use social media to navigate risk. Current literature in the field of Big Social Data and Health, mainly looks at how social media offers opportunities to socially share or disseminate public health information between organisations and the public, as well as how the use of wearable technology and apps are used to quantify health. It does not look at how the chronically ill share symptoms, identity and self-care across social media platforms. This thesis adds to the literature by bringing together the fields of SHI, Big Social Data and Health, and Social Science research into Coeliac Disease to understand and visualise the way Coeliac patients actively use social media platforms in the process of self-care and self-identity. It explores how social media can be used to tell a chronic illness narrative, and thus illustrate the process of diagnosis, and how individuals adapt to life as a Coeliac on the gluten free diet (GFD). In doing so, this research provides an illustrative example of how social media data can be used to both inform and complement research on Coeliac Disease specifically, and the fields of SHI and digital social science more generally.

Glossary

Arthritis: is a term often used to mean any disorder that affects joints. Symptoms generally include joint pain and stiffness (NHS Choices, 2015).

Big Social Health Data: The term “Big Social Health Data” is different to the standard understanding of “Big Data”, in the way that it focuses on digital “social health” as a series of interactions and communications that occur via social media when discussing or sharing the experiences of managing illness.

Biosociality: The modern creation of social relationships, communities and identity - based on shared genetic or biological conditions (Rabinow, 1996)

BioCitizenship: The collective sharing of knowledge about a specific biological disease, as well as how people within those communities build and share their identities and self-care practices around this (Rose & Novas, 2007:p.440;441; Sarrett, 2016).

Biosocial Citizenship: How people take the way in which they are described by science and the medical system and transform that definition into their own identity. (Ene, 2009).

Clean Eating: (also the hashtag #cleaneating): a diet based on eating foods that are unprocessed, or minimally processed, refined, and handled.

Chronic Fatigue Syndrome (CFS): is a long-term illness with a wide range of symptoms. The most common symptom is extreme tiredness. CFS is also known as M.E (**Myalgic Encephalomyelitis**) (NHS Choices, 2015).

Coeliac Disease (CD): 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 small intestine.

Coeliac-tivist: A Coeliac that engages in activism in defence of the perceived right of Coeliacs to have safe access to gluten free food

Crohn's disease: is a type of **inflammatory bowel disease (IBD)** that may affect any part of the gastrointestinal tract from mouth to anus. Signs and symptoms often include abdominal pain, diarrhoea (which may be bloody if inflammation is severe), fever, and weight loss (NHS Choices, 2015).

Diabetes: is a lifelong condition that causes a person's blood sugar level to become too high. There are two main types of diabetes: Type 1 Diabetes – where the body's immune system attacks and destroys the cells that produce insulin. Type 2 Diabetes – where the body doesn't produce enough insulin, or the body's cells don't react to insulin (NHS Choices, 2015).

DX: Diagnosed or Diagnosis

Fibromyalgia: is a condition characterised by chronic widespread pain, and fatigue, as well as gastrointestinal problems (NHS Choices, 2015).

Gamification: The turning of mundane practices into fun or competitive games

GF: Gluten Free

GFD: Gluten Free Diet

Gluten: Gluten is the common name for the proteins in specific grains that are harmful to persons with Coeliac Disease and gluten-related disorders. These proteins are found in all forms of wheat (including durum, semolina, spelt, kamut, einkorn and faro) and related grains rye, barley and triticale (BeyondCeliac.org, 2016).

Glutened/Glutening: A term used to describe the act of or resulting symptoms from the accidental ingestion of Gluten hidden as micro particles in food otherwise presented as gluten free

HRQoL = Health-Related Quality of Life

Hashimoto's Thyroiditis: is swelling (inflammation) of the thyroid gland. It causes either unusually high or low levels of thyroid hormones in the blood (NHS Choices, 2015).

Irritable Bowel Disease or Inflammatory Bowel Disease (IBD): is a term mainly used to describe two conditions: ulcerative colitis and Crohn's disease. Ulcerative colitis and Crohn's disease are long-term conditions that involve inflammation of the gut. Ulcerative colitis only affects the colon (NHS Choices, 2015).

Irritable Bowel Syndrome (IBS): is a common chronic disorder that affects the large intestine. Signs and symptoms include cramping, abdominal pain, bloating, gas, and diarrhoea or constipation, or both (NHS Choices, 2015).

Lupus: is a long-term condition causing inflammation to the joints, skin and other organs (NHS Choices, 2015).

Myalgic Encephalomyelitis (M.E): is a medical condition characterised by long-term fatigue and other symptoms that limit a person's ability to carry out ordinary daily activities (NHS Choices, 2015).

NCGS: Non-coeliac gluten sensitivity (NCGS) or gluten sensitivity is defined as "a clinical entity induced by the ingestion of gluten leading to intestinal and/or extra-intestinal symptoms that improve once the gluten-containing foodstuff is removed from the diet, and celiac disease and wheat allergy have been excluded" (Fasano *et al.*, 2015a).

Postural orthostatic tachycardia syndrome (POTS): is a condition in which a change from the supine position to an upright position causes an abnormally large increase in heart rate, called tachycardia (NHS Choices, 2015).

Spoonie: An individual who suffers from a hidden chronic illness (Miserandino, 2003). 'Spoon' refers to measurements of energy needed to manage daily life while suffering from symptoms.

Spoonie Living App: An app created to study and help visualise the embodied experience of living with chronic and comorbid illness (Martin, 2015).

X-Contam: Cross-contamination

Chapter 1: Introduction

The idea for this thesis originated in 2010, when I was diagnosed with Coeliac Disease, and used Twitter to search for information about where to eat out while sticking to a prescribed gluten free diet. I found that information about Coeliac Disease and the gluten free diet I needed to follow was being shared on Twitter both in text and visual form. This motivated me to develop this thesis which focuses on how Coeliacs use social media to manage their diagnosis, and share their experiences. More specifically, as will be seen, this thesis has culminated into contributing to two main fields: the sociology of health and illness, specifically in the way it speaks to Coeliac Disease; and the field of Big Social Health Data. In doing so, it provides an illustrative example of how social media data can be used to both inform and complement research on Coeliac Disease and digital social science more generally.

Coeliac Disease (CD) is an autoimmune disease, where eating gluten, which is found in wheat, barley and rye, can lead to significant damage of the small intestine (Coeliac UK, 2015a). CD is now seen as an increasingly common disease globally, with studies showing a prevalence of around 1% across many populations (Uenishi *et al.*, 2014; Rubio-Tapia *et al.*, 2012; Lionetti *et al.*, 2015). In the UK, 1 in 100 people have been diagnosed with CD, with a fourfold increase in the incidence of CD in the United Kingdom over 22 years (West *et al.*, 2014); similarly in the USA, the rate is around 1 in 141 (Rubio-Tapia *et al.*, 2012).

For people diagnosed with CD, symptoms from ingesting gluten can vary in type and severity between individuals, ranging from mild to severe. They can be both intestinal, such as diarrhoea and abdominal pain, and extra-intestinal, such as fatigue, joint pain, skin rashes, anaemia, headaches, depression, “brain fog” (e.g. muddled thinking and memory problems), and peripheral numbness. These symptoms may last from a few hours to a few days. In contrast, some patients may be asymptomatic (Kurppa *et al.*, 2014) and experience no symptoms at all. Nevertheless, for both symptomatic and asymptomatic Coeliacs, continued exposure to gluten can ultimately lead to certain types of gut cancer (Coeliac UK, 2014).

The only way to manage this chronic condition is to follow a lifetime Gluten Free Diet (GFD). Post-diagnosis, it is up to each individual to find ways to manage and cope with their diet, and increasingly people are turning to social media to help them do this. Indeed, early in the research, it became apparent that the sharing of the self-management of CD was not confined to Twitter, but was linked to and spread across various social media platforms. This drove me to shift the focus of the study from looking only at Twitter to looking at the activity of Coeliacs across *three* social media platforms: Twitter, Instagram and Facebook. In turn, as will be further explored in Chapter 3 in discussing the methodology of the research, this cross-platform study has used a range of quantitative and qualitative digital methods. With respect to quantitative digital approaches, I have used text and co-occurrence analysis of hashtags and tweets (Hingle *et al.*, 2013; Marres, Gerlitz & Studies, 2016). Qualitative approaches have involved textual analysis of Facebook comments and the visual analysis of images posted to Instagram and Twitter (Ledford & Anderson, 2013; Zappavigna, 2016). This use of digital social media advances both the sociology of health and the work on CD.

Statement of Gap in Literature

While there is a huge body of research relating to health and the interaction between people's online engagement and their health practices (Pickard & Swan, 2013; Fox & Duggan, 2013), the literature is still in relative infancy when looking at how individuals utilise social media for self-care (Michael & Lupton, 2015). Furthermore, there is no literature (at the time of writing), that looks at how Coeliacs utilise social media in particular. What is particular to Coeliac Disease, is how Coeliacs use social media to share their experience of managing the gluten free diet, their experiences of illness symptoms, and their use of social media to gain new knowledge and lobby food suppliers for more and safer options. It is arguable that by studying how Coeliacs utilise social media to share these aspects of self-care, we can gain more insight into how their experiences are affected by their access to resources, their self-perception of their own adherence to the gluten free diet, and how they vary in different self-care practices. Main

approaches look at how e-health can be used for medical intervention to promote healthy behaviour and self-management of chronic conditions (Pingree *et al.*, 2010), while Pickard and Swan have investigated the sharing of health information for research purposes (2013). England and Nicholls (2004) have investigated the quality of e-health information on websites, and Greaves *et al.* (2014) have looked at patient tweets about the quality of hospital care. Murthy *et al.* (2011) have looked at different methods for visualising the support networks of twitter communities for cancer sufferers.

In parallel to these debates in e-health, there has also been an outcry that the social sciences in general is facing an empirical crisis in the new age of Big Data (Savage & Burrows, 2009). Ruppert, Law and Savage argued that what was needed was more access to training and tools that help sociologists better understand the social practices of individuals producing the Big Data and the devices they use to do so, from a more sociological context (2013). Driscoll and Walker have also noted that there is now an unprecedented opportunity afforded to sociology by Big Data, which gives us the potential to analyse human life and interaction (2014). However, Golder and Macy also point out that these opportunities have also come with a number of methodological and logistical opportunities and challenges (2014). They argue that those trained in the traditional social sciences may need to devise more innovative digital methodologies to tackle, both in terms of epistemological practice and the tools used to do so from a sociological/ social sciences perspective (Golder & Macy, 2014).

However, while literature exists on the use of social media networks in the support and sharing of experience of self-care, there is little in the literature with regards to how individuals who self-manage chronic conditions use real-time digital social media platforms as decision-making and risk-aversion tools to navigate their daily environments, as well as share symptoms of their disease. This may be because of the challenging methodological issues involved in studying such behaviour over multiple social media platforms, as well as the relative infancy of the use of social media analysis to study chronic illness activity online. Social media platforms and smartphones allow individuals to embed health knowledge into the fabric of the city (Gordon & de Souza e Silva, 2011). For example,

in the case of Coeliac patients, who must follow a lifetime gluten free diet (Coeliac UK, 2015a), they may not only use social media to question where to find gluten free food, but can also add health-related commons knowledge about these particular venues in real-time. The study of such practices is important as it is arguable that insights from these shared practices may shed light on areas where Coeliacs may be struggling to gain access to gluten free resources vital for their self-management of their health on the GFD. A study of the way that Coeliacs disclose, examine and memorialise their experiences may also offer further information with regards to how well information is being disseminated regarding Coeliac health guidelines with regards to food safety guidelines in general, and regulations that pertain to restaurants and food suppliers and the labelling of food allergens, as well as guidelines with regards to the suitable management of symptoms.

Following from this, little research has been conducted into how we make sense of, or visualise Big Social Data and its relation to health and everyday self-care practices. Ziebland and Wyke (2012) argue that the role of visual information based on online patients' shared experience is a new field with no agreed theoretical and methodological basis, and that the scientific base underpinning this activity needs strengthening. Although there has been a lot of research into the psychosocial effects of managing CD (Howard, Law & Petty, 2011; Sainsbury & Mullan, 2011; Schroeder & Mowen, 2014), and recently, Yi-Frazier et al (2015), have conducted a study looking at how teenagers with diabetes share information on Instagram, an investigation of the current literature has found that (at present) there are no specific studies on how individuals with CD manage their comorbid illnesses, or how this is shared or visualised over social media.

In terms of comorbid illness, as well as a single diagnosis of CD, other associated conditions and complications with CD include osteoporosis, and an increased risk of other autoimmune diseases such as Type 1 diabetes and thyroid disease. The risk of developing these complications is reduced if the gluten-free diet is followed (Coeliac UK, 2015a). While there has also been emerging research into how chronic illness sufferers who also have chronic pain use visual methods via social media to express themselves

(Gonzalez-Polledo & Tarr, 2014), there has yet be any in-depth study into how individuals with CD together with comorbid illness visualise their self-care. The research in this thesis aims to fill these gaps in the literature, by conducting an illustrative exploration that researches how Coeliacs with comorbid illnesses visualise and express their experience of self-care across social media platforms. By using cutting edge quantitative digital methods and experimental 'live methodology' techniques (Back & Puwar, 2012) this thesis explores how Coeliacs self-manage and also visualise their illness(es) via social media technology and platforms.

Having identified the general problem areas to address in terms of further investigating how Coeliacs use social media platforms for self-care, I developed the following research questions:

- How are social media used to self-manage CD?
- How might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness?

As will be shown, these two research questions drive the entire thesis and have helped to frame the empirical analysis throughout.

Chapter Summaries

Following this introduction, Chapter 2 delves even deeper into contextualising the contribution of this research. This second chapter provides a critical appraisal of the literature surrounding the self-management and embodied experience of CD. It positions the empirical chapters within the specific field of the sociology health and illness. It looks at how Coeliacs' social media interactions sit within notions of risk in relation to managing their GFD. It also looks at how the visualisation of symptoms can be used to enhance the understanding of patient experience of chronic disease.

Chapter 3 details the methods of data collection and analysis used to conduct the research. I discuss how I collected images and text from Instagram, Twitter and Facebook. Moreover, I outline how the way that these social media platforms are configured affects the data output,

collection and analysis. Indeed, I show how the data I collected for the first two empirical chapters informs the build and structure of the digital research tool used to visualise comorbid self-care in the fourth empirical chapter.

Chapter 4 is the first empirical chapter. It explores how some Coeliacs use social media to share their symptoms, as part of their overall illness narrative, and adjustment to life as someone with a chronic illness. Issues of selfhood, identity, and biosocial citizenship are also discussed, as well as the use of social media hashtags that are created and used as markers of Coeliac biosocial citizenship, identity and affiliation with symptoms. The use of Coeliac created hashtags like '#glutened' and #NoCureNoChoice, are analysed in terms of how they are used as affiliating identity markers with CD, and the effect that this use of hashtags has on the way symptoms are expressed by Coeliacs within supportive social media networks.

Chapter 5 is the second empirical chapter. It explores how Coeliacs use social media to perform/share their navigation of risk in their daily interaction with food. It also discusses how consumers with CD respond to food product recalls and share information about the food risk that has occurred because of cross-contamination. With an introduction to the term "Coeliac-tivism", this study also looks at how, during a food product a recall, where trust can be temporarily broken in a food brand, some Coeliac consumers' use collective resources to confront manufacturers who they perceive are not handling issues of cross-contamination correctly.

Chapter 6 is the third empirical chapter. It explores how the results of social media research and different modes of gamification can be used to visualise the concept of chronic disease into a gaming format. It also explores how the use of super hero characters may help with the forming of positive self-care practices. The analysis of gamification concepts in this chapter are used as a base for the design of the empirical analysis tool created in Chapter 7 of this thesis.

Chapter 7 is the fourth empirical chapter. It explores how individuals visualise CD and other comorbid disease. As part of this exploration, there is also discussion of how the results of the analysis of Big Social Health

Data from the first empirical chapter on symptoms, were used as a basis to create a digital research tool that explores how Coeliacs with comorbid illnesses visualise their embodied experiences of symptoms. As part of this process, I also discuss how the use of inventive and experimental 'live methods' (Back & Puwar, 2012) can be used in the research of visual interaction on social media, to give a nuanced and visual insight into how people self-managed Coeliac and comorbid chronic disease in particular.

Overall, then, this thesis carefully responds to the two main research questions (i.e. how are social media used to self-manage CD? And how might we use new kinds of gamification to explore the self-management of CD and comorbid illness?). The result is that this research builds on and extends the sociology of health and illness, and especially that which uses digital data, in three main ways. Firstly, it is multi-platform; most work tends to use only one platform – for example, Twitter, or Facebook or recently only Instagram, but not all three. The use of all three platforms is ambitious, innovative and forward-facing. Secondly, the study employs a range of digital methods; most work tends to use either quantitative (e.g. datamining, and sentiment analysis) *or* qualitative (discursive analysis on Facebook comments) digital methods, but not both. Thirdly, within the context of CD research, this research is uniquely situated in terms of how it relates to the digital, mainly because there is as yet very little research on how Coeliacs share their experience of self-care across social media platforms. In addition, the research in this thesis provides further knowledge for the future practice of using health-based social media analysis and smartphone devices to help health authorities better understand self-reported patient practices and the visualisation of CD and comorbid chronic illness.

Chapter 2: Literature Review

In this chapter, I situate the work in this thesis by showing how this research contributes to the field of Sociology of Health and Illness (SHI). More importantly, I show how this study advances this field, and also brings together a number of key scholarly fields that are especially relevant in the context of this study and the findings.

It is worth saying from the outset, that unlike some literature reviews which focus only on one substantive topic, this chapter highlights key fields of scholarship that are relevant to this study. Moreover I show how they build on and each feed into each other. Indeed the order of this discussion develops is quite important to understanding the whole thesis. That is to say, I begin by introducing the notion of biographical disruption. This is a key concept in the sociology of health and illness, which I use to understand how the diagnosis of CD interrupts, what I outline in the second section to be illness narratives.

Because I am using social media to explore this chronic condition empirically, I show that once we start to situate biographical disruption within social media, we also have to critically engage with what digital data are in the context of such things as tweets, Facebook comments, hashtags when they are used within the context of communicating the experience of chronic illness. To do this I show how Foucault's notion of the technologies of self can be particularly helpful in this regard. This discussion of technologies of self constitutes the third part of the chapter. The fourth section builds on the previous three sections, and shows how the concept of risk and Coeliac-tivism become key frames of reference through which I have sought to understand some of the collective behaviour of Coeliacs practices of self-care across these social media platforms. The chapter then shifts a little in its scope in sections five and six. That is, I show how the sociology of health and illness, once viewed through a digital lens with contemporary tools and technologies, offers new venues of digital social science research. Thus in section five, I show how modes of gamification can be used to learn about social science such as the experience of CD. In the sixth section, I also outline the ways in which digital social science can

be explored visually and how the use of digital images, visualisations and apps can further enhance the research of the sociology of health and illness. Finally, I end with a short section, bring the chapter to a close, and signalling how these fields inform each of the empirical chapters more precisely.

Biographical Disruption

The majority of individuals are usually diagnosed with Coeliac Disease (CD) in their third decade, after a period of time with gastrointestinal and other symptoms such as tiredness, skin rash (Dermatitis Herpetiformis), fatigue, weight loss (in some cases), osteoporosis, hair loss, ataxia and depression (Coeliac UK, 2014). In other cases, Coeliac Disease can be asymptomatic or 'silent', however despite lack of presenting symptoms, the long-term health damage has been found to be just as prevalent, and a gluten free diet is still recommended (Hobday, Law & Howard, 2015:p.140). While the majority of people are diagnosed later in life, there is a growing incidence of children being diagnosed after the age of five (West *et al.*, 2014). Where children also have Type 1 Diabetes, a prevalence of Coeliac Disease has been reported at between 5-7 times higher than the general population, with the Coeliac Disease usually presenting as the 'silent' or asymptomatic form of CD (Hobday, Law & Howard, 2015:p.140).

For people in their third decade, being diagnosed after a lifetime with an unrestricted choice of diet, can feel like a huge disruption to their lives. For many, switching to a completely gluten free diet may mean a vast change from their pre-diagnosed life in relation to food, where such a change away from all wheat and gluten-based products may leave them feeling helpless and anxious as to how to navigate finding safe gluten free food in a Western culture dominated by gluten (Howard, Law & Petty, 2011).

As a result of a big change in diet, for some individuals the diagnosis of chronic disease and prescribed lifestyle change can result in what Bury (1982) termed a biographical disruption. That is to say, for newly diagnosed coeliacs, all previous food-related behavior is disrupted and new eating habits need to be formed. Social encounters where the safety of food is

unknown can result in extreme psychosocial stress (Howard & Law, 2011; Rose & Howard, 2014a).

In the context of Coeliac Disease, biographical disruption can occur especially where the onset of symptoms has been sudden. The onset of a chronic illness like Coeliac disease, may disturb not only a Coeliac's physical body, but the trajectory of an individual's life at a number of levels. A person's whole self-biography in relation to how they socialise, consume and engage with food can become disrupted, for example, from how they access gluten free food at home, at work, in meetings, while traveling, and in social eating situations. In these cases, the diagnosis of CD can be experienced as a complete or partial alteration of an individual's lived biography (Williams, 2000a). Indeed, some studies into the effects of diagnosis on individuals have found that some Coeliacs can go through a grieving process linked to the loss of all the foods they used to love eating, and experience feelings of anger and resentment towards the autoimmune disease itself (Skjerning *et al.*, 2014; Schroeder & Mowen, 2014). Extreme cases can even result in depression and withdrawal from social situations (Sainsbury, Mullan & Sharpe, 2013b; van Hees, Van der Does & Giltay, 2013; Ford, Howard & Oyebode, 2012b; Addolorato, 2001).

Importantly, the biographical disruption is not always negative. For some Coeliacs, it can actually be a welcome outcome. Where some individuals may have been ill with gastroenterological symptoms for a long time, or they have been misdiagnosed with other chronic illnesses that present similar symptoms (i.e. Lupus, Thyroid disease, Crohn's Disease or Irritable Bowel Syndrome [IBS]), a correct CD diagnosis may bring a sense of relief. In these situations, after the frustrations of a long and drawn out diagnosis process, individuals may feel that their illness finally has a 'name', and that they have been given confirmation of the legitimacy of their own bodily experiences (Hilbert, 1984).

In instances where there is a positive reaction to diagnosis, the process of biographical disruption can be argued to be more of a 'biographical reinforcement'. The notion of 'biographical reinforcement' has been defined by Carricaburu and Pierret (1995), and later Williams (2000a), as how someone who is already experiencing multiple symptoms/illnesses, reacts

to an additional diagnosis. This new diagnosis is not so much considered to be a major disruption to the individual, but more of a continuation of their biographies, where they have already experienced health difficulties. In this situation, the accumulated comorbidity of chronic illness, and the similarity of digestive symptoms between the two diseases may arguably be less of a major disruption, and more of a continuation of their chronic illness biography. Finally, in situations where the individual is in the middle stages of life (in their mid 50s to mid 60s), diagnosis of a chronic illness may be viewed as just part of the life course of getting older and no longer being young and healthy – and in this case, a biographical continuity (Pound, Gompertz & Ebrahim, 1998).

There is also a growing body of work relating to how the notion of biographical disruption is applied to how children cope with chronic illness. For example, when it comes to children who have been diagnosed with CD at an early age, who are in a sense ‘growing up with’ this chronic illness, some studies have found that a tension can arise between their general actions of coping or living with managing CD, and dealing with peer pressure to ‘fit in’ with their friendship groups (Howard & Law, 2011). Further studies have found that, when faced with revealing their illness to other young peers in social situations, for instance in an attempt to blend in, younger individuals (and at times adults) use ‘normalisation’ as a coping technique, where they ‘bracket off’ the illness so that it affects their social identity as little as possible (Bury, 1991; Kelleher, 1988). In such social situations, despite the harmful results, studies have found that some individuals with CD can deliberately ingest gluten in an effort to normalise their social identity fit in (Chick, 2014; Howard, Law & Petty, 2011; Henricksen & Viller, 2012; Kelleher, 1988).

While well documented research suggests that changing harmful dietary behaviour for patients with CD is a complex process, which can come up against many barriers (Sainsbury, Mullan & Sharpe, 2013b; Kothe *et al.*, 2015), it has also been found that changing harmful behaviour involves new learning and access to resources within the context and physical environment, which can in itself have the most positive outcomes in influencing the learning process (Hingle *et al.*, 2013). It has also been suggested that mapping occurrences of these incidents in the city and

around school and university areas, may be useful in diverting policy and resources into further educational workshops about the damage that gluten can do to the Coeliac gut, as well as providing more gluten free alternatives/options in these areas (Chick, 2014).

While there is a large body of work that looks at how biographical disruption has been managed in everyday life, what has not been studied is how the chronically ill communicate their daily experiences of biographical disruption within social networks and via social media. It is proposed that to gain further insight into how individuals communicate their experience of the diagnosis of chronic illness within social networks, that the notion of biographical disruption needs to be looked at within the context of the digital. What is important about gaining more insight from people's self-reported experiences of biographical disruption on social media, is that it has the potential to give deeper insight into how newly diagnosed and long-term Coeliacs deal with any difficulties in managing their GFD outside of the formal medical setting. As has been found in much social science research, individuals may often reveal more about their ongoing struggles with managing chronic illness in a less formal setting, than they might when interviewed or at a doctor's appointment (Murthy, Gross & Oliveira, 2011). It is arguable that studying examples of biographical disruption as expressed in the digital may provide us with new insight into otherwise unrevealed issues, such as any difficulties of access to gluten free food, overlapping symptoms with other comorbid illnesses, otherwise unreported incidences of gluten cross contamination in restaurants or products labelled as gluten free, and other illness-related issues that might otherwise go undiscovered in more formal settings. It is within this context I propose, that locating biographical disruption within the digital era is one of the ways that this thesis aims to bring the concept up to date empirically and with CD.

As well as an exploration of how Coeliacs self-report their experiences of adjusting to the GFD in empirical Chapter 4 (Symptoms, Subjectivity and Selfhood) and Chapter 5 (Risk Communication and Activism on Social Media) we will also see in Chapter 6, that I present an illustrative exploration of the creation and utilisation of a visual research tool to investigate how Coeliacs share and visualise chronic illness identity precisely to cope with biographical disruption, and share their on-going

illness narratives, can go some way to adding to the literature in this respect.

Whereas in the past, doctors might have been seen to confer diagnoses on passive patients (Foucault & Sheridan, 1973), with increased access to the internet and social media, patients are now, more than ever, becoming *co-authors or co-constructors* of their own diagnoses, working in partnership with doctors in noting symptoms and acting upon found knowledge in the pursuit of a diagnosis (Nettleton & Burrows, 2003; Jones, 2013). This has led to growing awareness of the need to look closely at how individuals use social media to both manage their chronic illness and re-construct their sense of biographical disruption. Thus, in the last decade, we see a growing movement within the research of health and illness that has looked at the use of social media to support the pre and post diagnosis stages of a wide range of different chronic illnesses (Murthy, Gross & Oliveira, 2011; Lee *et al.*, 2014). For example, within the context of cancer support groups, Murthy *et al.* have found that social media platforms like Twitter can enable shared narratives of chronic illness experiences to receive almost synchronous responses and support that can occur regularly throughout the day as individuals check their social media feeds (both digitally and metaphorically) (2011).

Similarly, in relation to communicating different experiences of healthcare, Greaves, Lavery, and Cano *et al.* have also looked at how patients increasingly use Twitter to share their experiences of the quality of hospital care (2014). Their study found that while the majority of tweets mentioned care quality and patient experience, other topics mentioned in tweets included messages of support to patients, fundraising activity, self-promotion and dissemination of health information (Greaves *et al.*, 2014). Other studies, such as that by Stoové and Pedrana (2014) have evaluated considerations for using social media in epidemiology and surveillance, such as tracking rates of discussion about HIV, as well as a tool to predict disease outbreaks, such as influenza and cholera (Broniatowski, Paul & Dredze, 2013; Menon, 2006; Chunara *et al.*, 2012; St Louis & Zorlu, 2012).

Generally speaking, the studies that I have listed are typical of work that has explored social media and chronic illness have tended not to use the

term biographical disruption per se. That is to say, they explore how individuals use social media to talk about the experience of diagnosis, and how to cope with its changing effects on their lives. They each in their own way highlight how social media can be a powerful vehicle in helping to alleviate the burden often felt by those newly diagnosed with a chronic, life-long illness. The consequence of shifting the focus of study from groups to the individual can also provide a deeper insight into how people may manage their experience of diagnosis in isolation, where they have no local support, and may turn to online networks to share their experiences and accumulate new knowledge about self-care practices. In this light, using both textual and visual modes of analyses to study the self-reported practices of individual Coeliacs as they post across different types of social media platforms (e.g. Twitter, Instagram or Facebook) may give us more of an idea of how the chronically ill utilise technology to share experiences of biographical disruption as well as their adjustment to life with a chronic illness.

That said, it is worth noting that, in a critical review of the literature studying patients' use of social media to manage health, Merolli, Gray and Martin-Sanchez (2013) point out this kind of research tended to cover only a very limited range of social media platforms, with a stronger leaning towards researching practices on online support groups, discussion forums and message boards. This may be because the technology for researching health-related user behaviour is still in its infancy, with access to Instagram and Twitter networks, and the in-depth analysis of them outside of hashtag frequency and sentiment analysis still in its early stages. In particular, Merolli, Gray and Martin-Sanchez suggested further analysis of how identity, illness narratives and adaption to chronic illness was discussed and shared over social media (2013).

Illness narratives

The concept of illness narratives was first coined by Kleinman to describe individuals' interpretation of the experience of illness as contributing to how it is understood (1988:p.49). It is concept that has long been studied in the sociology of health and illness. Indeed, Bury speaks specifically about the

ways in which biographical disruption can be expanded by discussing how illness narratives can be instructive to understanding how people make sense of, experience and adapt their illness into their own social identity, depending on the resources available to them (2001). As will be seen later in the empirical chapters, I also use this concept of illness narratives to interpret how Coeliacs use social media to discuss biographical disruption; illness narratives are, therefore, an important concept throughout the thesis. In this way, I follow Bury in bringing together biographical disruption and illness narratives in order to understand chronic illness.

Frank outlined three different types of illness narratives, based on the type of illness or circumstances around that illness (1995); as is illustrated in Chapters 4 to 7, each is relevant to the ways that Coeliacs communicate their experience biographical disruption. The *restitution narrative* is broadly based on non-chronic illnesses, where a person becomes sick, seeks medication or help, and eventually becomes better (Frank, 1995:p.75). The *quest narrative* occurs when an individual shares their own journey with a long-term illness (Frank, 1995:p.115). Along this journey they narrate their quest to readjust their lives to living with a chronic illness, documenting how the illness affects their sense of self, their experience of daily tasks, and their self-awareness (Frank, 1995:p.115).

The final illness narrative category is the *chaos narrative*, this is where individuals share their experience of living with the symptoms of a medically unexplained illness (Frank, 1995:p.97). In these situations, feelings of confusion, frustration and uncertainty are often shared, where the desire to be diagnosed and treated has been found to be the main focus. Feelings of a lack of resolution are most concurrent here, especially where there is no label with which to define the illness under investigation (1995:p.101), or where the embodied symptoms being experienced mean that peoples' daily routines become unpredictable and chaotic themselves (1995:pp.102–103).

The notion of illness narratives is a significant concept that many people have used, but it is only recently that it has been applied to the digital. One of the key authors to locate illness narratives to the digital is Ziebland (2004). She has noted that the use of the internet and social media by some people to share their journey with long-term illness has become

increasingly common, where people not only share their experiential knowledge and document their illnesses, but also interact with others to gain more information and support (2004). In terms of interacting with others, the Internet, she argues, can play a role in influencing an individual's sense of responsibility in terms of managing their illness, and the use of internet sources to share their quest narrative with others (Ziebland, 2004:p.1786).

Ziebland went on to document the sharing of 'quest narratives' through her study of a chronically ill sufferer of inflammatory breast cancer, who documents her journey towards diagnosis via a website, and her multi-channel campaign for information about the disease to be more widely disseminated (2004:pp.1787–1789). This form of online activism, and how it connects to the quest narrative, is also investigated further in this thesis, where the Chapter on Risk and Activism (Chapter 5) explores the activities of Coeliacs who also campaign for more robust screening processes in the manufacturing of gluten free foods alongside the tweeting of their quest narratives. There, I argue that this propensity for using social media to tell a chronic illness narrative can be used to further explore and illustrate the process of diagnosis, how individuals communicate their experience of adapting to life as a Coeliac on the gluten free diet (GFD), spread awareness of their chronic illness, as well as how they actively engage with online communities and food suppliers throughout their life course.

Once we start looking at how digital illness narratives are used to share both positive and negative notions of biographical disruption, and we also recognise the importance of the role of social media in the way that people co-author and identify their own biological illness, then we begin to see the emergence of what Rabinow called 'biosociality' (1996), and what later Rose and Novas called the 'biosocial citizen' (2007). That is to say, the term Biosociality was first used by Rabinow (1996) to describe the modern creation of social relationships, communities and identity (based on shared genetic or biological conditions).

Rabinow's work was pioneering in the way that he argued that, in an age of scientific and technological progress, the creation of new biosocial identities could lead to changes in the way that the chronically ill could interact with

institutions, manage their illnesses, and use shared knowledge to transform themselves in the face of diagnosis. This new form of biosocial identity also had the potential to enable the experience of empowerment as a result of biosocial support and activism. Rabinow further argued that biosociality could also act as a quest of self-education, as well as the acquirement of shared knowledge about diagnosed conditions (Rabinow, 2005).

Later, Sociologists Rose and Novas also discussed issues of linking the biological features or diagnosis of individuals to their personal or social identities, in relation to the term 'biological citizenship' (Rose & Novas, 2007). Biocitizenship, like biosociality, was described as a practice that was simultaneously "individualising and collectivising", due to the way it collects individuals into biologically similar groups, based on how deeply these individuals could "deeply know their somatic selves" (Rose & Novas, 2007:p.440;441). Thus, biocitizenship was based in part on the collective sharing of knowledge about a specific biological disease, as well as how people within those communities built and shared their identities and self-care practices around this (Sarrett, 2016:p.26).

In 2009, Ene discussed the similarities between both the terms Biosociality and Biocitizenship, and came up with the third term of 'Biosocial citizenship'. She says:

Biosocial citizenship is about the role people play in their own health and sickness. It looks at how people take the way in which they are described by science and the medical system and transform that definition in order to negotiate their own identity.
(Ene, 2009:p.1)

As will be further discussed in Chapter 4, it is this third definition of 'biosocial citizenship', whereby people actively co-construct their digital identity and experience of biographical disruption, that best describes how Coeliacs utilise social media in their everyday lives. In chapter 4, we will see how I have applied this notion of biosocial citizenship in understanding how, by using hashtags, individuals can signal that they belong to a certain group. For example, on social media it is common for users to use the hashtags #Coeliac or #NoCureNoChoice to signal their identity as fellow

Coeliacs, as well as signal to non-Coeliacs that their gluten free diet is prescribed and not a fad.

Technologies of the Self

Foucault (1988) argues that individuals in society moderate or self-govern themselves as subjects of consumerism through what he labels the practices or “technologies” of the self. He discusses how these self-shaping practices of subjectivity came forth – first with early institutional practices of frugal government in the early Middle Ages through to the early 16th and 17th centuries, and later with the rise of neoliberalism and are mainly based on self-observation and self-interrogation. Foucault discusses how these self-shaping practices of subjectivity came forth – first with early institutional practices of frugal government in the early Middle Ages through to the early 16th and 17th centuries, and later with the rise of neoliberalism and are mainly based on self-observation and self-interrogation (1988). These practices were first described by Foucault as coming in three stages: ‘Disclosure of Self’ (e.g. the cultivation of the self); ‘Examination of Self’ (‘taking stock’ and self-reflexivity), and the ‘Remembrance of Self’ (‘memorisations of deeds’) (1997:p.234).

For Coeliacs, ‘Disclosure of self’ can be described as the cultivation of the newly diagnosed Coeliac self and identity in terms of the way that food, and the need to follow a more restricted diet can be closely linked to their social eating habits, cultural roles and movements in society. Post diagnosis, Coeliacs are usually advised that it is necessary for them to disclose their chronic illness to others when eating out, to make sure that the food prepared/served to them is gluten free, and therefore safe for them to eat. This disclosure of self, and new chronic illness identity as a Coeliac can sometimes be a trying experience for a Coeliac, and result in the experience of biographical disruption, where feelings of a loss of choice, loss of access to favourite foods, and embarrassment at perceived social stigma may cause a degree of psychosocial stress (Ford, Howard & Oyebode, 2012b). Based within the context of the sharing of practices of self-care by some Coeliacs on social media, ‘Disclosure of self’ can also be found to come in the form of users actively sharing information about their

adjustment to life on the gluten free diet (GFD) after diagnosis. This may be whether these experiences include tweets or posts about biographical disruption, or are more of a general sharing of gluten free food found while eating out, knowledge shared about CD, or questions asked of the social media community using the hashtags #coeliac/#celiac or #glutenfree.

In terms of Foucault's second principle, the 'Examination of the Self', this can be described as 'Taking stock' and 'self-reflexivity'. For Coeliacs, this can be in the form of the examination of their own individual behaviour when following the gluten free diet. Upon initial diagnosis, some Coeliacs are instructed to keep a food diary to help them track what they eat on the GFD, and as a way to spot times when the accidental ingestion of gluten may have taken place (e.g. "what did I eat that made me unwell...?") (Coeliac UK, 2014). When using social media, 'Examination' within the context of Foucault's concept of technology of self, may involve a Coeliac tweeting about being glutened, taking stock of the situation, and discussing in a series of tweets or Instagram posts whether what they have eaten may be linked to food contaminated with undeclared gluten.

Finally, Remembrance of Self involves 'Memorizations of Deeds' that can be related to via the capturing and recording of practices via archives. In terms of Coeliac social media updates, it seems that while text-based tweets and links to blog posts often map what some new Coeliacs call their 'gluten free journey' – the utilisation of more image-based platforms like Instagram lend themselves to the long-term visual archiving of self-care practices or 'remembrance'.

Expanding on Foucault's theory of technologies of the self, and discussing healthcare practices, Rose (1999) argues that the idea of good health and the goal of staying healthy, is intrinsically marketed by the government to individuals in the same way that consumer goods were marketed. This system of 'Healthism' helps foster an internalised notion of responsibility – a situation that Rose defines as "responsibilization". Rose argues that this notion of Healthism utilises the technologies of self to encourage individuals to self-manage their bodies and overall well-being, where the burden of remaining healthy is no longer on the shoulders of the government, but must be endured by individuals, who then are held to blame or

responsibility if they get sick (1999). Thus, by adhering to the principles of Healthism, and listening to experts of health, individuals' personal health goals are aligned with political goals, which in the end, renders them more governable. Such practices of Healthism may be seen as an assemblage of meaningful practices worked on the body that are characterized by performances of self-care, aesthetic and moralistic self-stylization and reflexive self-awareness or quite plainly: taking care of oneself (Shankar, Cherrier & Canniford, 2006).

Liegl also expands on Foucault's analysis of self-governmentality through his discussion of "care of place", and how this relates to Foucault's concepts of 'technologies of governance' and 'technologies of self' within a series of processes of self-shaping practices of subjectivity, self-observation and self-interrogation (2014). Care of place in the context of Coeliac Disease, is closely intertwined with the self-governing of the chronically ill body. Here, finding food in social spaces that necessarily fits within the new self-shaping practice of subjectivity that encapsulates the gluten free diet– becomes the top priority. To stick to the GFD, many Coeliacs need to engage with the choices (or lack of choices) that consumerism and market forces allows them within the context of eating out. And in some cases, they may need to subvert the possibility of a lack of gluten free options by proactively bringing their own gluten free accessories (e.g. gluten free burger buns or bread to restaurants) when eating away from home/familiar environments (Howard, Law & Petty, 2011; Rose & Howard, 2014a). Within the context of the GFD, the Coeliac practice of 'care of place' can be further expanded when some Coeliacs use social media to tweet or post questions, or share their own experiences in relation to searching for food venues that safely cater for Coeliacs eating out. Their form of self-expression via tweets may also be seen as a way of understanding the experience of how a prescribed gluten free diet contributes towards the construction of the healthy gluten free self/subject (Bladh, 2014:p.3). The use of social media by individuals to share self-management of chronic diseases, most specifically Coeliac Disease can be argued to bring new meaning to Foucault's notion of 'technologies of the self' (Foucault, 1984), and a look at how this reflects on the reconfiguration of 'expertise' in matters of health and illness.

However, while practices of the self-management of Coeliac Disease via the GFD may fall within the general concept of technologies of the self, the concept does have some limitations, in that it does not fully cover the multi-layered intricacies and complexities of self-managing the gluten free diet on the move. One criticism of Foucault's concept of 'technologies of self' by Crossley, is that Foucault seems to ignore the active role of embodied agents within these practices, but instead keeps separate: "texts which prescribe ways of acting and the more messy and complex reality of those ways of acting..." (Crossley, 2004:p.41). Within the context of Coeliac Disease, this distinction between the more structured self-care remit prescribed by medical authorities in the structured prescription of the gluten free diet, versus the sometimes complicated and ad-hoc way that Coeliacs find themselves trying to keep to the diet in circumstances where gluten free options are not always available, becomes more apparent.

Crossley notes that Foucault admits that his concept of the structured management of technologies of the self was never really meant to deal with the "witches brew" of complexity that these practices create in real life (Crossley, 2004:p.42). Indeed, when trying to apply Foucault's concept of self-care to the numerous ways that Coeliacs self-report their management of the gluten free diet while on the move, one finds it hard to only focus on these modes of sharing via the lens of self-governance at the behest of the state. We can see in Chapter 6, that Crossley's point that the technologies of self-care are more complex and multi-layered than Foucault would have it. That is to say that Coeliacs practice self-care on the GFD in many different contexts, e.g. on the move, at work. We see further examples of this complex practice when Coeliacs share comorbid practices of self-care online.

When trying to understand how the sharing of personal self-care via Tweets and Instagram posts can be considered as an epistolary practice via social media (Bladh, 2014), a reading of Foucault concerning the care of the self as a constitutional practice for the individual can be quite useful (Foucault, 1988; Markula, 2004). Foucault describes epistolary practice as: "a written account of oneself: an account of everyday banality, an account of correct or incorrect actions, of the regimen observed, of the physical or mental services in which one is engaged" (Foucault 1997:219). The care of the self

here, can also be understood as a domain of complex and regulated practices about how one should take responsibility for treating oneself throughout one's existence as one's own object (Foucault 1997:95, 96). Again, through these practices, Foucault also argues that it is implied by the state authorities that one also has the responsibility to practice freedom the *right* way or make the right choices through self-governance (Foucault 1997: 292). However, what the right choice may be is not completely straightforward, and as individuals practice self-care, decisions can be made through negotiation or through agency (i.e. in social media via Twitter or Instagram conversations/mentions). In this way, choice as well as the governance of self may be seen as dependent upon agency (Bladh, 2014).

With the practice of blogging and social media status updates in recent years becoming more popular, the analysis of social media discourse has also become a useful instrument for trying to comprehend how humans make sense of their social and health reality. It has also become a useful way to make sense of how different food cultures are represented (Serfaty, 2004:p.457; Murthy, 2012). The need for Coeliacs to follow a gluten free diet, and the way that communities discussing this chronic illness culture as it relates to the use of food for self-care can also be seen as a reflection of online representation of an illness-related food culture. In this way, then, applying an updated version of 'technologies of self' in relation to studying how social media is used in a health-context provides a powerful way of understanding users illness-related narratives of everyday life, and their utilisation of technology to share this care for the chronically ill self. Indeed, Bladh notes that personal tweets may be seen as a narrative of selfhood (2014:p.2). Indeed, this thesis provides a unique example of how social media data can be used as a way of charting the process of renegotiating the process of biographical flow (Williams, 2000a) after an incidence of biographical disruption (Bury, 1982).

The use of hashtags and how to interpret the data that is intrinsic to them is a key part of this thesis. As will be evident throughout the empirical chapters, I have used hashtags extensively to analyse the data mined from the three different social media platforms. One of the key concepts I have used to interpret hashtag data in the process of sharing self-care practices is Foucault's (1988) 'technologies of self'. Although there is a growing

literature about the use of technology and health (Swan, 2012; Pickard & Swan, 2013), this literature does not apply the notion of technologies of self in the way that I am doing here in relation to hashtags. The utilisation of hashtags to study practices of self-care and the technologies of self in terms of chronic illness provides the opportunity to study how some with chronic illness can use and create specific hashtags to build support communities and share specific experiences that relate closely to their biological illnesses. At the time of writing, there have been no studies that specifically look at community-created chronic illness hashtags, and how they are utilised to share modes of self-care. The research in this thesis aims to fill this gap by using the concept of Foucault's technologies of self to study these practices.

Risk Coeliac-tivism on Social Media

As we will see in Chapter 5, even though individuals use social media to share the practices of self-care, they nevertheless continuously need to negotiate relatively high levels of risk when pursuing the GFD. One of the things that comes out clearly from the findings of this thesis, is that in addition to Coeliacs turning to social media to share their experiences, they are also seen to rely on using various social media platforms for information about how to reduce everyday risk of being glutened. There are already sociocultural theories of which highlight the importance of looking at risk in relation to everyday experiences of different social and geographical situations (Tulloch & Lupton, 2003:p.10). 'Doing risk' or 'performing risk' can be seen as a dynamic phenomenon, where allergic or chronically ill individuals such as Coeliacs, must develop strategies to deal with food risk in different settings (Stjerna, 2015). Exploring how risk is performed in relation to health and self-care is important for this current research, as it can enable us to better understand how some Coeliacs share experiences of risk, and perhaps learn to better manage their gluten free diets via social media.

The area of risk in modern society has long been discussed in relation to the complexity of social, economic, financial, technological and health factors faced by people daily. For example, Beck argues that modern

society both creates risks by our ways of living (working conditions, multi-use food processing and more), and also compensates for these risks by means of calculation and political regulation (Beck, 1992a:p.99).

In this thesis, I do not attempt to sum up the existing work on risk in general nor risk in relation to food, since others have already done that very well (Lupton, 2002; Jones, 2013; Bury, 1997; Beck, 1992a). Instead, what I do is explore how some Coeliacs use social media to share how they deal with the daily risk of cross-contamination while they pursue their gluten free diet. Similarly, in relation to modern society's increase in processes that expand the complexity of risk, Bury (1997) discusses the inherent difficulties in communicating risk and its impact to the body in a way that the lay people can understand. He argues that the official statistical language of risk experts means that at times: "...there are inherent difficulties in making sense of expert advice about the impact of [...] contaminated food or 'risky' behaviour on the workings of the body" (Bury, 1997:p.194).

One might think that an obvious way that Coeliacs can reduce or avoid risk is to look at food labels. Several attempts have been made to clarify food labelling, and how it communicates risk to consumers who are at risk of for example of ingesting allergens (Madsen *et al.*, 2012a; Pyrz & Galvin, 2015; Munro *et al.*, 2015). While some laws have become clearer in terms of gluten cross-contamination (Food Standards Agency, 2014), other laws are less clear where food processing is done in factories that handle multiple and complex allergens.

In terms of unclear allergen laws, Dunn Galvin *et al.* have noted that currently there seems to be an inconsistent application of EU directed precautionary allergen labels which state that foods "May contain..." certain allergens. Dunn Galvin *et al.* argue that the "May contain..." statement can still be hard for many consumers to understand, or fully trust (2015). The use of precautionary labelling that shows the terms 'may contain wheat/nuts', or 'made in a factory that handles wheat/gluten', has been argued to contain enough ambiguity to still confuse consumers as to what they should subjectively judge as a 'tolerable level of risk' (Madsen *et al.*, 2012a:p.31). An example of clear allergen labelling practices, is the licensed Crossed Grains symbol, a system that 59% of Coeliacs reported

as helpful to them (CoeliacUK.org, 2015b). The Crossed Grains symbol is an indicator to Coeliacs that certain food products have been tested and certified by Coeliac UK as gluten free. This has been assessed as helpful in an environment when food allergen labels and law changes can be confusing for some Coeliacs (CoeliacUK.org, 2015b).

When defining risk, Douglas notes that risks by their very nature "[...] clamour for attention, probable dangers crowd from all sides, in every mouthful and at every step" (1986:p.59). Indeed, the presence of risk in key parts of life could be argued to be true in the context of Coeliac Disease, where, the ultimate risk is cross-contamination with food preparation or hidden gluten in foods that aren't explicitly labelled (e.g. wheat breadcrumbs used as a thickener in sausages/meatballs).

In the case of gluten free food product recalls, the management of food risk becomes even more intensified, where the once familiar and relied upon 'safe food' becomes a source of risk and anxiety. The concept of there being no complete escape from food risk is further exacerbated by the modern practice of food manufacturing, processing and preparation. Here, the sheer multitude of variables from allergens present in the process from growing to storing, to shared factory lines in manufacturing to processing, and finally from purchase to preparation – mean that there can never really be a zero % risk of allergens present in food (Madsen *et al.*, 2012a).

Qualitative analysis of the psychological consumer perspective of food allergens has revealed that while consumers with food allergies or intolerances do understand (with adequate explanation) that zero risk is not possible – they still want more control of that risk in terms of information about levels of allergens, food labelling and manufacturing processes (DunnGalvin *et al.*, 2015). In this respect, an awareness of risk means that consumers need to have trusted information about allergens, so that they can make necessary decisions that will help them navigate the risk of harm. As Giddens (1991, p. 35) argues: "Trust presupposes awareness of risk, offering reliability in the face of contingent outcomes and thereby serving to minimise concern about possible risk". Trust can play an important factor where Coeliacs look for foods that they can trust to be gluten free and will

not make them accidentally ill. Developing such trust, arguably still contains a fraction of risk, as not all variables can be 100% controlled.

Perceptions of trust, Lupton argues, can, amongst other things, be regarded as a means of dealing psychologically with risks that would otherwise paralyse action or lead to feelings of engulfment, dread and anxiety (2013c:p.105). For example, many post diagnosis Coeliacs can suffer from psychosocial anxiety, where there is a heightened perception of the risk of getting glutened, a need of support in learning which foods to avoid and how to best communicate the parameters of Coeliac Disease to others (Ford, Howard & Oyeboode, 2012b). For Coeliacs, a reliance on trusting others to manage one's personal risk, is inherent in daily practices of negotiating gluten free options. Like others whose bodies react negatively to specific food allergens, Coeliacs necessarily must learn to trust the actions of strangers in the manufacturing and processing of food that they can safely eat. As Lupton (2013, p. 105) argues about trust in general: "Without trust, people could not engage in the 'leap of faith' that is required of them in dealing with these expert knowledge systems of which they themselves have little understanding or technical knowledge because they have not been trained in them". Within the context of eating out with Coeliac Disease, there is a reliance on both expert knowledge at the manufacturing level, as well as local knowledge in terms of on-site food preparation and cross-contamination in local cafes/bars/restaurants. For some Coeliacs, this balance of trust and risk has the potential to become amplified when the risk backfires, and unseen cross-contamination can have a direct and adverse effect on their health-related quality of life.

Modern lay access to knowledge and information, and an increased public awareness of the fallibility and limitations of expert knowledge, has also been argued to have led to a situation where lay people are now more likely to be more sceptical and doubtful of expert knowledge when failures arise (Cohn, 2000:p.205; Beck, 1992b). Wariness of experts becomes even more apparent in situations where expert knowledge on safety practices is shown to have failed, and lay people become sick as a result. Such is the complexity of modern food practices, that there exists somewhat of a paradox between great advances in manufacturing expertise in producing gluten free food, and an increase in product recalls that have been the

result of some failures by the experts to mitigate risk of allergen contamination (Madsen *et al.*, 2012b).

Beck (1992b) and Giddens (1991), and Moore and Burgess (2011), have discussed the reflexive aspects of risk, where reflexivity has been singled out as the primary response to increased complexity, uncertainty and insecurity in late modernity. Reflexivity and its relation to health are argued to have been amplified by how in modern society, people are constantly called upon to be aware of possible threats to their health, and are thus anxious to avoid situations that imply health risks (Moore & Burgess, 2011).

Reflexivity in the case of Coeliacs, points to how they must constantly be aware of the possible threats that cross-contaminated food and hidden gluten will have on their health. This becomes more problematic when foods that were once trusted as 'safe', are then recalled due to errors in production, manufacturing or storage practices. When cross-contamination occurs, it is arguable that levels of trust need to be re-evaluated, as well as the re-evaluation of perceived risk of foods labelled as gluten free. Levels of uncertainty around the presence of food allergens may lead to a greater awareness on the part of individuals, that the claims of experts about risk are not always certain, or that expert opinions tend to clash with each other (Madsen *et al.*, 2012b). The opposite may also be said, however, when stricter food accreditation standards are upheld (e.g. with the Coeliac Cross Grain symbol), and food allergen bodies carry out constant checks and updates of manufacturing process (CoeliacUK.org, 2015b).

Rutsaert *et al.* (2013) note that very little research has been done on the effect that social media has had on the food risk communication, especially in terms of consumers and being able to trust the credibility of information shared, and the ability of organisations to retain control of how information is disseminated or re-tweeted. There have also been some studies of Twitter during incidents of food risk and uncertainty, where it was found that in comparison to focus groups and survey data, Twitter gave little explicit evidence of a breakdown of trust (Draper *et al.*, 2016). In this particular case, Draper *et al.* found that an analysis of tweets during the 2013 UK 'horsemeat scandal' (where consumer food labelled as containing regular beef and lamb was found to have been substituted by horsemeat), showed

more expressions of humour than outrage in the crisis, and little evidence of explicit mistrust of food suppliers (2016:pp.3–6). Hamshaw et al. (2017) have also studied Twitter and traditional media with regard to national debate on the impact of 2015 EU food allergen legislation on the UK and the reluctance of restaurant chefs to adapt their menus and follow legislation. Here, consumers were found to utilise social media in direct answer to news items and traditional media, where they used platforms like Twitter to express and emphasise medical concerns around managing risks associated with food allergy/intolerance, the assignment of responsibility, levels of trust and access to food that was safe for them to consume.

The link between risk and trust is explored further in Chapter 5 of this thesis, most specifically in terms of how some Coeliacs use social media to share how they navigate this risk and cultivate trust in certain gluten free brands/products. As will be shown empirically, Coeliacs utilise notions of risk management and the collective self-mediation of technologies of self for collective action.

Cammaerts argues that social media platforms themselves act as technologies of self-mediation through which people can construct collective identities, based around shared options, causes or points of view (2015:p.89). The building of a collective identity can thus be formed through the practices of disseminating, communicating, recording and archiving information – that through collective self-mediation and collective action can empower a group to challenge the status quo (2015:p.92). Cammaerts argues that the asynchronous affordances of social media platforms as both public and private, enable social media movements to publically capture, record and archive information, discourses, as well as use this to mobilise action to exert change.

This type of online mediation and utilisation of technologies of self can be argued to apply to the case of Coeliacs using social media platforms to not only forge a social and biological identity around the genetic components of their disease, but also in terms of collectively sharing information about perceived dangerous manufacturing practices that can lead to alleged cross-contamination of food products labelled as gluten free. Staying within Foucault's Technologies of Self, these actions are described by Cammaerts

as again coming in three stages: 'Disclosure of Self' (e.g. the cultivation of the self); 'Examination of Self' ('taking stock' and self-reflexivity), and the 'Remembrance of Self' ('memorisations of deeds') (Cammaerts, 2008).

Based within the context of collective action by some Coeliacs on social media, 'Disclosure' is found to come in the form of users actively disseminating/sharing information based around incidents of accidental glutening believed to come from the same source (e.g. a food product or restaurant). This collective disclosure comes with the action of 'examination' – taking stock of the situation, and discussing whether the evidence may be linked to unsafe or risky manufacturing or production practices. A result of this examination and collective disclosure may then enable them to 'mobilise' themselves into collective action. Here, this would be collecting/archiving all reports of being glutened by a particular product, and mobilising other Coeliacs on social media to report these incidents to a regulatory body, like the Food Standards Agency, or Food and Drugs Administration. Remembrance can come into play through the archiving of this information via Tweets and blog posts, and referring back to it if/when further instances of accidental glutening via the same or other products arise. In these situations, there seems to be a heightened awareness of the risk involved when Coeliacs need to rely on third parties to prepare or serve food to them. The complexities involved in the perception and management of risk by some Coeliacs is discussed in the following section.

The mobilisation of the chronically ill into movements that advocate for better rights and protection for specific groups was first discussed in terms of the phenomenon of Health Social Movements by Brown and Zavestoski (2004). They conceptualised Health Social Movements as "collective challenges to medical policy and politics, belief systems, research, and practice that include an array of formal and informal organisations, supporters, networks of cooperation, and media" (Brown & Zavestoski, 2004:p.679). Health social movements were found to have acted as an important bridge to push medicine to evolve by connecting the movement's health concerns to "other substantive issues such as social and environmental justice, poverty, and occupational or environmentally-induced diseases" (Brown & Morello-Frosch, 2011:p.1).

Brown and Morello-Frosch later went on to describe a different kind of health movement that was based on the embodied experience of patients, and their interactions using internet platforms, where communications and collective action could be organised across geographical boundaries (2011). They say that as people with chronic illness have felt ignored in the past, they have tended to come together in what they call 'embodied health movements'. They explain:

That, these social movements focused on the biological body in terms of the embodied experience of people who have a shared disease or condition. The collective illness identity that then emerges is based on the experience of the biological disease within diagnosed individuals' bodies.

(Brown & Morello-Frosch, 2011:pp.6–

7)

The idea of CD as an example of an embodied health movement is evident in my study (especially Chapter 5), as we see Coeliacs coming together via social media, moving from individual to groups of "Coeliac-tivists", who lobby manufacturers and government organisations for stronger allergen regulations that help them better manage food-related risk.

Gamification

So far in this chapter, we have situated the study within the sociology of health and illness literature. In particular, I have drawn out key concepts of that body of literature which play a key role in interpreting the findings, namely: biographical disruption, illness narratives, technologies and self, and risk in relation to living with CD. All along, I have highlighted the ways in which the digital is fundamental to understanding contemporary practices of self-care and chronic illness.

That said, once we appreciate the implications of researching issues such as chronic illness in the social media domain, it becomes necessary to push the boundaries of the current sociology of health and illness research even further still. Indeed, this thesis takes an innovative methodological and substantive leap in how chronic illness such as CD can now be explored. In the remaining two sections of this chapter, I introduce the ways in which

new modes of gamification and visualisation can now be used in contemporary social science research in general, and to study CD specifically.

Gamification and its relation to health is a topic that has been discussed with increased interest within the social and health sciences over the last decade, especially with reference to how it relates to encouraging patients to engage more positively with chronic illness via online games and apps (Van Grove, 2011; Van Laere, De Ruyck & Willems, 2013; Whitson, 2013; Munson *et al.*, 2014). This form of gamification is coming under more academic scrutiny as body sensors and wearable technology that can track the body gain popularity (Lupton, 2013a; Walker Rettberg, 2014). More consumers, employers, schools and health care providers are becoming interested in wearable self-tracking tools like FitBit, and body-monitoring apps that can help them track, organise, and make sense of their health data (Swan 2013). Gamification as a concept first came to light in the field of marketing, behaviour change and efficiency, where it has been defined as the use of game design elements in non-game contexts, that could be applied to many different situations (Khaled, 2014). However, gamification in this early form of employing game design mechanics like leader boards and achievement rewards to entice users to play behaviour changing games, was heavily criticised by Bogost, in his paper “Gamification is Bullshit” (2014).

Bogost argued that employing gaming techniques to turn a specific task into a game, was bullshit [sic], as it’s only true purpose was as a marketing strategy with the aim of proving that a using gamification as a marketing technique was better at getting sales than other marketing strategy (2014). Bogost, argued that one of the only areas where the use of gamification was meaningful in terms of benefits to the people playing the game in terms of educational or public communication purposes. This critique was also taken up by game developers, who viewed the co-opting of gamification by sales and marketing teams, as “exploitification”, essentially the cynical presentation of software and apps as “games”, that games developers saw as “largely devoid of the expertise and craft of game development” (O’Donnell, 2014:p.355).

Bogost tends to agree with this concept, by arguing that gamification stops being “exploitification” when a game or piece software is open and apparent in what it is doing, and built using principles closely linked to the expertise and craft of games developed for a transparent, non-marketing purpose. Thus Bogost argues that true gamification arises when a game or software: “[...] was conceived and created for a specific purpose; it was designed and developed from the ground up; it mustered specific subject knowledge rather than general purpose incentives into its design; and it was intended as a tool for public communication and education rather than as a hook for online engagement...” (Bogost, 2014:p.70). This then, is when gamification stops being purely for the pursuit of profit, and arguably becomes more interesting, and useful to the wider public. Indeed, when further investigating the application of gamification techniques to software and games focused on increasing better adherence to chronic health care, and healthy behaviour, Munson et al., highlight the need for extensive social sciences research that covers how the game or application will relate to the users’ social context, accessibility issues, goals and preferences (2014:pp.612–616).

Within a digital health context, gamification can be further described as the introduction of game elements to otherwise mundane self-care activity, turning the self-care of chronic illness (e.g. diabetes) or overall fitness and lifestyle activities into a fun experience, with either health or educational benefits (Weiner & Will, 2015). Where gamification is linked to wearable technologies, like fitness bands or self-tracking apps, the use of badges, leader boards again uses the experience of enjoyment or fun is a tool to help people engage with data, facilitate behavioural changes, or gain understanding of how their bodies function in relation to their health (Weiner & Will, 2015). Gamification is also discussed in the context of the quantified self in terms of self-tracking lifestyle and exercise habits: ‘...by gamifying everyday tasks such as exercise and healthy living, users can make solitary and tedious activities more enjoyable’ (Whitson, 2013).

While there are now more than 300,000 health tracking apps in various smartphone app stores, and a growing market in wearable quantifying technology, there are still questions as to what is happening with individuals who face technical or financial barriers to the widespread adoption of

wearable technology and sophisticated self-quantifying applications (Lupton, 2014). Are they instead finding other methods to communicate their lived experiences, and if so, how? In trying to answer these questions, it has been argued that at least some individuals who don't use apps or wearable technology to quantify their movements, fall within what is called the 'qualified self' domain (Davis, 2012, 2013). This is a distinction that challenges the term 'the quantified self' and describes a process where individuals instead use less number-crunching methods of self-tracking or self-knowledge accumulation and sharing, by instead posting text, photo and video updates cataloguing their lived experiences via more general social media platforms like Twitter and Instagram. In this way, it has been argued that the practice of self-tracking can also "be regarded as a way of thinking *through* as well as *with* information, working to make connections between one kind or source of information and others [...as well as] interrogating the quality or validity of the data" (Lupton, 2014).

A much broader sociological discussion seems to be occurring in terms of what it means to self-track using various forms of technology. A discussion of the notion of the Qualified Self, and posts by Carrigan on Qualitative self-tracking and the Qualified Self (2014), and Deborah Lupton (2014) on "Beyond the Quantified Self: On The Reflexive Monitoring Self" are good examples of this. Lupton argues that 'self-tracking' isn't simply about quantified or quantifiable information, but about "...a broader and more inclusive [...] range of practices..." based within the contexts of the various social, cultural and political contexts in which they are carried out: "Many self-trackers record non-quantifiable data as part of their practice, including journaling accounts of their daily activities, emotional states and relationships, collecting audio data or visual images and producing visualisations that centre on their aesthetic or explanatory properties rather than their representation of numbers" (Lupton, 2014).

It is arguable that what is and is not quantifiable depends on the perspective of how it is quantified. What this means, is that information is communicated in the public domain (like Twitter, Instagram, Pinterest or Facebook), then the data can be quantified to some extent, depending on the mode and method used by the data scientist/researcher/marketing analyst using it. However, for the purposes of self-tracking/quantifying, if

data, such as photographs, tweets or blogs are not linked to a quantifying application or monitored with analytics, then the data shared becomes unquantifiable to the average user. As Lupton notes:

Some commentators seek to position the 'qualified self' as a practice involving reflection and interpretation of information, whether this information is in the form of numbers or not. For several writers, the qualified self involves interpretation and assessment of any form of data...

(Lupton, 2014)

In this sense then, the status updates of Coeliacs via Twitter or Instagram seem to fall within the mode of the 'qualified self'. Examples of this are Coeliac's daily reflections, photographic and spatial sign-posting of new gluten free finds and venues, and how this is interpreted within the context of self-managing a chronic autoimmune disease. Analysis of both the images and the text that is posted alongside these visuals, can arguably go some way towards humanising the raw data found in the number of posts and images shared. As both Davis (2013) and Lupton (2014) comment, it creates and extends a subjective narrative around the data shared, and "the mechanisms of which the data morphs into [digital] selves" (Davis, 2013). In this way, selfhood thus becomes "inextricably entangled with [the] interpretation of information" that is shared (2014).

Although the main goal for Coeliacs' use of social media seems to be the sharing of information, rather than the quantifying of it, perhaps it is this process of daily textual updates and photographs of gluten free food that acts as means of making the daily (and sometimes frustrating) experience of the gluten free diet more manageable. From the initial biographical disruption (Bury, 1982) of the initial diagnosis of Coeliac Disease, and the immediate need to switch to a life-saving gluten free diet, perhaps the digital collecting, sharing and interpreting of data about themselves and their experiences is best described as 'the reflexive monitoring self', thus part of the work in the journey towards becoming a new 'self' after chronic illness diagnosis (Lupton, 2014). In this case, the 'new self' is an individual self-managing the gluten free diet, or perhaps a 'healthy Coeliac'. As Munson et al put it:

To encourage individuals to invest in their personal well-being and to overcome challenges related to interpreting rich and sometimes complex data, some people propose turning tracking and improving one's health into a "game" or adding game-like elements to existing health tracking technologies [...] gamified systems offer to turn the wash of personal health information into an experience that is meaningful and motivating and to reframe daunting health problems into challenges that are enjoyable to solve.

(Munson et al. 2014, p.597)

These and more on-going discussions of the qualified and quantified self, seem to be going some way to untangle the tension between the quantified tracking of wearable devices and the question of where/how tweets, Instagram photos and other social media, could also fall (be it more broadly) within the context of self-tracking for specific chronic health-management reasons. It is arguable that this reconfiguring of general social media platforms for self-tracking and knowledge sharing could also be seen as 'gamifying the mundane', where self-surveillance is used to gamify everyday life via the participatory surveillance encouraged by social network platforms (Whitson, 2013).

Pols argues that practical patient knowledge, gained as they self-care for their disease, is different to the type of medical knowledge transferred between medical practitioners and patients at the point of diagnosis, and follow-up appointments (2013b). Indeed, while patient knowledge sharing practices have been found to be beneficial to new and continuing chronic illness patients, there has also been a call for the social analysis of this practical, lived knowledge to be utilised and transferred into different forms that will help others (Pols, 2013b; Oudshoorn, 2015). It is proposed that one such way to do this is to gamify existing health practices into more engaging, fun and enabling formats, so that the mundane acts of self-care can be experienced in more positive, behaviour-changing ways (Munson *et al.*, 2014; Rigby, 2014). As Pols (2013b:p.82) argues, there needs to be a way that we can articulate the knowledge that patients develop and use in their daily lives (patient knowledge) and make it transferable and useful to others. She argues that more creative strategies need to be used to bring

people together, and that those strategies can be created by looking at the valuable patient knowledge already shared (2013b:p.91).

As exemplified in Chapter 6 and 7, I demonstrate how we can 're-gamify' the patient knowledge results found in applied social media network analysis, and reformulate them into tools that can help new and continuing patients. By 're-gamifying' I mean to visualise the results of social network analysis as a game that teaches Coeliacs the basics of self-care. This means summarising the tweets and Instagram posts made by Coeliacs as simple concepts or examples of self-care, and visualising those concepts within instructional game-play. For example, by extracting the patterns and co-occurrences found in the communication of patients in social media data, we may be able to turn social science enquiry into a format such as e-learning games and an e-Health learning tool and a research device. To do this, however, we need to use our understanding of gamification and how and why certain types of games or gamified personal informatics tools can help enable patients to achieve health goals in self-managing chronic illness. There is also a need to critically reflect in the design, format and games mechanics of such an application in a way that is appropriate for creating, displaying, engaging with and organising health information (Munson *et al.*, 2014:pp.597–598).

One of the things that I do in this thesis, is bring together a key concept within gamification and CD research, that has so far remained separate. This is the Theory of Planned Behaviour (Ajzen, 1991). In the gamification literature, the Theory of Planned Behaviour (TPB) is used to model decisions in games that aim to help players make lifestyle changes (Munson *et al.*, 2014). In CD literature, TPB has most specifically been applied to the study of Coeliac Disease, in terms of analysing how, based on their daily environments, individuals make decisions about lifestyle changes in relation to adapting to the gluten free diet (Sainsbury, Mullan & Sharpe, 2013a).

In turn, I show how the use of a gamified health app can help with key behavioural changes that research has found that many Coeliacs may need assistance with:

1. Perceptions about the costs and benefits of adherence to the gluten free diet (the new behaviour), in relation to the reduction of painful symptoms and improvement of overall health;
2. Individual and social perceptions of cost and benefits of a change in behaviour or adoption of the gluten free diet. This comes into play where Coeliacs tend to experience most psycho-social stress in situations where they do not have control over access to gluten free food or the cross-contamination of food prepared for them in social situations

(Rose & Howard, 2014a).

In terms of gamification, health and helping to intervene in planned behaviour, Munson argues there are three approaches: personal informatics (collecting and interpreting information about one's self); gamified interfaces (adding games mechanics onto applications to make their use more engaging); and games-based applications (using games worlds, fantasy or games-based tasks to enhance health-based learning, or slightly change behaviour) (2014:pp.600–601). Munson argues that a games model can be used to reframe health tasks by breaking a daunting challenge down, so that people perceive that they have better odds of eventually succeeding (2014:p.602).

As Munson notes, the quick feedback environment of games means that any expected early failures can be overcome by restarting the game, and building up skills and confidence levels, so that challenges are perceived as most surmountable, and can be positively learnt from (2014:p.602). This is especially so, when even failures are rewarded in the game, by the tallying of high scores achieved. Goal achievements can be given special bonuses, especially when a previous game level is tried again, and won. Other options to display status and see where one ranks amongst other players, can also be helpful incentives (Munson *et al.*, 2014:p.603).

That being said, it is also noted that adding rewards for certain behaviours might encourage cheating or less favourable reactions, leading users to become bored with rewards or stop playing altogether. In more general terms, there is also the possibility that the users that the game designer hopes to influence are not the users/players that ultimately end up playing

the game. Depending on the aim of the game or task at hand, this may be seen as a failure, or as an opportunity to educate those outside the target range about the health issues focussed on in the game.

Lieberman argues that games can be used to increase motivation for self-care, as well as acquiring more knowledge from individuals' social networks about self-managing chronic illnesses. She says:

Video games oriented to health promotion, for example, can help players learn about prevention and self-care and improve their health-related skills and behaviours. The video game format lends itself well to health promotion because games offer unlimited chances for repetition and rehearsal [...]. To engage young people in health-related behaviours while they play, video games can represent appealing role-model characters, provide scenarios that involve making health decisions and carrying out self-care skills, and epic realistic consequences in response to players' decisions and actions.

(Lieberman, 1997:p.103)

While the literature has reviewed the many eHealth apps that promote specific diets, as well as track eating habits (Swan, 2013; Lupton, 2013a), for the purposes of gamifying the mundanity of the GFD, at the time of writing, there were no games-based apps that used a gaming environment to gamify the concept of the self-care of CD. There were also no apps that used games mechanics or the gamification of hashtags to visualise the symptoms of chronic disease. The absence of apps or absence of the study of the visualisation of self-care in this area, is again a reflection of Ziebland and Wyke's note of a gap in the literature in terms of explorations of how those with chronic disease visualise their illness experience (2012). Because of this gap in the literature, in this thesis I use Chapter 6 to explore the use of games-based apps and the use of role-model characters to visualise the self-care of the GFD, and Chapter 7 to further demonstrate the potential offered by a gamified interface to visualise the symptoms of CD and comorbid illnesses.

Chapter 6 therefore provides an illustrative exercise in engaging with the games-based model for two prototype apps that I built, 'Gluten Fighters' and 'Coeliac Sam'. Here, the super-hero character 'Coeliac Sam' operates in a fantasy world, where her and Coeliac friends are the superheroes of their Coeliac guts, and continuously hunt for gluten free food, and struggle with cross-contamination issues as they try to self-care through the GFD. The observations and analyses from the creation of these apps and the visualisation of the concept of CD in Chapter 6, is used as the basis for the build of the main visual research tool developed for this thesis, the Spoonie Living app. This research tool forms the final empirical study of this thesis, as an exploration of the use of a gamified interface, a gamified social media hashtag (#spoonielivingapp), and live methods to create a tool that may be useful for further enabling Coeliacs with comorbid diseases to visualise their self-care. The data that forms the app is conceptualised and visualised from the patient-shared knowledge collected from both Twitter and Instagram during the collection of data in Chapters 4 and Chapter 5.

In the next section, I discuss the literature that informs the visual function used in the final formulation of the Spoonie Living app. As part of my investigation into how Coeliac Disease and comorbid illness is discussed and visualised by some Coeliacs via social media, I also address some of the current literature on visualising the self via Photovoice (Wang & Burris, 1997). I then address the emerging literature with regards to using social media to visualise self-care (Yi-Frazier *et al.*, 2015), and look at how my research with Coeliac Disease can question and contribute to the literature.

Visualising Self Care

While there is clearly a large literature on visual methods (Strangleman, 2008; Mizen & Wolkowitz, 2012), digital visual methods (Thelwall *et al.*, 2015; Gibbs *et al.*, 2014), visual sociology (Grady, 1996; Shortt, 2012) and visual sociology with its relation to chronic illness (Drew, Duncan & Sawyer, 2010; Bates, 2011), my focus is to make a contribution to more recent debates about the role of social media in the visualisation of chronic illness (Yi-Frazier *et al.*, 2015).

As mentioned in my previous discussion of the use of gamification techniques and the visualisation of chronic illness, when trying to understand how patients communicate their self-care of long-term illnesses over the internet, Ziebland and Wyke noted that the extent to which patients could visualise their symptoms and share images of this over the internet was under studied (2012). Ziebland and Wyke noted that the presence of images and videos on health websites had been treated mainly as a design issue, rather than as a source for communication by the chronically ill (2012:p.237). Ziebland and Wyke went on to argue that images used in health care communication should also be considered in terms of the potential consequences their use had in influencing how people shared some of their experiences of chronic illness in parts of their daily lives (2012:p.237).

An example of work on visualising illness pre-social media, can be found in Alan Radley's (2009) research in using visual methods such as pictures and narratives, to study the way that pictures can give shape to communicating the chronic illness experience to others. As Kennedy (2012:p.7) remarks, Radley reminds us that the visual narrative of chronically ill individuals is not merely a matter of communication, but can also be a way in which "critical moments about illness are established for those concerned". Pols also argues for the importance of acknowledging that patients don't just self-care for their illness in isolation, they manage their chronic diseases in the process of managing their other daily practices as parents, employees, partners and more. With this in mind, it is arguable that any helpful gamification app/intervention needs to be cognisant of fitting into how patients manage their lives as well as their illness(es) (Pols, 2013b). At the time of writing, there was very little literature found that explored how chronically ill patients used digital tools and social media to catalogue or visualise their self-care experience within the specific context of their chronic symptoms. In terms of the study of the visualisation of chronic disease via social media - while analysis of the literature has found a recent study of how sampled individuals with Type 1 Diabetes share images of the disease via Instagram (Yi-Frazier *et al.*, 2015), there is currently no research that investigates how Coeliac sufferers with comorbid disease(s) share and visualise the experience and self-care of this. However, what also needs to be explored is how images are used to

specifically visualise the actual embodied experience of chronic symptoms and comorbid symptoms. In this respect, notions of visual co-presence and focalised subjectivity in these images (Zappavigna, 2016) will be discussed.

As is shown in Chapter 6, by developing the Spooning Living app (further details about this in that chapter), I was able to address this gap by offering a way to study chronically ill individuals and how they visually express symptoms and self-care. Research into the genetic susceptibility of Coeliacs to other chronic illnesses, has also found that those who tend to get diagnosed at a later stage with CD (where exposure to gluten is longer and untreated), are more likely to have other autoimmune diseases, or comorbidity (Fasano, 2006). More recent studies have also found some direct genetic factors linking CD with diseases such as Diabetes and Crohn's Disease. In general, the literature shows that 1 in 8 people are more likely to have another chronic illness or co-morbidity alongside CD (Mazzarella *et al.*, 2008; Hermann *et al.*, 2003).

Chapter 6, will go towards giving even further insight into how people enact self-care for Coeliac Disease and comorbid illnesses. In this way, the Spoonie Living app project is an attempt to address the research question:

- How might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness?

Chapter 6 explores this question by finding out how individuals with chronic illness visualise the symptoms of their disease (Ziebland & Wyke, 2012:p.237), and what aspects of chronic illness are most shared.

To recap, a singular diagnosis of a chronic illness like CD (or any additional comorbid illnesses) may necessitate an individual readjusting their lives, eating and social habits to cope with their long-term condition, which may lead to individuals looking online for support from other people with the same biological illness (Fox & Duggan, 2013). The gradual adaption of their lives and relationships to cope with illness, may also affect how individuals share their personal illness narratives, and experience of symptoms online, at some points disclosing personal accounts of pain, frustrations that they would not necessarily share offline (Gonzalez-Polledo & Tarr, 2014).

Since the time of the Ziebland and Wyke paper (2012), social media in general has become an increasingly more image-based medium, with between 2010 and 2015, more than 400 million people sharing photographs and videos on visual platforms like Instagram, and on Twitter 316 monthly active users, with 216 million tweets shared daily (Woollaston, 2015). However, despite there being many quantitative studies measuring the rates of use of images via social media (Kaufer, 2015), there have been just a few studies that used mixed methods to study how patients are visually sharing their lived experience with chronic illness. One good exception worth mentioning, though, is of a study on how chronic pain was communicated via the social media platform Tumblr, found that individuals used a combination of historical images reflecting pain and image-based pain memes to express their symptoms (Gonzalez-Polledo, 2016). Another recent study looked at the feasibility of diabetes patients using Instagram to communicate self-care, and found that the most popular images shared were in the categories of diabetes care, humour, or food (Yi-Frazier *et al.*, 2015). However, by 2015, there had not been a study on how people with Coeliac Disease share their management of comorbid illnesses via social media. At the time of writing, there were also no specific social science smartphone apps or specific research tools that had been developed to study the use of image-based social media within the context of chronic illness.

In Chapter 7, I investigate the use of image overlays as a tool to visualise illness. The thinking behind using image overlays in the app, came from a study of the literature around internet image memes, and the prevalence of their use in modern image sharing practices around chronic diseases (Yi-Frazier *et al.*, 2015). As a specific form of data, digital images have been argued to have a depth and density that words often lack, and allow for a much richer communication beyond the short sentences of most status updates, enabling a more nuanced understanding of this data and its social context (Vis, 2014).

The use of text over images has long been a feature of printed publications in the form of comic strips and graphic novels. In her chapter on Comics, Pinar discusses how the multimodality of the use of captions over images

brings the focus on how authors use text with images as a narration of what is going on in the image. Pinar notes that this also operates as the first, second or third voice of the narrator, with a commentary of what is going on in the image. Thus, she writes: "[...] The importance of captions [on top of a] story is that they are used as a story within a story to explain the anachronisms the author has introduced" (2014:p.384).

This use of text over image has also crossed over to Internet meme or micro image culture. Individuals and communities on social media have over the years become quite creative in their use of images to share opinions, humour and experiences, from the digital alteration of images and overlays of text, to the use of animated photographs used as general commentary on various aspects of daily lives, trends and occurrences (Malik, 2014; Araujo *et al.*, 2014). As Peck notes, "By sharing digitally altered images across networks, users engage in a vernacular process that creates and participates in discourses concerning shared expectations and communal values"(Peck, 2014).

This type of digital image sharing has been classified as an 'image macro', or 'meme image', which consists of various images or photographs with an overlay of text, used to communicate a humorous, sarcastic or emotive commentary to others (Mercer & gi97ol, 2015). As a sub-group of this, where the use of text over images that have been shared and tweaked and re-shared over the internet and social media has been described as "interior monologue captioning": "[...] a practice which involves placing randomly dispersed text on top of an image to represent what the subject is thinking or feeling [...]" (Don, 2013).

The use of photography tools in participatory research, where users visualise and discuss their experiences, falls within the realm of photovoice (Wang & Burris, 1997). Photovoice, Wang and Burris suggest, is a participatory action research method that traditionally involves giving a group of participants cameras, enabling them to capture, discuss and share stories they find significant (Wang & Burris, 1997). It was developed to help communities and sometimes marginalised individuals share images as a tool for discussion of key issues, in health psychology and social science research, that could potentially inform public health and policy decisions

(1997). Photovoice has been used to study communities with health issues, such as adolescents with cancer, as well as youth with obesity and mental health illness (Necheles *et al.*, 2007; Kramer *et al.*, 2013). It has also been claimed that Photovoice enables participants “to record things relevant to their life which health professionals and researchers may not have previously had access to” (Williams, Sheffield & Knibb, 2013:p.1171). Thus potential outcomes from using this methodology, and the process of individuals sharing their images to tell their stories and describe meaning behind the images, have been found to include “improved meaning-making, life satisfaction, and empowerment” (Yi-Frazier *et al.*, 2015). It has been argued that such outcomes have the potential to provide a glimpse into the visual social realities of individuals with chronic illnesses, and a deeper understanding of individual embodiment of chronic illness, that researchers may never have had access to before (Williams, Sheffield & Knibb, 2013:p.1171).

While in recent years, Photovoice has been used to study otherwise digitally active communities with traditional disposable cameras (Garner, 2014; Faucher & Garner, 2015), at the time of writing, it seems that so far, only one study has looked at the use of Photovoice through social media platforms like Instagram. Yi-Frazier *et al* (2015) also used digital Photovoice to explore the feasibility of using Instagram to study 20 teenagers with type-1 diabetes, who were asked to use Instagram to post any diabetes-related photo for three weeks. Here it was found that “shared photos were most likely to fall into the categories of diabetes care, humour, or food. However, while participants universally reported the project to be a positive experience there were technological issues and personal issues of privacy to consider for future widespread implementation” (Yi-Frazier *et al.* 2015: 1378,1380). What is missing is a deeper study of how the chronically ill self is visualised in social media photos, and how this reflects complex modes of self-identity and self-care with singular and co-morbid illnesses. The research in this thesis fills this gap and further explores these visualisations by utilising different digital representations of Photovoice, that are based on the insights of hashtag analysis of self-care practices.

Visualising the Self in Photos

One of the key things found when analysing user photos taken to visualise an invisible illness was the different levels of presence, co-presence and non-presence of individuals in submitted photos. The term 'visual co-presence' describes an ambient 'sharing' experience most typical with visual social media platforms like Instagram, where the part played by the photographer is presented within the image. The photographer's subjective and unique experience is foregrounded in the photograph, and is often performed with the perspective used in the photo, or where some part of the photographer appears. This can be in the form of a self-portrait (or selfie), where the photo is taken from first-person perspective (e.g. an arm, foot, or other body part is present), or where the setup is presented as from an individual's personal perspective/point-of-view e.g. a coffee mug, plate of food, or other people are positioned in front of the camera (Zappavigna, 2016:p.18).

Thus, one way that social media has influenced smartphone photography is by allowing the expression of a form of 'intimate visual co-presence', a relational occurrence that arises out of the sharing of subjective photos with others in the temporal and portable nature of social streaming technologies (Mizuko & Okabe, 2005; Zappavigna, 2016). This flexibility has allowed a style of what Zappavigna calls "you could be here with me" photography, where social photographers include a part of themselves or experience in the image, and also invite viewers to imagine themselves into the frame/experience (Zappavigna, 2016:p.2). It is arguable that this visual co-presence becomes even more intimate when the user has a chronic illness and invites the viewer to share in their experience of painful or frustrating symptoms.

Indeed, as Zappavigna (2016) argues, although selfies have taken off in social media, there haven't been much work on the different types of self and subjectivities. As she sums up, "Most of this [selfie] research focuses on the context of Instagram usage or its technical dimensions, rather than the specific visual meanings made in the images" (p.2). The empirical research in this thesis will go some way to tackling the chronic illness meanings made through the visual choices of some Coeliacs who use images and app tools to share their lived experience via social media.

Conclusion

Overall, then, this chapter has cover a lot of ground. To recap, it has reviewed the various different fields in which the study is positioned. More specifically, this chapter has outlined the key ideas that frame the entire thesis, which are: biographical disruption, illness narratives, technologies of self, risk, gamification and visualisation.

Each of these distinct scholarly areas feed into a greater or lesser extent, one or more of the empirical chapters within this thesis. For example, biographical disruption, illness narratives, and the technologies of self-feature predominantly in Chapter 4 in which I discuss symptoms, self and subjectivity in CD. The techs of self and risk feature especially in chapter 5, where I show how Coeliacs use social media to navigate risk and engage in activism. Chapter 6 expands on and presents an example of how I have built two apps in order to show the potential of using modes of gamification to investigate social science topics, specifically CD. In Chapter 7 I show how I developed a third app in order to further study the visualisation of comorbid symptoms. This extends on modes of gamification and the use of visualisation for contemporary digital social research.

Of course, although each of the specific scholarly fields features primarily in one or more chapters, in actual fact, the scholarship overlaps and intertwines in the thesis overall. It is important to note that I make no claim of presenting any of these fields as a definitive literature reviews in any of the distinct areas; the literature in each one of these scholarly niches is vast and historical, and increasingly crosses the boundaries of disciplinary practice. Instead the aim of this chapter has been to: a) position this particular study with the field of sociology of health and illness, and CD in the digital age, and b) highlight some of the key ideas within each of the fields that has driven the thesis intellectually. Like all interdisciplinary projects, and empirical ones at that, it is possible to have done the same study using many other alternative kinds of scholarly positions. What I have done in this thesis is both situate and highlight the literature that best fits the research questions, and subsequent analysis and findings. The next chapter details the methodological approach used to conduct the research.

Chapter 3: Methodology

Having established my aims and research question, in this section, I will outline how I designed and conducted this research, as well as the methodological considerations involved in the selection and analysis of data in this thesis. These were primarily driven by my aims and research questions in terms of:

- How are social media used to self-manage CD?
- How might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness?

In what follows, I break the discussion into eight sections, as a way of providing a thorough overview of the various methodological issues intrinsic in doing the research. Firstly, I explain how I have selected samples from social media. I then introduce readers to the notion and use of APIs in this study, including interface restrictions and the problem of different timelines across different platforms. Thirdly, I discuss the issues involved in using cross-platform media. Here I also outline how and why I have concentrated on two main cities, mainly London and New York. Fourthly, I explain my use of hashtags throughout the study. Fifthly, I zoom in on Facebook comments and why I have analysed those, specifically in the writing of Chapter 4. Sixthly, I discuss of Instagram and the issues involved in reading digital images. And finally, I summarise the ethical issues involved in this study, and how I have tackled them, before concluding.

The chapter is divided into two parts. In the first part, I talk about the general methods of data collection and sampling that I have used, using hashtags.

Selecting Social Media Data Samples

When researching the health-related behaviour of individuals on social media, one must be cognisant of the variety of ways that users use social media, as well as the different kinds of devices they employ to do so (Marres, Gerlitz & Studies, 2016). As social media platforms have started to

be used to share similar sorts of information, such as images and text across both Twitter and Instagram, social researchers are increasingly having to adapt their research methods to catch-up with the myriad of ways that information on key aspects of social life (and in turn chronic social life) are communicated (Michael & Lupton, 2015). This involves understanding how data is channelled, stored and propagated via social media platforms like Twitter and Instagram, as well as how the data produced by individuals can be changed, re-shared and ultimately communicated. Indeed, this thesis is somewhat unique in the way it uses a range of digital data to explore a particular area of social life.

Most traditional social science theses are structured in a way that allows them to collect and analyse data from a specific source, be it interviewees, archived data, or data from statistical databases. However, the way that my methodology is structured is somewhat different, due to the evolving nature of the topics that were captured and followed over the period of time that specific events played out over social media. With regards to the structure of data output by different social media platforms, for the purposes of answering my research questions, the data from Twitter and Instagram were interpreted in different ways. Within the context of researching the representation of CD/comorbidity, the anatomy of the text/images within a tweet or Instagram post were categorised as either statements about a Coeliac's experience of self-managing CD/comorbidity, as questions about self-managing CD/comorbidity or the GFD, or as part of an ongoing conversation about their experience of CD/comorbidity or the GFD within the Coeliac community or to their social network audience at large. Some of these conversations were short, or extended over a prolonged period of time. For example, when looking at data informed by analysis of my first research question of how some Coeliacs use social media to self-manage CD, and in particular how they dealt with risk at the time of a gluten free food recall – the usual 31 day data collection period had to be extended over the course of two years. This was because it took that amount of time for both the incidents in both the UK and the US to play out, and for me to fully capture the events, statements and conversations as they happened.

A key tool I used was Netlytic.org (Gruzd, 2016) to maintain a data collection feed of Twitter and Instagram feeds in relation to key Coeliac and co-related risk hashtags for a continuous period of time between January 2014 and September 2016. This was due to the very nature of these particular social media platforms. That is, due to a cap on free historical data, I had to maintain a period of continuous sampling to make sure I collected a robust and active data sample. This is because Twitter and Instagram do not allow free retroactive data sampling, and because in my situation (and potentially those of other social researchers) there was no budget to pay for expensive and large amounts of historical data.

Table 1 gives an overview of each main data collection period, and how it relates to each chapter in this thesis. It also shows the sub-sample periods for each topic discussed, as well as the sample methods used for each dataset. There are two main datasets, the Symptoms dataset, and the Risk dataset. Both datasets were sampled and used to answer my two research questions:

- How are social media used to self-manage CD?
- How might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness?

The Symptoms dataset sampled a total of 18.15k tweets and 15.7k Instagram posts between January 2014 and September 2016. This data was used to answer both research questions, in terms of looking at how the discourse within tweets and Instagram posts mentioning symptoms could help explore and visualise how social media can be used to communicate the self-management of CD and comorbid symptoms.

Chapter 4 explores the first research question of asking how social media is used to share the symptoms and self-management of CD. With the analysis of 10.7k Instagram posts and 13k tweets, it specifically looks at how certain hashtags like #NoCureNoChoice or #glutened can be created or utilised by Coeliacs and those with similar symptoms as way of spreading awareness of their illness. Chapter 4 also looks at how co-occurring hashtags like #symptoms + #Coeliac OR #Celiac can also be used to explore how the symptoms specific chronic diseases like CD are being managed.

The hashtag and social media discourse data from Chapter 4, is further utilised in Chapter 6, which uses gamification to answer the second research question, of how modes of gamification may be used to explore and visualise the self-management of CD and comorbid illness. In Chapter 6, the 10.7 k Instagram posts and 13k tweets from Chapter 4 are further analysed and visualised using data visualisation, games mechanics and gamification techniques, in the build of eHealth gaming apps 'Gluten Fighters' and 'Coeliac Sam'. The same hashtag and discourse data is also further visualised in Chapter 7, with the build and deployment of the visual research tool, the Spoonie Living app. The Spoonie Living app is used to explore how individuals visually communicate their experiences of symptoms and feelings of biographical disruption with CD and comorbid illnesses.

The methodology table (Table 1) also shows the data output that occurred from the smartphone applications that were built for Chapters 6 and 7. The data from the apps in Chapter 6 (Gluten Fighters and Coeliac Sam) is represented in terms of the number of downloads of each app. This is because as prototype gaming apps, they were built more as a visualisation of the concept of illness and quest narratives first explored in the way that hashtags relating to symptoms were shared in Chapter 4. The Gluten Fighters and Coeliac Sam apps were created to address the research question of how modes of gamification can be used to visualise the social media data shared with regards to the self-management of CD and comorbid illnesses, but not as a way to investigate user interaction with each app. Impact for these two apps was measured through the number of downloads for each app, and any reviews of them in the Apple or Android app stores, and this is further explored in Chapter 6.

In Chapter 7, further analysis of the self-management of CD in the 15.7k Instagram posts of the Symptoms dataset, showed that Coeliacs were also using images to visualise their illness and quest narratives in terms of diagnosis, biographical disruption, and adjusting to life on the GFD. However, analysis of these images found it hard to differentiate between general selfies and photos taken, and those taken by users with CD and comorbid illness. To better explore how modes of gamification could be used to better visualise and differentiate these chronic illness photos from

the rest of the visual data stream, I devised a way to re-use the hashtags that were visualised for the Gluten Fighters and Coeliac Sam app, and turn them into visual tags and markers of symptoms and biosocial identity with chronic illness. This was done by the creation of the Spoonie Living app, which incorporated making the same hashtag data used in Chapter 4 and 6, into visual stickers that enabled new users to self-label their symptoms and experiences of CD and comorbid illness. It was proposed that allowing users to visually tag their symptoms with previously collected hashtag data might provide new insights into how users felt about their symptoms, and how different modes of biosocial identity can be visualised as co-existing with comorbid illness.

The build of the visual research tool, the Spoonie Living app incorporated the utilisation and analysis of data output in the form of the visual chronic illness stickers added to images, that were shared from the app to the social media platforms, Instagram, Twitter and Tumblr, as well as shared to the internal wall of the app for more private data. This data was also classified by posts and tweets linked with the hashtag #spoonielivingapp, as well as an analysis of the internal posts submitted within the Spoonie Living app.

A separate social media dataset was used with Chapter 5, to explore how Coeliacs communicated how they dealt with the risk of cross-contamination of food with gluten while self-managing CD with the GFD. The use of a separate dataset was because the social media activity that occurred around the Genius Foods and Gluten Free Cheerios incidents between 2014 and 2016, had a distinct set of co-occurring hashtags and keywords related to each incident. These were #cheerios AND #glutenfree or #geniusfoods, with keywords without hashtags, like "Cheerios" or "Genius Foods". It was also found that within the time period of 2014 - 2016, that there were more tweets and Instagram posts about the two food recall incidents that mentioned the following co-occurring hashtags in conversation: #coeliac OR #celiac AND #risk; and #glutenfree AND #recall, in addition to #cheerios OR #geniusfoods. As discussed in the next section on APIs, because at the time of writing, the free and public Twitter API only output a small sample rate of all conversations on Twitter and Instagram (boyd & Crawford, 2011), it was important to specify the terms

that were more likely to co-occur in conversations connected with risk and coeliac self-care on the GFD, to ensure a more relevant and robust sample of data was retrieved. Thus, in the knowledge that the two incidents of gluten free recall and controversy were playing out, it was decided that a live and continuous period of data sampling from Twitter was the best course of action. As further discussed in this chapter, Facebook was also a source of data, mainly because Genius Foods and Cheerios pointed customers to their Facebook pages, which then made it possible for me to sample data from ongoing conversations on these pages, within the time period of the food recall.

Main Dataset	Chapter	Sub-Sample Period	Social Media Data Output	Data Sample Method	Data Analysis Tool	LEGEND	
						RQ 1: How are social media used to self-manage CD? How might modes of gamification be used to explore & visualise the self-management of CD & comorbid illness?	RQ 2: Data Visualised + Explored in RQ 2
Symptoms Dataset Twitter: 18.15k tweets Instagram: 15.7k posts ... Sample period: Jan 2014 - Sept 2016	Ch4. Symptoms	Jan 2014 - Sept 2016	#NoCureNoChoice OR #glutened + #symptoms + #Coeliac OR #celiac Tweets: 13k (3500 users) Instagram: 10.7k (2139 users) Population: Coeliac mentioned in bio	Netlytic TAGS DMI Instagram Tool	- Netlytic - Aiyien - Google Data Addons - Gephi	RQ 1	
	Ch 6. Gamification	Jan 2014 - Sept 2016	#cleaneating + gluten + #Coeliac OR #celiac Tweets: 5k (2000 users) Instagram: 5k (3600 users) Population: Coeliac mentioned in bio	Netlytic DMI Instagram Tool	- Netlytic - Aiyien - Google Data Addons - Gephi	App	App Data Output
			#50ShadesOfCoeliac Tweets: 150 (20 users) Population: Coeliac mentioned in bio			Gluten Fighters Downloads: 2800	
	Ch 7. Visualising Comorbidity	Jan 2014 - Sept 2016	Jan 2014 - Sept 2016	#NoCureNoChoice OR #glutened + #symptoms + #Coeliac OR #celiac Tweets: 13k (3500 users) Instagram: 10.7k (2139 users) Population: Coeliac mentioned in bio	Netlytic DMI Instagram Tool	- Netlytic - Aiyien - Google Data Addons - Gephi	Coeliac Slam Downloads: 3500
#Coeliac/Celiac + Risk Twitter: 2.3k (350 users) Instagram: 3.1k (390 users) Population: Coeliac mentioned in bio							#spoonielivingapp Instagram: 800 posts (40 study participants 500 general users) Twitter: 20 (15 users) Tumblr: 20 (12 users)
Risk Dataset Twitter: 3.3k tweets Facebook: 1k posts Instagram: 3.25k posts ... Sample period: Jan 2014 - Sept 2016	Ch 5. Risk	Jan 2014 - Sept 2016	#glutenfree + #recall OR Cheerios OR GeniusFoods Tweets: 1k (200 users) Facebook: 1k (104 users) Instagram: 150 (25 users) Population: Coeliac mentioned in bio	Netlytic Netvizz DMI Instagram Tool	- Netlytic - Aiyien - Google Data Addons - Gephi Excel Spreadsheet		

Table 1. Social media data and tools used in thesis

APIs

An API (Application Programming Interface) is a set of routines, protocols, and tools for building software applications. The API specifies how various software components should interact. For example, an API controls how a link to another website is shortened and shown on Twitter, so that it fits within the 140 character limit set. Access to APIs is the primary way for many researchers to retrieve user data from a wide variety of social media platforms.

Although APIs make it easier to collect data, for many researchers, the proprietary nature of APIs can mean it can be a struggle understand each API's functionalities and constraints imposed by the terms of service related to data collection, storage and dissemination practices. While there are several proprietary tools that researchers can use to get data from social media networks (Gnip, 2016; Pulsar, 2016), a few free and low subscription platforms have emerged, which utilise the public APIs, and offer ways of downloading consecutive samples of Twitter, Instagram, Facebook and other social media data over periods of time.

The impact that different historical access rules for different social media platforms can have on data collection, is just one of a range of things that can affect how students and social researchers with little to know Big Data collection budgets can follow incidents that occur across different social media platforms over a prolonged period of time. These and other factors have an impact on the quality and type of data harvested from the Application Programme Interfaces (APIs, see below) of social media platforms, and how they are understood. This also impacts on how additional digital research toolkits are designed to fit within user communication practices in this area, as well as how the data output from such toolkits are analysed and understood for further user research.

For the purposes of harvesting data about Coeliacs across social media, I chose to use four different pieces of software. This is because social media platforms like Twitter (2015a) and Instagram (2015) do not allow free historical searches of data via their APIs. In this case, I had to find a piece of software that would allow me to harvest data from these platforms for a

maximum of 31 days, and then allow me to download and store this data onto a secure server.

For harvesting Twitter and Instagram data, I primarily used Netlytic (Gruzd, 2016), a free (tier-based) data mining and social network analysis platform for academic research. The pros of using this software, were that the data harvesting facilities for Netlytic worked across different social media networks, and were thus very useful for monitoring the same hashtag at the same time on both Twitter and Instagram (i.e. #NoCureNoChoice). The platform also provides comprehensive analytical software, that can be exported and further analysed externally. However, the 31 day cut-off point for harvesting each data stream meant that the data feed had to be reset each month, so a continuous stream of data was not possible.

Ideally, it would have been good to use Netlytics to harvest data I needed from Facebook, and Tumblr. However, Netlytic's Facebook capture feature does not currently allow historical timeline capture of data, but only live data from Facebook Pages, and did not harvest from the Tumblr API. Instead for Facebook data, I used Netvizz (Rieder, 2013). Netvizz is a tool that allows the user to add a historical date range, the name of a public user group or Facebook Page, and then harvest all comments/likes for that period.

The pros about Netvizz are that one can download data from Facebook's timeline retroactively makes it a powerful resource, without the need for constant monitoring. One of the main drawbacks is that each dataset has to be manually downloaded, and cannot be saved in a user account. This means that, although it allows the exporting of data into spreadsheet files for further analysis, the tool has to be used in isolation, and not (like Netlytic) as a platform that exports data into an online repository. For the small data samples of Tumblr, I used the Digital Method Initiative's co-hashtag and post data tool (Borra, 2015). This tool was used mainly because it was the easiest tool to use for capturing small amounts of data from Tumblr's API. Again, it is a tool that can only be used in isolation, and needs some knowledge about how to process .tab and .gdf output files. However, as a resource for grabbing a small amount of data, it worked quite efficiently.

For more in-depth graph analysis of Twitter, I also used NVivo's NCapture tool for real-time harvesting and coding of Twitter hashtags (NVivo, 2014). I will go into more detail about how each of these were used within each chapter project, with a summary of any challenges encountered below.

Because preliminary research at the start of my thesis found that Coeliacs discuss self-care across different social media networks (e.g. A tweet could have links out to an image and longer post on Instagram, or a blog post on Tumblr or a complaint in a Facebook post to a food manufacturer about cross-contamination), such different data outputs could confuse results. It was therefore important to take into account the effect that these different types of data formats from each of these platforms would have on each illustrative study.

User interface restrictions occur when some social media platforms like Twitter impose character restrictions or proprietary image linking restrictions, which act to skew data output. I found this out early on in my Twitter data collection (2013 -2014), where some tweets that had been tweeted via the Instagram platform, failed to show the attached image, and cut off part of the text posted with the image. In these cases, to avoid large chunks of null data, the link to the original post had to be followed, to fully understand the whole context of the post. However, I also noted that the 2015 introduction of a new sharing algorithm via third party tool called "If This Then That" (IFTTT.com, 2015), meant that users could automate the sharing of their image posts on Instagram to Twitter without losing the overall image. Where this tool was used, it seemed that fewer images were being lost. This only related to those users who were cognisant of this tool; where they were not, the skewed/truncated output was the same.

The way the different APIs of social media platforms like Twitter, Instagram and Facebook report timelines can also have an effect on the quality of data output and data analysis. The free API for Twitter research restricts data harvesting to within a seven day period (Twitter.com, 2015), so for research based over an extended period of time, there is need to use a data harvesting tool like Netyltic (2016) to chronologically pull data every day over a 31 day period (and then repeat this over period of months,

depending on the time span of one's data analysis). If this is not done, then the researcher may experience many gaps in the data due to limit of the seven day cut-off point.

In comparison, accessing consecutive timeline data from both the Facebook and Tumblr APIs is much more straight-forward via use of the Netvizz tool (Rieder, 2013; Borra, 2015). While both APIs do have certain restrictions on the type of data you can harvest, when just searching for public Facebook page posts, or public Tumblr blog posts, both APIs do give the researcher consecutive date parameters to pull data from via a user selected date period. This proved to be both relevant and useful for my study on how Coeliacs discussed risk during product recalls of gluten free food. I was able to use the calendar tool to pull data from different periods of time from both platforms, without the need to worry about setting up a script to capture data every seven days, as is needed with the public Twitter API. Such features are important to social researchers who would otherwise have to pay for historical data archives on other social media platforms. This is also relevant in terms of cutting down on the time spent harvesting data over prolonged periods of time, as I had done with previous with historical data that had access restrictions on other platforms. The historical access to Facebook data also seems to give access to a full sample set, not just the 1 – 2% allowed via the public Twitter and Instagram APIs. When comparing the harvested data with the comments data that was visible on the live Facebook page, the archive data mirrored the visible data. Having such free access to public Facebook Page data thus makes data collection and analysis easier, as well as data sampling more robust. At each point of sharing sample Facebook data in this thesis, despite the public nature of these Facebook posts, it was considered ethical to anonymise the name of the person posting, unless explicit permission was given. However, while at the time of writing, Facebook Pages for brands and companies are not permitted by Facebook be made private. Private or secret Facebook Groups mean that unless authorised visitor access is given, there are restrictions on any data harvested/analysed (Thrul *et al.*, 2017). This means that any discussion of topics of interest to the study are thus hidden from research. In some cases, researchers can ask administrators for access to the discussions in private Facebook groups,

however permissions and ethics issues around the use of such restricted data also remain factors of concern (Prabhakar *et al.*, 2017).

Yet, if one is doing analysis on the same hashtag on Instagram, the timeline restrictions and indeed general rules of data retention are a lot less clear. In my chapter on the self-reported symptoms of Coeliacs (Chapter 4), I found that searching across certain hashtags like #glutened can sometimes pull data from up to two years previously, especially if a user has also done a search against that hashtag and commented on a post that is two years old. In these cases, the old post can turn up in a current dataset. For ethical reasons, another data anomaly that must be taken into account, when some Instagram data that was once in a public account and that has now been made private, this now private data can be automatically harvested. When this occurs, the onus is on the researcher to check the status of Instagram account that they might want to feature in a sample, to make sure they are acting within the rules of the Instagram terms of service, and only using data that has been tagged as public by the user (Instagram.com, 2015a). When looking at these issues of flexible timelines, and privacy issues across social media platforms, one could argue that these challenges/occurrences make the reading of so-called 'live data' output quite flexible, as time becomes less of a consecutive flow, but more of an elastic stream of data that through different kinds of interactions, can be pulled into and out of focus depending on the current or pertinent issue of the day (Kleinman & Barad, 2012).

As well as being affected by the unstructured nature of the data output from these APIs, sample timelines are also affected by the fact that the sample rates allowed from public APIs are very small (1% for the small Twitter 'spritzer' sample (boyd & Crawford, 2011)). I decided to test this 1% argument, by creating a small pilot study, between March and April 2014, where I took samples from Twitter's proprietary API (GNIP), and samples from Twitter's free API during the same period. At the beginning of my pilot study of the utility of Twitter APIs, I used 4,000 GNIP credits shared with me in a trial sign-up to another social media data harvesting tool, Discovertext.com (2015), to compare the data output of the full GNIP Firehose with the Streaming API output. As previously mentioned, with a

limited budget as a student researcher, it was not possible to fully utilise the full extent of the Twitter Firehose, with the average cost of harvesting historical data reaching to £500 p.c.m for a maximum of 240,000 tweets (Pulsar, 2015). For this reason, mining the full extent of the Twitter API for the prolonged period of time that I wanted to research Twitter (two years), with a full analysis of all tweets was not possible.

For this pilot study, I ran two queries to cover the same date and time 3rd March 2014 – 3rd April 2014 – searching for the term “glutened” or “glutening”. For the GNIP query parameters, I used a query to search for all tweets containing the hashtags #glutened or #glutening. To make sure that there were no errors in the data collection – I compared all meta-data between the two datasets by matching up the unique tweet IDs, screen names and user IDs, as well as the timestamp and geo-location data of each tweet (where a geo-location tag existed). An example of compared Streaming and GNIP meta-data can be seen in Figure 1.

Streaming API						
id_str	from_user	text	created_at	source	user_followers_count	user_friends_count
590994759713497081	Fasiontolive	Going on week 2 of feeling sick from being glutened uughhh #imsoovertthis	Wed Apr 22 21:45:05	Twitter for Android	425	271
Gnip API						
[M] id:	[M] username:	Text	[M] posted_time:	[M] source:	[M] followers_count:	[M] friends_count:
590994759713497081	Fasiontolive	Going on week 2	4/22/2015 21:45	Twitter for Andro	425	271

Figure 1. Comparison and testing of Streaming and Gnip metadata.

To see if the returned results would contain more and relevant data - I then ran a search query for “#glutened OR glutened OR #glutening OR glutening”, this would make sure that all tweets containing either the hashtag or the words by themselves would be scraped. Once the time period for the two searches were complete, I compared the results to find out if there were differences between the number of tweets and hashtags returned, and the completeness of results. Closer analysis of the results of this data collection by daily intervals, can be seen in Figure 2. You can see that data is output via the GNIP Firehose at much more frequent intervals than the Streaming Data. Gaps in the streaming data points are due to hourly rate caps, while peaks in the streaming data in comparison to

shorter data clusters in the GNIP data, reflect trending topics and re-tweets. Towards the end of the collection period, activity dies down, and from 19 – 27 April, both streams have similar rates of tweeting.

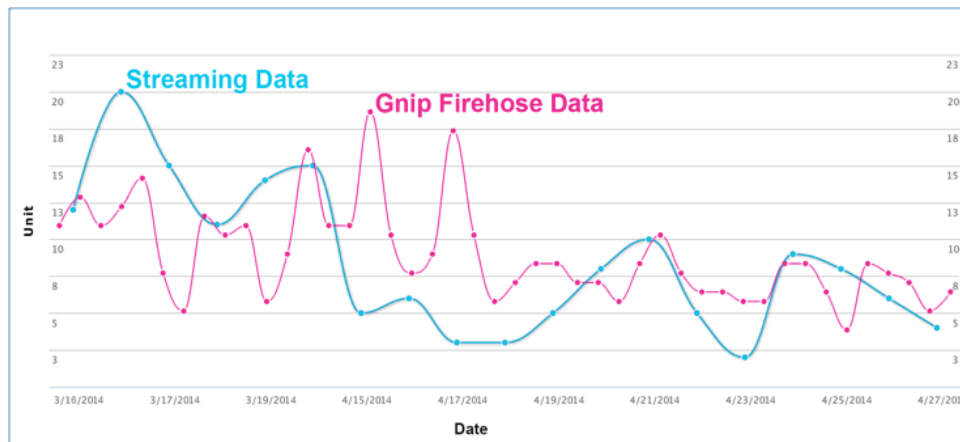


Figure 2. Skewed trending tweet rates in Streaming API vs Firehose tweet rates

For my study of Twitter data tweeted by Coeliacs, the effect of the different output rates of restricted Streaming data versus full Gnip Firehose data means that rather than capturing 1% of all Coeliac data from the public API stream, my data output is restricted to only 1% of trending data. This restricted output skews any results in the favour of trending topics, and is thus not a true 1% sample rate of all topics, but instead only a biased 1% sample of trending topics (Figure 2). These results provided me with a concrete example of the smaller frequency rate and smaller amount of data outputted by the Streaming API. Such small samples from the free Twitter API arguably mean that it is very hard to get a broad overview of activity on social media as a whole, especially when the parameters of the random sample remain proprietarily hidden behind ‘black box restrictions (González-Bailón *et al.*, 2012; Driscoll & Walker, 2014) of the large social media companies.

Based on these factors, it is arguable that researchers should be careful not to generalise the research of data samples from public APIs, as these are not necessarily representative of social media use (in whichever context) as a whole (Driscoll & Walker, 2014). Thus the kind of method used can have an effect on the data output and the effect that data has on the way we as researchers talk about our results.

Crossing platforms

The next part of this chapter discusses the issue of avoiding the studying of social media platforms in isolation (Mahrt & Scharkow, 2013; Driscoll & Walker, 2014). I discuss my use of mixed methods to analyse and unpack complex linked data occurrences found in the social media datasets harvested for this thesis. I do this in an attempt to gain a broader overview of the way individuals use different formats and modes of data to communicate snippets of their lived experiences.

One of the main criticisms about the study of big data is the often simplified way that analysis is done with a heavy reliance on rates of frequency and number counting. However there tends to be little deep analysis of what is going on under the surface of these marketing stats, user count hashtag trends (boyd & Crawford, 2011). This is most specific in the case of Twitter data, where boyd and Crawford (2011) argue that analysis is needed at a much deeper level than the public discourse focused on frequency trends based on the raw number of social media tweets and posts available. Indeed, this research focuses on creating a deeper methodological understanding of my data sample by exploring how social media is being used by Coeliac patients on a much more meaningful level than the raw numbers or network influence of Coeliacs who use it to tweet and post about their illness.

The textual analysis of words produced by social media has been found to be used differently in commercial communications versus social sciences fields (Marres & Weltevrede, 2012). That is to say, commercially focussed analysis of text looks at the frequency of words co-occurring within a social media corpus, and thus draws conclusions on the current happening or live-ness of trends and data, as well as the reach and influence of key actors within networks of digital economy and influence. While the use of quantitative methods was used in the data collection and big social data analysis in the case studies for this thesis, I have also used qualitative research methods to analyse smaller data samples to gain a deeper understanding of some datasets, where the data outputs have been presented in visual or heavily discursive form.

The illustrative study in Chapter 6 is completed in two parts. First, the study of geo-located tweets and posts of the self-reported experience of symptoms as a result of accidentally being glutened, and second, an exploration into the way that this data could be used as a reflection of Coeliac practices of self-care, as a games-based learning tool for newly diagnosed children with Coeliac Disease. While testing different search parameters to find the richest data corpus that would show how some Coeliacs use real-time social media, my initial pilot studies have found that some Coeliacs use social media in a variety of multi-layered and innovative ways. A data scrape of the Twitter API found that data and experience was shared in a multitude of ways: from sharing photographs of ingredients labels on food that they are unsure about – to sharing the nature of symptoms endured from accidentally ingesting gluten, as well as hints and tips as to where to find gluten free food. A standard frequency count of the amount of tweets mentioning gluten free food would in this case, only give us a one-dimensional understanding of the Coeliac network on Twitter. To understand the means, motives and more innovative ways that Coeliacs use Twitter and other social media to navigate their diet – a more contextual and relational analysis of strengths and ties within this network is needed. To do this, the use of co-word analysis was employed.

Instead of just measuring the frequency and trending of words that appear in association with others, co-word analysis attempts to answer Boyd and Crawford's critique (2011) by determining the relevance of terms through measuring the strength and intensity of relations among them. Here, only words that appear frequently ¹and that appear next to one another make it onto co-word maps (Marres, 2012b). In this respect, co-word analysis delivers the most 'happening' content by measuring fluctuations in the presence of words and word associations (Marres & Weltevrede, 2012).

¹ Frequency in this context, does not only rely on popularity, but is strengthened by words that appear together with frequent words – thus making it easier to build up a full picture of the actual conversation topics that are trending, rather than a broad notion of words that are trending.

Indeed, as noted by de Albuquerque et al., the approach of just looking at mass patterns of posting/tweeting social media messages means that: “[...] the actual content of social media messages is largely ignored, and with this, much of their potential to improve the current knowledge about the unfolding situation is lost.”

(2016:p.312)

Bearing this in mind, I aimed not just to rely on ‘big data’ as a barometer for all data on how Coeliacs use social media, but to instead use different types of analytics to investigate the content of social media posts across platforms. In this sense, I also wanted to find out if tweeted clusters or conversations only represent Coeliacs talking about gluten free food, or if they are also talking about health-related activity, such as being glutened, the symptoms of Coeliac Disease, or extended conversations about their daily management of the gluten free diet. To investigate further, I used co-word analysis to find out what related words and hashtags within my sample of twitter conversations, to query medical terms related to the diagnosis, symptoms and general self-management of coeliac disease. A co-word analysis of hashtags in the data showed that, as well as user discussion about the best places to find gluten free food, just under a quarter of hashtag terms used discussed medical issues to do with coeliac disease. These included words associated with presenting symptoms, medical tests, diagnoses (#dx), possible associated diseases that were being tested for (#thyroid, #ibs [irritable bowel syndrome]), and more general discussions around health and the gluten free diet.

An example of one of the conversations that made up the discussion around diagnosis of coeliac disease, and which contained the word-pair “thyroid” and “celiac” is shown in Figure 5. Thus, content and word-pair analysis of conversations mentioning key medical terms can show a heavy weighting towards words associated with diagnosis, blood work, symptoms and test results.

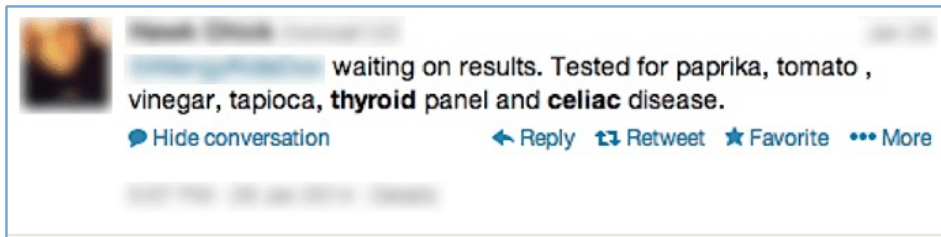


Figure 3. Example of Coeliac Tweet sharing medical details.

Projects such as the Google Flu and HealthMap have already shown that patient annotated text on social media sites have been a reliable data source for tracking disease trends, whole novel insights into comorbidities and drug-treatment effects have been discovered on sites like CureTogether and PatientsLikeMe (MacLean & Heer, 2013). The analysis of real-time Twitter data in relation to a corpus of Tweets related to discussion of Coeliac disease, also shows a shift to patients discussing key medical terms in relation to the management of an investigation into their chronic illnesses. Indeed, McLean and Heer (2013) argue that while these conversations may not contain scientifically accurate or systematic data, on a deeper analysis. It may be shown to comprise of rich descriptions of many patients' experiences of singular and multi-morbid conditions in real-time.



Figure 4. Word cloud showing strength of conversation re. diagnostic blood tests and CD symptoms.

The word cloud in Figure 6 shows a deeper conversation analysis of this subset of tweets shows the context of this discussion. Next to the 12,000 mentions of term “coeliac” and “disease”, the next most popular terms were “bloods”, “test”, “diagnostic/diagnosis” and “new” (in relation to new diagnosis), these were in turn connected with associated word synonyms

like “disease”, “negative”, “ask” and “GP” within related Twitter conversations. While, drilling down into the actual conversations, a word-pair analysis of “blood and test” (Figure 7) shows discussions that concern negative blood tests, and asking GPs and charities for more information.

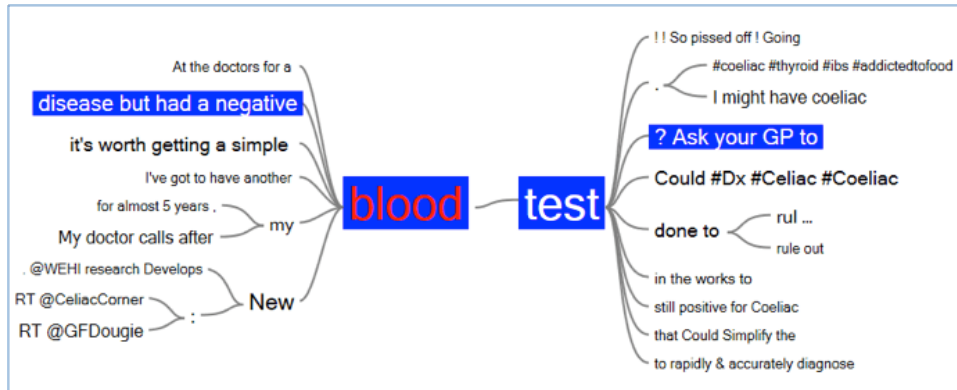


Figure 5. Word-pair analysis of blood test conversations.

In this respect, we can see that, when one investigates the data at deeper linguistic level, we can find patterns revealing the extent to which Twitter users are discussing their management of the body within the context of food and health.

The use of co-word analysis can, however, also raise issues of reliability and comparability. When most web and social media applications, including Twitter, rely on self-indexing in the form of users providing keywords and digital tags or hashtags, which means that the data which I am analysing is only as good as the source from which it is derived (Marres, 2012b).

If a user with Coeliac Disease tweets about having digestive problems after eating out at a recommended restaurant, but does not tag her tweet with the hashtags #glutenfree, #coeliac or #celiac, then she will be missed in my data-mining and therefore in my sample analysis. Thus my results will only be as good as the classificatory practices and format of the digital device on which I rely.

There will always be questions as what extent can frequency data techniques alone really show us the truth of what is going on outside the

conversations that have not been efficiently tagged with medical data. However, it is hoped that my robust use of these methods in my case studies will go some way to highlighting ways to deal with the problem of the 'truth' of big data. However, it is also arguable that while randomised samples of data can only give us a snapshot of life in the city, perhaps these snapshots and the way the data is used to inform policy and food safety decisions about the availability of gluten free food and information about it on the non-digital, ground level, may in turn lead to helping those who may not have access to these digital social media networks.

In the chapter on Risk Communication and Activism (see Chapter 5), for the first part of the chapter, data on the risk aversion practices of Coeliacs on Twitter and Instagram was harvested and analysed using quantitative data-mining and hashtag analysis methods. However, for the second half of the chapter, a lot of the data was harvested from Facebook, where customers responded to official company messages with queries and evidence of sickness as a result of the mass cross-contamination of popular gluten free food items. Because hashtags were not being used in these Facebook posts, rather than rely on a quantitative hashtag or co-occurrence analysis of the text of these particular posts, I opted to explore the 900 posts on a deeper level, by carefully coding and annotating them with Nvivo's coding and annotating tools. This would enable me to answer my research question, to explore how Coeliac customers in particular were responding via to the gluten free food recall with regard to its effect on their self-management of CD. This helped me to identify key patterns of information seeking and knowledge sharing behaviour, as well as analyse specific discussion of symptoms after ingestion of contaminated food from the recalls. I was also able to identify when external factors affected the Facebook discussions, such as mentions of Twitter activists. This also helped me identify links to external evidence from blog posts, where Coeliacs had archived glutening incidents they perceived were a direct result of ingesting the contaminated food items.

In the chapter on the Visualisation of Coeliac Disease and Comorbid Illness(es) (see Chapter 7) mixed methods were again used. While the creation of the visual stickers that were the main feature of the Spoonie

Living app and research tool – were based on quantitative co-occurrence hashtag analysis, and text frequency analysis — the study of the images harvested from Instagram and Twitter was completed using careful visual analysis of photographs shared on these networks.

Hashtag Analysis

In the chapter looking at how some Coeliacs talk about the symptoms of Coeliac Disease (see Chapter 4), I chose a small selection of hashtags that I thought would result in good data for each topic, and searched using these parameters across all three social media platforms, checking for useful information within each dataset returned. For example, for the chapter on how Coeliacs talk about symptoms, over an initial period of two weeks, I queried the Twitter and Instagram APIs using a combination of the following hashtag terms (abbreviations used by Coeliacs have been explained in brackets): “#coeliac OR #celiac” AND “#glutened OR #symptoms OR #dx (diagnosis) OR #diagnosis OR #x-contam (e.g. cross contaminated) OR #cross-contam OR #cross-contaminated”. In this initial query the term ‘AND’ means that all tweets or Instagram posts must also contain the hashtag #coeliac (UK spelling) or #celiac (US spelling) as well as other terms related to experiencing the symptoms of Coeliac Disease. It was found quite early on in my preliminary research, that Coeliacs contextualise and signpost their tweets/posts to other Coeliacs by using the hashtag #coeliac or #celiac. This form of social tagging is used so that other Coeliacs searching for topics they are interested by using the #coeliac hashtag can more easily find these posts (Zappavigna, 2010), in this way a loose hashtag or biosocial community is formed, based around a specific biological illness (Rabinow, 2005; Gibbon & Novas, 2007; Ene, 2009). I discuss more about hashtag and biosocial communities in the Literature Review section of this thesis.

Once I had the data output from these queries, I checked the data to see if the content of the tweets/posts contained enough relevant information about the way Coeliacs discussed symptoms to give me a good dataset to analyse. Relevancy was based on if the tweets/posts included conversations about symptoms (e.g. being glutened stomach pains, brain

fog), the avoidance of symptoms, or the exchange of remedies used to treat symptoms. Posts were not deemed as relevant to the context of the thesis if they were automated advertisement posts that were created by spam-bots, or if they were links to news articles that contained no personal commentary.

Secondly, I checked posts from each dataset, and using the 'source' tag in each API index, I sorted them into groups that 1) contained posts that were direct posts to the relevant social media platform (e.g. Twitter or Instagram), and 2) contained posts that had been cross-posted from another source. In this way, I could hope to capture any posts shared from Instagram to Twitter, where the text was cut off (truncated) due to platform character restrictions of Twitter, or the image shared was replaced by a link (due to Twitter's proprietary restriction of revealing images from the Instagram platform (BBC.com/News, 2015)). Wherever this happened, I coded/tagged these posts for later investigation, so that I could follow these links, to better understand the context of each post, and verify whether it fit within my symptoms dataset.

Thirdly, in order to query the most frequent co-occurring words and hashtags in each symptoms dataset, I exported data from my Netlytic queries of Instagram and Twitter into the Gephi social network analysis platform (Bastian, Heymann & Jacomy, 2009). Within the first set of analyses for how tweets/posts about symptoms could be used to study the health-related quality of life of individuals with Coeliac Disease, an export of all the data from both London and New York in Figure 4, and a use of the edge betweenness algorithm in Gephi, shows that out of over 6,000 tweets, the 10 most common co-occurring words occurring with the shortest path to the hashtag "glutened", four were most strongly linked to eating out. These were "restaurant", "Celiac", "Coeliac" and "glutenfree". This pilot real-time data scrape therefore showed me that using queries that incorporate the terms "coeliac/ceeliac", "restaurant" and "glutenfree" with the term "glutened" will get me data with the more relevant results. The comments found within these self-reported posts on Twitter and Instagram have been useful in revealing both the implicit and explicit attitudes and practices of Coeliacs sharing their experience of symptoms via social media networks. The

comments collected for this study were therefore useful for analysing how and why Coeliacs share these experiences via biosocial networks on social media, and how this layer of health-related knowledge can help us to better understand how they perceive their health related quality of life.

The Gamification chapter (6) is concerned with exploring: to what extent might the data analysis from the self-reported patient knowledge of symptoms be used, visualised and explored to understand health-related decision-making via social media and its impact on Coeliacs' health-related quality of life. Following Pols' (2013a) discussion of using methods of gamification to use research on patient knowledge in a way that would help other patients:

“What is patient knowledge, how does it relate to other forms of knowledge, and how can it be made useful to people with chronic disease?”
(2013b:p.82).

Pols goes on to argue:

“Chronic disease is here to stay – people will have to appreciate the limits one faces when one has a chronic disease, but they can also be encouraged to creatively explore the possibilities that emerge for living with chronic disease in a good way. Developing and sharing knowledge and learning to relate different forms of knowledge might be just the thing for Patients.”
(2013b:p.92).

This call for researchers to engage with creatively sharing patient knowledge of disease for the benefit of other patients, also related to my research question of: how might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness. By visualising the social media data of the most reported CD symptoms into a simpler and more interactive format, it was thought that it might be possible to utilise this data to engage with and teach younger Coeliacs about positive self-care activities. Two initial formats were chosen to do this, the first, the use of games mechanics to visualise the psychosocial stress

sometimes experienced when trying to stick to the GFD as a Coeliac while eating out. This social media data was visualised in an interactive game in the form of the Gluten Fighters app (Martin, 2014d). And the second a game to visualize the learning process of searching for gluten free food, which was most mentioned in Coeliacs' social media conversations about the gluten free diet, in the form of the Coeliac Sam gaming app (Martin, 2014a). Both apps used the character of a superhero with Coeliac Disease. In the Coeliac Sam app, the main character's mission is to find gluten free food, while avoiding harmful foods when out and about. She also exhibited loss of energy and pain when consuming food that wasn't gluten free – thus mirroring the self-reported tweets of Coeliacs from my dataset. By using key principles of games-based-learning and gamification techniques, I was then able to monitor general usage and feedback, to see if adopting Pols' technique could indeed be beneficial to Coeliac users within the chronic illness and big data setting.

Analysing Facebook comments

In Chapter 5, I look at how Coeliacs use social media to manage risk, and speak to third parties about the risk of cross-contamination of gluten free food from within their own context of chronic illness. To do this, I gathered examples of social media posts created by both consumers and manufacturers who used predominantly Twitter and Facebook to discuss questions of risk and cross-contamination during two separate incidents of a mass food recall (in the US and the UK), when these items were found to be cross-contaminated during the manufacturing or transportation process. While the main basis of my data sampling for this study followed along the same lines as the hashtag queries, data source and co-occurrence analysis techniques as used in the Symptoms Chapter (Chapter 4), as a result of using these same techniques, I also discovered URLs within tweets/posts that pointed to a lot of activity that was actually being directed away from Twitter and instead towards the Facebook groups managed by manufacturers involved in these gluten free food recall incidents. In both food recall incidents, this seemed to stem from the manufacturers issuing press releases on both their official websites and via Twitter, that steered customers to ask questions about the food recall on each company's official

Facebook Page (as well as email and telephone numbers for customer support). This concerted steering of consumers to Facebook meant that a lot of the data linked to answered questions from consumers by the manufacturers was tunneled into Facebook, which made it prudent to follow the data flow in this direction, while also listening to other data channels like Instagram and Twitter for any overlaps or tangents in discussion, using the Netlytics tool (discussed further in this chapter).

As previous studies on how companies use social media for pharmaceutical product recalls have shown, one of the benefits of using Facebook pages for research is that the user interface on Facebook allows for the sharing of a lot more text and information per post. In some cases, may have been seen as easier to manage in terms of the layout of each post, with a thread of comments and replies in consecutive order for each query (Ledford & Anderson, 2013; Dreyfuss, 2015).

When querying the Facebook pages of the manufacturers involved in the food recall incidents, I used Netvizz to download all posts during the respective time periods of each recall, and then used NVivo's coding feature to sort out the posts that mentioned Coeliac Disease, as well as code posts into four different types of queries: 1) information seeking, 2) information sharing, 3) satisfied, and 4) dissatisfied. This made it much easier for me to get a broad overview of how each company handled the food recalls, and how Coeliacs responded to the incidents within the context of how it affected their health-related quality of life, and perceived levels of risk. I also used Netlytic's text analysis tools and NVivo's coding tools to sort these tweets and the text of Instagram posts into relevant categories for further analysis, to find out to what extent disgruntled Coeliacs used these platforms to create small activists groups.

In contrast to the relatively straightforward process of harvesting Facebook data from the Facebook timeline (as noted above), analysis of Twitter and Instagram data using the Netlytic platform, was done in live chronological downloads of data during the two food recall incidents from May – June 2015 (Genius Foods recall incidents), and October 2015 – March 2016 (Gluten Free Cheerios cereals recall incident). It was found that the Twitter

and Instagram platforms were mostly used by Coeliacs or Coeliac advocates who were unhappy with the way that manufacturers were handling things, and used Twitter to voice their grievances, via tweets, and links outwards to blog posts. Analysis of the data found that they used these mediums to encourage other Twitter users to log any incidents of sickness due to the cross-contaminated food, and report them to the appropriate authorities.

Using Instagram and reading images

Chapter 7 was created to find out the extent to which it is possible to explore and develop innovative digital methodologies that are suitable to social science analysis of how Coeliacs and other chronic illness patients visualise their self-care and health-related quality of life. After an analysis of the source data that referred to self-reported Coeliac symptoms in Chapter 4, I found that 35% of 3,000 Tweets were linking to Instagram posts that went into much longer descriptions of the symptoms of Coeliac Disease, and comorbid illnesses. To investigate these occurrences further, this final study used those examples, and the additional hashtags that were found in the linked Instagram posts, to create an investigation into how Coeliacs actually visualise self-care of comorbid illnesses. Based on the resulting data, and a desire to see if the introduction of further visual tagging techniques would produce richer data, I developed a photo-tagging smartphone application called the “Spoonie Living” app. This m-Health app was then used in an experimental pilot study, with 40 users who suffered from both Coeliac Disease and another chronic illness. I categorised the 40 co-morbid users by checking their user accounts to see if they referred to being diagnosed as Coeliacs with co-morbid conditions in their account profiles or the posts in their accounts. If users only referred to eating gluten free food, but made no mention of being a Coeliac, or having an additional chronic illness, then these users were not included in the study. The rationale in choosing this different subset of Coeliacs from within my Twitter and Instagram corpus was to study if and how the reports of Coeliac comorbidity discussed in the literature (Megiorni *et al.*, 2008; Van Olmen *et al.*, 2011) were being shared or visualised on social media, and so answer my second research question of: How might modes of gamification be used

to explore and visualise the self-management of CD and comorbid illness? This would also go to address the gap in the literature about the visualisation of chronic illness on social media, where at the time of writing, outside of a study of how sampled individuals with Type 1 Diabetes share images of the disease via Instagram (Yi-Frazier *et al.*, 2015), there was no research that investigates how Coeliac sufferers with comorbid disease(s) share and visualise the experience and self-care of this.

By testing the hashtag data I had analysed in the Symptoms chapter (Chapter 4), I hoped to triangulate my initial results, by comparing the qualitative feedback received from the use of this visual analysis tool – to see if it matched or challenged my previous quantitative analysis with regards to how comorbid Coeliac symptoms were shared across Twitter and Instagram. While Chapter 4 looked at the general sharing of Symptoms across networks, it focused on the text shared, rather than a visual analysis of photos and the visualization of symptoms or comorbid symptoms. Chapter 7 and the use of the Spoonie Living App pulls out a sample of comorbid users from the original corpus from Chapter 4, and aims to compare the visualization of shared comorbid symptoms and identity, to the general sharing of Coeliac symptoms and assertion of biosocial identity in the text of tweets and social media posts in Chapter 4. It was also hoped that this tool (the Spoonie Living app), could also be used as a research tool by other social researchers to study other chronic illnesses. Before I go on to address the methods used to create the images used in the app, I will discuss the methodological literature considered behind the decision to us create this research tool, and the gap it hopes to address.

While Ziebland and Wyke have called for further investigation into how chronic patients visualise their experience of illness (2012), Vis also argues that images are currently an under-researched area within social media research and Big Data overall (2013:p.5). Vis argues that the reason why images are under-researched may be because they do not easily lend themselves to popular Big Data ‘mining’ techniques. A lot of the text mining, text analytics, sentiment and co-occurrence analysis techniques now used to study Big Data produced by social media platforms are actually a by-product of older qualitative analysis techniques developed in

the 1980s - pre. the Web 2.0 era for academic, government and business practices (Ignatow & Radev, 2016:p.5). While these methods have been found relatively easy to adapt to modern uses of text in the age of Big Social Data (Ampofo *et al.*, 2014), the in-depth and content analysis of images is still in its infancy (Megha & Sang, 2015). With the latest object and colour analysis of images only just coming to the forefront of technological progress in recent years (Manovich, 2011; Hochman & Manovich, 2013). Vis argues that the huge increase in the numbers of images produced and shared by social media shows just how valued they are by users themselves (2013:p.4).

Yet because of the infancy of analysis software and techniques, as well as the complexities inherent in the current production, viewing and circulation practices (public versus private), images themselves have become a 'discarded data object in such enquiries' (Vis, 2013:p.5). With these issues, it is arguable that we need to look at how images can, or should be valued within a research context, especially if they also reflect how a growing number of users communicate their everyday lives. By doing this, it has been suggested that researchers need to "draw on a range of theories and methods to make sense of these emerging visual cultures and social media" (Vis, 2013:p.5). Back and Puwar (2012), and Marres (2012c), have also suggested that sociological research would benefit from responding to this by using the sociological imagination to rejuvenate research practices with the use of live methods, creative, public and experimental methods.

It is argued that the re-imagination of methods and devices used to study digital cultural practices will in turn bring a fresh and attentive focus and insight into how social communications and practices continue to be affected by the digital age. In terms of developing new tools or devices for 'real-time' or 'live' investigation, Back discusses the use of multi-modality research devices that enable a more sensory attentiveness to the embodied social world. In particular, Back discusses the use of photography as a particular form of research that enables a research participant to "pause the ebb and flow of social action in order to subject what was in the frame to close inspection." (Back, 2012:p.31). As Ziebland and Wyke discuss:

“The incorporation of photographs and videos on health websites has been treated mainly as a design issue rather than considered in terms of the potential consequences for the way that people deal with their health problems [...] images—in a variety of forms—are increasingly used in health care communication and can be powerful ways of communicating important messages. We suggest that the Internet is inherently visual and that the ability to post and access images of people dealing with health issues may be another important, albeit rarely explored, feature of health experiences and the Internet.”

(2012:p.19)

More recent observers have also discussed the creative use of experiments in participation in ways that intensify the generative potential of the participatory experience of using basic platforms, the results of which produce new evidence and documentation about social life in the process (Lezaun, Marres & Tironi, 2016).

Bearing these discussions in mind, the chapter on Coeliacs and Comorbidity attempts to speak to these invitations in the literature, with the creation of the Spoonie Living app (Martin, 2015), a research analysis and user interaction tool, that has been designed in an aim to find out how individuals with chronic illness visualise their self-care and embodied experience of illness. In terms of health care communication, the Spoonie Living app was built to use a specific form of tagging images with visual overlay stickers that are chronic illness specific (Figure 8).

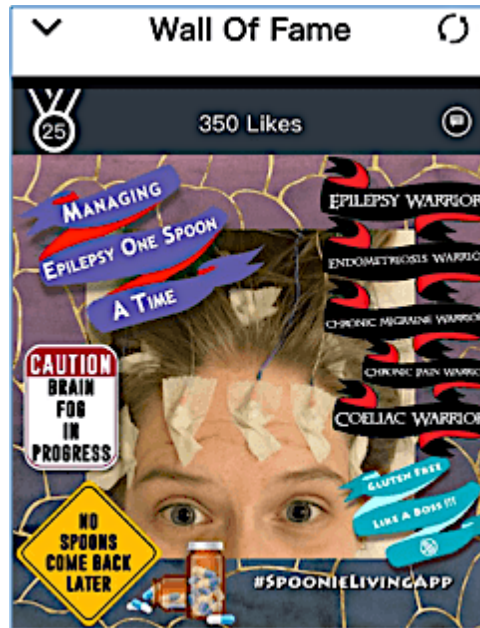


Figure 6. Spoonie Living app: CD and comorbid illnesses.

While the design of the first set of 100 chronic illness stickers were based on my initial hashtag analysis of images posted by Coeliacs to Instagram, I wanted to use some form of the Live Methods suggested by Back and Puwar (2012) to see if the results of my initial analysis reflected the ongoing experiences of Coeliacs with comorbid illnesses. To test whether I had captured enough sample data to give me a good overview of the other chronic illnesses that were being managed, I turned to the collaborative participant method discussed used specifically by Puwar and Sharma (2012) in their investigation of inventive ways to curate sociology, the “Call-and-response”. When talking about using this method to investigate the actions of many contributors to a large scale public event called the ‘Noise of the Past Project’, Puwar and Sharma argued: “It was discovered that this problem required a multimodal approach because there is not necessarily a single response to how a multicultural nation can be re-routed and experienced otherwise.” (2012:p.54). This is similar to my investigation into the different and inventive ways that Coeliacs express self-care via social media, study of these practices require a multimodal approach, as with the multitude of different social media platforms available, there is not necessarily a single set of practices or response to how a varied set of people with the same condition (and in some cases differing comorbid conditions), express their experience of self-care online. And, as argued by Vis and other scholars, where this multitude user output via different modes

of expression occurs, the challenge is for the social researcher to find different and inventive ways of studying and exploring these behaviours (Vis, 2013).

Puwar and Sharma describe call-and-response as a process of communication “which activated a chain of reflexive responses between the researchers, the creative practitioners and their cultural productions (cf. Minh-Ha, 1991)” (2012:p.54). Within this illustrative study, I instigated call-and-response through a process of tweet, email, and direct messaging interaction, where individuals requested stickers they felt better represented their experiences. Upon receiving these responses, I collaborated with users in the design process of stickers, by tweeting sticker designs in progress, and, where needed, asking for further input. Live tweeting some aspects of the design process seemed to more fully engage users, and encouraged them to request additional stickers if needed (Figure 9). Once this process was finished, I implemented user requested stickers in updates of the app, so that users within could go on to use them in better representation and visualisation of their embodied experiences.



Figure 7. Twitter: Call-and-response sticker collaboration.

Data collection and analysis of individuals use of this image was implemented by using the Netlytics and Digital Methods Initiative social network analysis tools to follow the hashtag #spoonielivingapp across the

Instagram, Twitter and Tumblr networks. This, coupled with qualitative visual analysis of how specific chronic illness stickers from the app were used in co-relation to Coeliac Disease and other comorbid illnesses, worked to give me a good overview of how patients were using the app to visualise their chronic disease(es). As well as these social network analysis tools, I used Gephi to analyse and visualise the co-related hashtag networks produced across social media with the use of the app. I also used basic app analytics reports from the Apple, Android and Amazon Developers' stores to understand the overall reach, anonymised daily use patterns, and general uptake of the app (3,000 downloads as of August 2017). The use of all of these tools came together to give me a working overview of how the app was performing across platforms, where imbalances might exist in terms of a higher rate of use of the iOS iPhone/iPad version of the app versus the Android versions, as well as the rate of use of both the app and the utilisation of the gamified hashtag created for the empirical study (#spoonielivingapp).

Ethical Considerations

The ethical outline for this thesis was developed by consulting the British Sociological Association's 2006 Statement of Ethical Practice (BSA, 2006), and the Social Media Research Guide to Ethics (Townsend & Wallace, 2016). All the terms, conditions and guidelines for social research or development, were read and followed for each Social Media platform accessed (Table 1). Townsend & Wallace note that some of the key things to bear in mind when conducting research via different social media platforms, are: a) adherence to all the relevant terms and conditions for the use of public data via the public APIs of social media platforms like Twitter, Instagram, Facebook and Tumblr; b) the ethical consideration and protection of the privacy of individuals who may share sensitive data, or who themselves may be vulnerable, and c) the need for the anonymisation or paraphrasing of data that is re-used or re-published, so that there is no risk of exposing sensitive health information.

Indeed, as Williams, Burnap and Sloan argue:

“Codes of ethical conduct that were written in the mid-20th century are being relied upon to guide the collection, analysis and representation of digital data in the 21st century. While these codes have been informed by recent writings on some forms of Internet research [...], social media presents new challenges.”

(2017:p.2)

Bearing this in mind, and that for the most part, data for this thesis was accessed via the public APIs of Twitter, Instagram, Facebook and Tumblr, when reporting on specific tweets or posts across all case studies – care has been taken to strip out usernames or identifying tags, so that individuals remain anonymous (Townsend & Wallace, 2016:p.11). Where a user’s face is visible in an image/figure as part of social media research in this thesis, that individual has been contacted, and informed consent has been given. As a further precaution, all images showing facial features have been blurred out to hide any identifying characteristics. Where I have asked social media users to produce new data with the Spoonie Living app in the fourth empirical chapter, I have been transparent about my own identity as a researcher at Warwick University. Full disclosure of the research project has been made on each app store that the app has been published on, as well as additional disclosure within the app itself, and via social media accounts setup for the app on Twitter (2016), Instagram (2016), Tumblr (2014) and Facebook (2016). This disclosure indicates to individuals that by downloading and using the app, or by sharing assigned hashtag (#spoonielivingapp) on social media, they have given me permission to use these public images as data in my research (Townsend & Wallace, 2016:p.11).

Where any users have had private accounts on public networks like Instagram, and have shared the hashtag #spoonielivingapp, following Instagram guidelines to third party use of data on its platform (Instagram.com, 2015a), I have contacted each user personally for informed consent, before reposting their data to the public Instagram page for the app. Contact was made via a private Twitter or Instagram Direct Message, or by tagging the user to any reposts on both platforms. Where

users later requested that their data be removed from the public Twitter or Instagram accounts, I immediately removed posts/images, and contacted users when this was done I have also taken precautions to remove any data produced by vulnerable adults or young children. Where users have requested that their data be used confidentially (e.g. where they have sent me images via email/direct message from an otherwise private social media account), I have paraphrased information, so that that it does not lead to the individual's online profile (Townsend & Wallace, 2016:p.13). In terms of re-using or re-publishing data in conference presentations or interviews in online blogs, I have also anonymised all data presented, and will take out any images showing users' faces from this thesis document once it has been marked, and is ready to be placed in Warwick University's thesis archive.

Conclusion

As this chapter has shown there are many issues involved when doing social science research with social media data. To recap, this thesis has used three platforms, and built three apps. The empirical approach to the thesis has therefore been rather ambitious, time-consuming, and has required a lot of technical and substantive expertise. Of course in the empirical chapters that follow, I focus mainly on CD and ways in which the users have talked about their ailments, practices and self-care on these platforms. However, it is important to note that a similar type of analysis might have been done on any number of social science topics. It is certainly not limited only to health issues.

As Williams notes, by drawing on a variety of perspectives and approaches throughout, I may leave myself open to potential criticism on various levels in terms of the potential ontological and epistemological tensions/problems with theoretical eclecticism (2011:pp.xxi–xxii). This is indeed acknowledged, it is also arguable that, the work in the current literature in terms of how Coeliacs use social media to share their self-care practices is limited and in its early stages. As such, using different theories to explore the complex issues arising in Big Social Health Data may be useful in

opening up different avenues or entry points in the complexities of managing and sharing the embodiment of chronic illness in the digital age.

In this respect, my intent in this thesis is to explore these complex issues from different perspectives and viewpoints, rather than attempt “some sort of grand and premature theoretical synthesis or integration of these different approaches and perspectives” (Williams, 2011:p.xxii). With the changing and complex nature of the use and application of social media to share and discuss health issues such as Coeliac Disease in the 21st century, it can be argued that by keeping the theoretical options open and exploratory, we may come to better understand chronic illness practices via social media. In this context, by approaching the communication of Big Social Health Data with a broad theoretical viewpoint, we may better come to understand the implication that the use of social media may have for continuing social sciences research, as well as their potential implications and influences for future health policy. In the chapters that follow, I have extensively used social media data and the development of apps to utilisation patient knowledge in a way that advances social science and the sociology of health and illness.

Chapter 4: Symptoms, Subjectivity and Selfhood

This chapter provides an illustrative example of how some Coeliacs actively use social media platforms like Twitter and Instagram to subjectively share how their lives are affected by the symptoms experienced as a result of this chronic illness. I explore how social media can be used to tell a chronic illness narrative (Frank, 1995), and thus illustrate the process of diagnosis, and how individuals adapt to life as a Coeliac on the gluten free diet (GFD). As discussed in the literature review, these narratives can also include communication of the biographical disruption (Bury, 1982) that diagnosis can create, as well as expression of the uncertainty of being undiagnosed when unverified or other symptoms are experienced. Finally, I explore how some Coeliacs have created illness narrative hashtags, like #NoCureNoChoice, as a way to reflect their self-identity as Coeliacs, their subjective experience of the GFD, and the stigma sometimes associated with it. Within this context, I also discuss the dual classification of the gluten free diet as “food as medicine” for the treatment of CD both in government policy, and in culture by some Coeliacs who see the GFD as medicine that is used to treat their CD.

The main dataset used for this chapter comes from the Symptoms dataset, which was harvested from Twitter and Instagram between October 2014 and January 2017, all sub-samples mentioned come from this main dataset (please refer to the Methods Table in the Methodology chapter of this thesis: Chapter 3, Table 1).

Symptoms in context

One continuing pattern revealed across the social media datasets collected for this thesis, shows that 35% of the sampled Twitter and Instagram account profiles of Coeliacs identify themselves as documenting their ‘coeliac journey’ or ‘journey on the gluten free diet’. Examples of such profiles are that of a Coeliac in her late-30s with a comorbid illness, whose Twitter profile reads: “Chronicles of a Celiac with Hashimoto's. #Glutenfree.

#Dairyfree. Organic Recipes. Diet tips. Travel. Lifestyle”. Another example is that of a Coeliac man in his mid-40s, whose Twitter profile sums up his struggles with his Coeliac journey: “Diagnosed with CD a couple of years ago and still struggling”.

These types of account and the running thread of sharing illness narrative throughout, show that some Coeliacs use social media as a place to share their embodied experience of the disease. Individuals like the Coeliac documenting his struggles with this journey, may also document their experiences of certain levels of biographical disruption (Bury, 1997) upon diagnosis. As discussed in the literature review (Chapter 2), biographical disruption can occur when an individual is diagnosed with a chronic illness, and finds it psychologically stressful to come to terms with the effect and changes that having a long-term condition may have on their pre-diagnosis identity.

In situations where support is needed, access to a community of people who share one’s illness or symptoms can be beneficial (Murthy et al. 2011). Rabinow (2005), and later Novas and Rose (2007) have discussed how the internet might be used to form communities of “biocitizens”, where individuals form groups where citizenship or membership is based around shared biologically similar illnesses, traits or symptoms. Biocitizenship was explained to work around the collective sharing of knowledge about the experience of disease, self-care practices, and feelings of a shared collective identity because of this (Sarrett, 2016:p.26).

Bearing this in mind, in the context of how some Coeliacs use social media, the term ‘biocitizenship’ could be used to describe how Coeliacs use the hashtags #coeliac or #celiac in their Twitter or Instagram posts to identify themselves or their experiences to others with the same illness. Adding the hashtag “#Coeliac” to a post about eating out in a restaurant can arguably change the context of that post from a general sharing about eating out, to a post about eating out while on the slightly more restrictive GFD, and the issues of cross-contamination, psychosocial anxiety that this might involve.

Consider the following two tweets:

- 1) In #NYC this week. Anyone suggest #good #restaurants in #Brooklyn?
- 2) In NYC this week. Can anyone suggest any good restaurants in #Brooklyn? #Coeliac

In the first tweet, there is a reference and emphasis to where the tweeter will be (#NYC and #Brooklyn), as well as the main focus of their inquiry #good #restaurants. This is a pretty general enquiry, which only requires good knowledge of the quality of restaurants considered to serve good meals in the Brooklyn area of New York City. However, in the second tweet the use of the hashtag #Coeliac changes the whole context of the tweet from a simple food and venue enquiry into one that very specifically requests knowledge and information about place and venue in relation to an autoimmune disease and the specific diet needed to safely treat that chronic condition. Therefore, the hashtag #Coeliac invokes a layer of association, that turns a tweet from a general social enquiry related to location and food quality, into a bio-social enquiry related to health, the biological, and the location of resources needed to safely manage a chronic condition crucially linked to the gut. It also acts as a signifier of how the tweeter performs their identity in relation to food in this tweet. The hashtag #coeliac and term 'Coeliac' can act both as a shortened slang name for the full name of the chronic illness #coeliacdisease, where some people will say "I have 'Coeliac'" instead of saying "I have CD", or it can act as self-identifier or label "I am a Coeliac".

While being a member or citizen of a group with similar biological traits works for a collective identity, Ene pushes this explanation further by defining a 'biosocial citizenship' (2009). Biosocial citizenship describes not only the collective biological trait of many Coeliacs, but also how their biological illness/symptoms affect how they interact socially. This describes how their illness affects and changes their social identity and how it is linked to food, their social interactions, work, travel, food shopping habits and daily routines. Thus, the term 'biosocial citizenship' describes the social experience of forming the identity of a Coeliac, or the experience of being a Coeliac in terms of how an individual's biological condition affects

their social interactions. Many Coeliacs may thus use their social media accounts to share or narrate their experience of the biosocial in a way that is connected to experiences of biographical disruption, readjustment of biographical flow. While each Coeliacs' illness narrative is unique to their own daily experience, the interplay of the biological effect on their daily interactions, and their use of specific hashtags to relate this, in turn helps to create a biosocial community, based on biosocial citizenship.

Behavioural adjustments to the GFD

In situations where an individual is in the middle stages of life (50+ years), studies have found that in some cases, diagnosis of a chronic illness may be viewed as just part of getting older, where chronic illness is anticipated as inevitable in old age (Williams, 2000a; Pound, Gompertz & Ebrahim, 1998). In contrast, when it comes to children who have been diagnosed with CD at an early age, who are in a sense 'growing up with' this chronic illness – as with most chronic illness - an interesting tension may arise between their 'biographical flow', and newer instances of 'biographical disruption' (Bury, 1982; Williams, 2000a). Here, their 'biographical flow' may be defined as the familiar gluten free diet (GFD) they have grown up with. The 'biographical disruption' may occur in new situations where peer pressure, and feelings of stigma may lead them to deviate from their prescribed GFD (Howard, Law & Petty, 2011; Skjerning *et al.*, 2014).

In some studies, individuals have been found to use a process of 'normalisation' as a coping technique, where they 'bracket off' the illness so that it affects their social identity as little as possible (Bury, 1991; Kelleher, 1988). In these social situations, studies have found that despite the harmful results – some individuals with CD may deliberately ingest gluten in an effort to 'normalise' their social identity and fit in (Chick, 2014; Howard, Law & Petty, 2011; Henricksen & Viller, 2012; Kelleher, 1988).

Evidence of the potentially harmful behavior of 'normalisation' as a coping technique was also found in analysis of a corpus of tweets mentioning the symptoms of CD, that was harvested between 1st April – 1st May 2014. Within this dataset, 103 out of 1350 tweets analysed contained tweets that

self-reported deliberate ingestion of gluten in social situations. The categories for detecting self-reported behaviour that revealed the deliberate ingestion of gluten were defined by tweets that contained co-occurring hashtags: #Shame AND #glutenfree or “gluten free”, and #glutenproblems or #celiacproblems (Figure 10). Of the 1350 tweets found, 103 individuals tweeted about deliberate ingestion of gluten from a confessional context in relation to eating out (see central node in Figure 10), sometimes acknowledging the potential damage done to their health, as well as commenting on the negative symptoms they suffered as a result of deliberate ingestion.

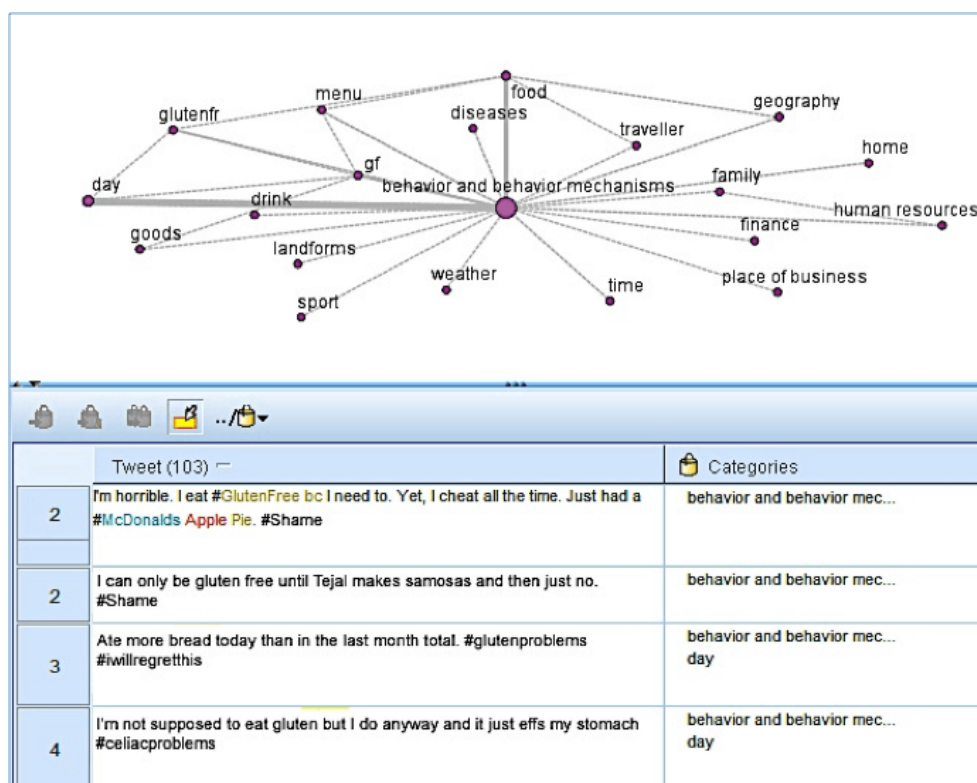


Figure 8. Symptoms from deliberate ingestion of gluten

It has been acknowledged in the literature that these lapses in adherence to the gluten free diet can come down to a number of factors, including for Coeliacs, a perceived inability to avoid gluten when multiple incidents of cross-contamination occur, as well as lack of access to food. Sainsbury (2013a) and Kothe et al. (2015) have conducted a series of studies where they investigated how successful individuals with CD were with adhering to their prescribed diet, and whether this was linked to behavior and individual perception of one’s ability to cope within daily activities. In one study the

Theory of Planned Behaviour was used to study whether planned behavior could predict how successful Coeliacs were in adhering to a gluten free diet, based on several factors - including an individual's attitudes about their own behaviour, their normative beliefs about that behaviour, and how they weigh their own attitudes against subjective norms (Sainsbury & Mullan, 2011). It was found that whether or not the intent to stick to the gluten free diet translated into adherence to the gluten free diet, depended on a Coeliac's perceived control over their food choices (e.g. are healthy food choices available, and does he believe in his ability to access healthy food?).

While well documented research suggests that changing harmful dietary behaviour is a complex process, that can come up against many barriers — research also shows that changing harmful behaviour involves new learning and access to resources within the context and physical environment, which can in itself have the most positive outcomes in influencing the learning process (Contento *et al.*, 1995; Rajpoot & Makharia, 2013; Hingle *et al.*, 2013; Shan *et al.*, 2015). It is arguable that actively using social media to gamify the pursuit of the gluten free diet within the online Twitter and Instagram community may help with the perception of being able to adequately manage the gluten free diet.

Visualising the GFD

To further explore this potential pathway and insight into connected user information with regards to the visual communication of the symptoms of CD, I took a sub-sample of 300 tweets from the original group of tweets (n=1200) in Figure 2, these tweets contained direct links to Instagram. I unpacked their short URLs, and then collected and analysed both the images and meta-data related to them. An image collage of this sampled data, shows how Coeliacs (who have identified themselves with the term “#coeliac” or “#celiac”) have used photographs of themselves showing visible symptoms of being glutened e.g. bloated stomach, or lying down unable to move through pain and lack of energy (Figure 11). There are also photographs of remedies taken to alleviate symptoms (e.g. tea, charcoal, soup or other foods), as well as images of textual representations

reception of these chronic illness images is finely tuned to other patients searching for and engaging these images and hashtags in chronic illness and biosocial discourse. From this perspective, the notion of self-mediation becomes productive both in the creation of digital objects archiving the continued self-care of CD, and the practice of engaged discourse and shared knowledge of its lived experience.

The process of Disclosure, Examination and then Remembrance of self can be found in examples of posts about being glutened – that are shared and linked to across both Twitter and Instagram. Here, Coeliacs share tweets or Instagram posts, where:

1) they first disclose that they suspect they have been glutened:

“Sadly, I think I've been slowly #glutened by some veggie burgers over a few days of eating them.”

2) they then go on to examine what they have eaten that could have been the reason for being glutened:

“When you're suddenly SO tired & panic you might have been glutened & go over what you ate?! #glutened #coeliac”

3) and then finally, they perform the act of remembrance by recording/archiving their experience or use of remedies via text/image:

a. Tweet with truncated text linking to Instagram image:

“Hello, world. Slowly coming back from the dead after being #glutened. Wouldn't wish it upon any fellow celiac...”

b. Actual Instagram message, with mention of remedy taken to alleviate symptoms of being glutened. Text: “Hello, world. Slowly coming back from the dead after being #glutened. Wouldn't wish it upon any fellow celiac. Not a fun few days but I'm feeling a lot better this morning. After only bone broth, soup, kombucha and water, this smoothie is everything [...]” (Figure 12)



Figure 10. Instagram: Remedy for accidental glutening.

Analysis of these posts shows that for Coeliacs, 'disclosure of self' is enacted in the cultivation of the self via social media comes in the form of sharing their gluten free journey, which may be from pre-diagnosis (i.e. blood tests, 'The Gluten Challenge' (Coeliac UK, 2015a) deliberately eating gluten pre-biopsy/endoscopy) to long-term life as coeliac on gluten free diet. 'Examination of the self', can be described as 'Taking stock' and 'self-reflexivity'. For Coeliacs, this can be in the form of frequent posts on social media involving the examination of individual behaviour in following the gluten free diet, and self-reflexivity, more so in times of accidental glutening (e.g. "what did I eat that made me unwell...?").

Finally, 'Remembrance of self' involves 'Memorizations of deeds' that can be related to via the capturing and recording of practices via archives. In terms of Coeliac social media updates, it seems that while text-based tweets and links to blog posts often map what some new Coeliacs call their 'gluten free journey', the utilisation of more image-based platforms like Instagram lend themselves to the long-term visual archiving of self-care practices or 'remembrance'. While sharing these experiences, some Coeliacs have also been found to use hashtags to enact/create/maintain the biosocial identity, by clearly marking out that this experience is a part of their experience of the autoimmune reaction of CD (#coeliac or #celiac).

This is in contrast to photographs of food that do not have the hashtag #coeliac or #celiac linked to them, that may otherwise be associated with the use of the gluten free diet for body fitness or healthy lifestyle reasons that are not linked to CD or Gluten Intolerance.

This can especially be so when individuals track what could easily be a mundane practice of daily food sourcing and preparation, and instead turn it into a gallery of neatly hash-tagged and sometimes artistically arranged food portraits. While at first glance, this sharing of images may be analysed as purely an aesthetic practice, a look at the co-related hashtags and text associated with these images reveals community created meta-tagging based around specific and sometimes multiple autoimmune diseases, as well as the appropriation of general healthy-eating hashtags like #cleaneating for the quantification of the micro-constituent ingredients of meals. In an age where awareness of food intolerances and autoimmune diseases associated with food are more prevalent, the focus on what foodstuffs are allowed to enter the body is even more acute. Lupton writes:

“Achieving good health through diet has become a matter of acquiring expertise in the micro-constituents of foodstuffs.”

(Lupton, 2012).

This can be applied to the use of hashtags such as #cleaneating, where the micro-constituents and distinctive properties of foodstuffs are indicated as key factors in controlling autoimmune diseases like CD (the gluten free diet) — as well as key in giving individuals more control in the aesthetic sculpting of the body.

The acquiring of ‘expertise’ in the micro-constituents of foodstuffs is one of the key factors in managing a gluten free diet, and seems to be highly prevalent in Coeliacs’ use of Twitter and Instagram to share their experiences of this. Broader hashtag terms such as #cleaneating have been seemingly appropriated from the wider healthy eating community, and appear quite frequently in Coeliac posts referencing gluten free food that they have eaten while on the move, or prepared for themselves at home. What is also interesting is that other autoimmune diseases that also rely on specific food diets have also appropriated this term, such as those with IBS, IBD, CFS and MS. It seems that where knowing the micro-constituents of

food for weight-loss and body-sculpting purposes is key, it is also key to become expert in this knowledge for managing chronic gut-related disorders.

Analysis of 10,000 tweets and 12,000 Instagram posts collected between January 2013 and January 2014 found that within the general health and fitness community, the use of the hashtag #cleaneating mainly covered the individual health-focused activities of weight-loss and body toning. This involves more noted 'self-tracking', where photographs of both food and body are used in combination with status updates, measurements and hashtags to document progress (Figure 13).



Figure 11. #cleaneating photos of users without CD, show majority body/gym shots.

However, when analysing posts that indicated CD and other forms of chronic illness, the use of #cleaneating here involves less active self 'tracking' in terms of measurement of the body i.e. weight, body tone, calories etc., but contained more references to 'self-care', in terms of the use of food as a medicine, and other associated hashtags that referred to hidden illnesses that people were otherwise stigmatised for (i.e. #spoonie) (and hashtag #cleaneats or #spoonie [refers to all 'hidden' illnesses]).

Most specifically, posts from Coeliacs that co-occurred with the #cleaneating hashtag held on average 40% more images of food (Figure 14), and 45% more textual discussion of ingredients and co-related multi-morbidity diseases, such as IBS, Chronic Fatigue Syndrome and Lupus.

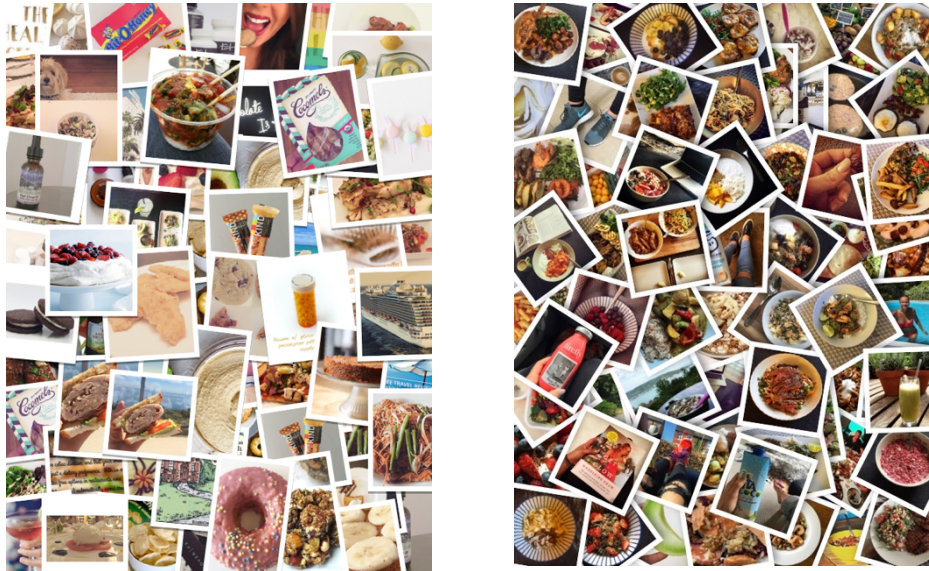


Figure 12. Coeliac posts with #cleaneating = 40% more food images

What is also interesting here, is that these practices can be read as a performance of the technologies of self-care, where Coeliacs utilize social media in the 'Examination of self', where they reflexively take stock of the gluten free food consumed on the GFD. Within the dataset, out of the 45% of posts that contained textual and reflexive discussion of gluten free ingredients, 23% of Coeliacs were found to be also sharing different remedies and alternative medicines they use to both care for the gut on a daily basis, as well as alternative medicines for dealing with accidental glutening. This is despite the official notice from health authorities that health food supplements like probiotics have not been scientifically proven to be useful in the treatment of CD, and the danger that at least in the US, that cheaper products might contain hidden gluten properties (Nazareth *et al.*, 2015).

While the use of co-related hashtags like #coeliac and #cleaneating can be signifiers of biosocial citizenship can help to establish a form of identity,

other hashtags used by some Coeliacs are also useful in expressing the biosocial challenges of cross-contamination and stigma sometimes experienced by Coeliacs when trying to eat out and follow the GFD.

Instagram and shared Coeliac symptoms

Further analysis of the meta-data related to the #coeliac and #cleaneating Instagram images found evidence of key emotive terms linked to the experience of symptoms, such as (i) Bodily pain and (ii) Physical Functioning. Here, key Instagram hashtags in relation the symptoms associated with being glutened were analysed to find the top ten themes and related co-occurring words used in discussions of symptoms within the linked corpus. It was found that the top ten themes related to questions of:

- What people could have 'Eat[en]' to
- What it was that could 'Making' them ill;
- What was 'causing' the symptoms;
- How to 'get' to the bottom of what was ailing them;
- Discussion of various 'Intolerance' to gluten;
- Different uses of the term 'Celiac';
- Discussion of symptoms in relation to their actual physical manifestations in relation to 'pain',
- Feeling 'sick',
- The 'Stomach'; and
- Emphatic feelings of 'Hate' towards being ill and the effect of gluten

In all, there were 112 nodes of emotive words expressing feelings towards being glutened, with the largest clusters based around finding out what the cause of symptoms were and what was making tweeters feel unwell (Figure 15).

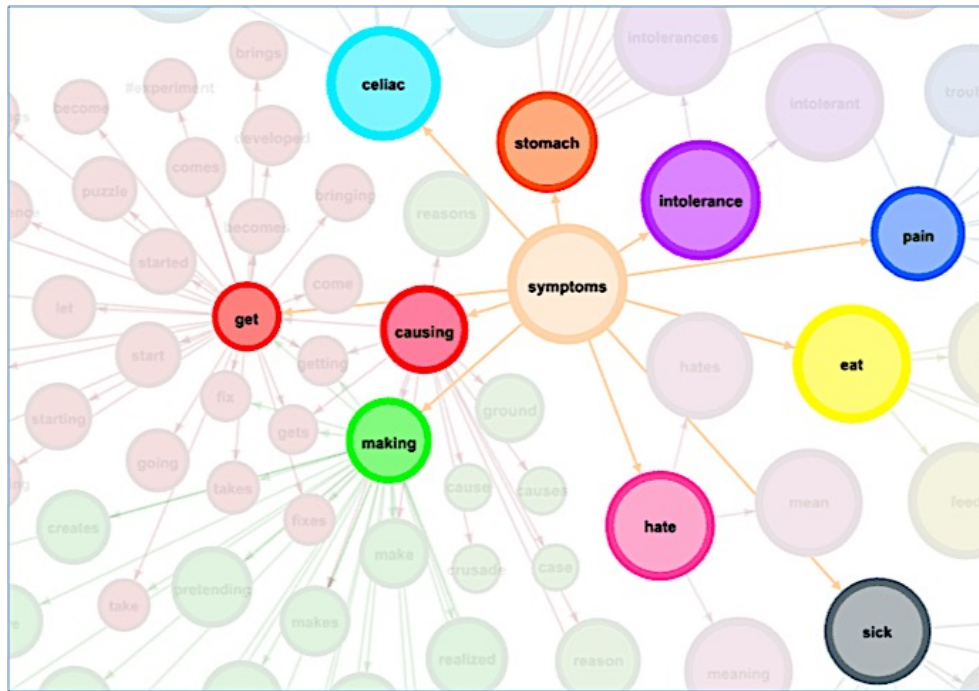


Figure 13. Top 10 words co-occurring with symptoms of CD

When discussing what was ‘causing’, or ‘making’ them ill, the terms used often overlapped with ‘get’, for example, when discussing what to ‘get’ that would help ‘fix’ the feeling of being ill, having just ‘realized’ they’d been glutened, and how this was ‘making’ them feel like ‘crap’. In all, there were 204 discussions with co-occurring themes based around the concept of ‘causing’ illness, and 175 in relation to the concept of what was ‘making’ people realise they had been glutened, while there were 98 discussions linked to how to ‘get’ better or fix the symptoms of being glutened (Figure 16).



Figure 14. Co-occurring words: cause of symptoms

In terms of the physical manifestations of being ill, there were 186 discussions around feelings of 'pain', with discussions of feeling 'sore', 'hurting', different parts of the body feeling 'painful', causing 'trouble', and more (Figure 17).

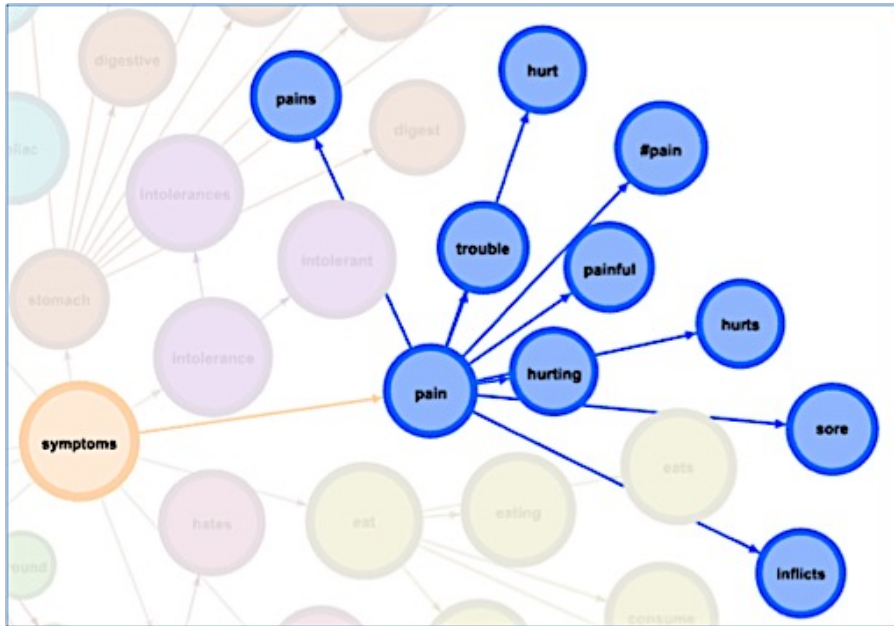


Figure 15. Symptoms, and co-occurring 'pain' words

In relation to the 'stomach', there were 160 discussions, where issues of 'digestion', how hard it was for the 'tummy' or 'abdomen' to 'tolerate', 'bear' or 'stand' gluten co-occurred (Figure 18).



Figure 16. "Stomach" and co-occurring words

Finally, there were 141 discussions mentioning themes of being 'sick' (Figure 19), with co-occurring words such as 'nausea', 'puke', feeling 'ill' and 'poor'; while 108 discussions of being 'intolerant' to gluten had few other similar words ('intolerant, intolerance'), as did 'eat', with 113 discussions mentioning the term directly, but with little variation of the word used (eaten, ate, eat) or the term 'celiac' (122 discussions: 'coeliac', 'celiac', '#celiacproblems').

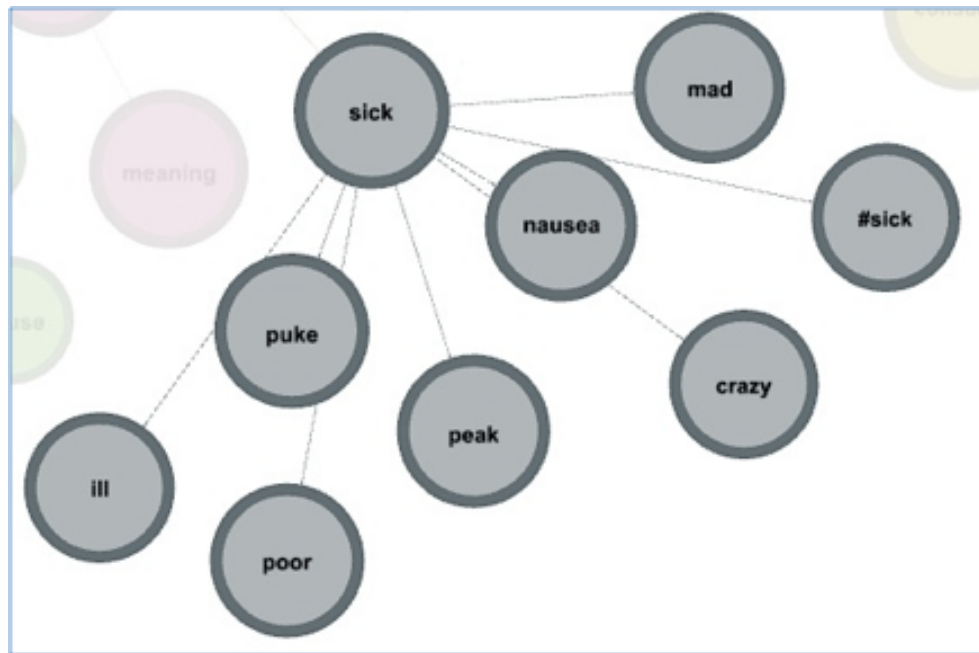


Figure 17. Being "Sick: co-occurring words

These discussions show that there is a high incidence of emotive language being used when people tweet about symptoms, with a future potential for mapping which parts of the city that these terms occur, so that local areas where tweeted symptoms in relation to the term 'gluten' or 'coeliac/celiac' are the highest can be pinpointed, and investigated to find out whether this correlates to a high instance of un-diagnosed CD or restaurants with high levels of cross contamination.

Sharing Subjectivity and Stigma via social media

Studies focused on the psychosocial burden that can be faced by individuals with CD, have identified a number of obstacles, including the cost and availability of gluten free food, as well as the dilemmas experienced when eating away from home, travelling and socialising (White, Bannerman & Gillett, 2016). Rose and Howard, have noted that some Coeliacs can find it hard to adapt to a new GFD, and can experience psychosocial stress when eating away from home (2014b). This may be because of dealing with the uncertainties of cross-contamination in food prepared by third parties, and having to deal with attitudes of stigma by those unfamiliar with their disease (Ford, Howard & Oyebode, 2012a).

For the majority of Coeliacs who do not present with dermatitis herpetiformis (a chronic and itchy skin rash of raised sin and blisters), CD can mostly remain a hidden disease with no immediate physical attributes. However, the actual symptoms of accidentally ingesting gluten cannot always be concealed, due to reactions like intense stomach cramping, diarrhoea, extreme fatigue, and memory loss. These intense symptoms have led some Coeliacs to worry about being stigmatised as being from their social group, in a way that inhibits their ability to function in a previously perceived 'normal' way in social situations revolving around food (Gilbert & Walker, 2010).

In a study focused on how Coeliacs addressed different types of stigma around the GFD, Copelton and Valle (2009) concluded that some Coeliacs can take on a series of coping strategies to avoid stigma, being labelled as an awkward or fussy eater, or risk rejection. In some cases, in order to avoid the risk of rejection due to their changed behaviour, some Coeliacs tried to maintain an identity of normalcy. Some resorted to redefining or re-purposing more socially accepted labels to apply to themselves, for example, by saying they had a wheat allergy rather than having to explain that CD is an autoimmune disease. This was perceived to help them to avoid being stigmatised for abnormal behaviour and having their social identity questioned or put under scrutiny, by only revealing part of their

condition in a more socially recognisable or culturally neutral format, Coeliacs felt able to escape probing questions or have to explain the full details of their medical history (Copelton & Valle, 2009).

Schroeder and Mowen (2014) also noted that some Coeliacs explained that in situations where they wanted to avoid stigma, they sometimes felt the need to overstate the seriousness of their disease in order to make restaurant staff or family aware of the harmful effects of gluten to their bodies, so that they could guarantee a meal free from gluten.

In order to better understand the sub research question: how some Coeliacs might use social media to share experiences - and in particular with regards to working against stigma, while eating out - I collected 1,500 Tweets and 700 Instagram posts focused on this topic, between October 2014 and January 2016. The main query I used to focus on Coeliacs eating out, as opposed to getting glutened while eating at home were “Coeliac OR Celiac AND glutened OR menu OR restaurant OR cafe”. I used these terms to make sure I collected tweets that were by Coeliacs in both the UK and US who had eaten out at restaurants or cafes, and shared their positive or negative experiences (more about my choice of tools and methodological thinking can be found in the Methodology Chapter of this thesis).

In terms of classifying posts that showed evidence of stigma experienced when eating out, the Netlytic natural language processor was used to sort posts into positive and negative sentiment. This method revealed that out of the whole dataset, out of the total 320 (out of 1,500) tweets and 250 (out of 700) posts on Instagram communicated negative experiences. Most specifically, the data revealed evidence of Coeliacs reporting being accidentally glutened despite being assured that food was safe for them to consume. One example is a tweet from a recently diagnosed Coeliac in her 20s, who commented:

“When you order off the gluten free menu and still get glutened < I think I'm dying”

(Female, unknown age, Twitter, September 2012).

Another example is from a woman in her mid-20s, who tweeted:

“Some days all I want to do is, be able to order in my food like normal people do, and not have to worry about the fear of being glutened :-/ ”

(Female, unknown age, Twitter, September 2012).

And finally, a long-term Coeliac, who shared an extended narrative about her experience of being glutened, plus the stigma and negative reaction from the bakery that served her:

“I got "glutened" at a bakery & shared my story. The owner asked me to delete the review. #GlutenFree #CeliacDisease #MyHealthMatters”

(Female, unknown age, Twitter, October 2013).

In this last tweet, alongside the self-identifying hashtags (#CeliacDisease and #GlutenFree), the individual also uses the hashtag “#MyHealthMatters”. In this context, the term “My Health Matters” may be interpreted as fight against the stigma of being labeled a fussy eater, and an attempt to get others to understand just how serious ingesting gluten can be for a Coeliac. This can be both in terms of the negative impact the symptoms have on health, and the damage that is done to a Coeliac’s immune system.

While the hashtag “#MyHealthMatters”, appeared only once in the dataset in relation to CD, in a search without the “#Coeliac AND Celiac” parameters, it appeared over 4,000 times in relation to general healthy lifestyle posts on Instagram, and over 1,000 times in the same healthy lifestyle context on Twitter. However, in terms of posts that documented some Coeliacs perceived struggles with stigma, one similar hashtag to the “#MyHealthMatters”, was a hashtag called “#NoCureNoChoice”. This hashtag occurred over 300 times on Twitter and over 1000 times on Instagram.

In all search queries, both with and without the “#Coeliac AND Celiac” parameters, the “#NoCureNoChoice” hashtag was found to only co-occur

with posts connected to CD on both Twitter and Instagram. To find out when this post originated on Instagram, I followed the timeline of posts back to February 2014, from when it was first used by a Coeliac blogger in her mid-20s, who posted photos of homemade recipes of her GFD. The hashtag was then used sporadically over the course of 1 year for another 21 times by 5 other users who spoke about their general management of the GFD, without any mention of stigma while eating out (between February 2014 and October 2015). However, the hashtag then suddenly peaked in its use by a new user (Coeliac#B) in October 2015, in co-occurrence with its use on Twitter, which also starts in October 2015.

On Instagram, the first October 2015 post reads:

“You have got to be kidding me! This can have serious consequences for those of us diagnosed with celiac disease. I don't think I will be eating Cheerios anytime soon. #NoCureNoChoice”.

(Male, unknown age, Instagram post/comment, October 2015)

Further investigation found that this post was in relation to a gluten free food recall of 1.8 million boxes of Cheerios cereal that were labeled as gluten free, but had been cross contaminated. As a result of this, in October 2015, Coeliacs had started to document incidents of some Coeliacs being glutened and becoming ill after consuming the cereal. A few months before the food recall, Coeliac advocates had expressed their reservations about the safety of the manufacturing methods used to process the cereal. A month before the Food Recall, a growing number of Coeliacs used social media to report getting sick because of eating Gluten Free Cheerios, with Coeliac advocates collating this data and reporting it to the Food & Drugs Association.

Following this, several tweets and posts were shared by Coeliac advocates. Chapter 5 on how Coeliacs deal with Risk explores this incident in more depth. However, coming back to one of the first initial uses of the “#NoCureNoChoice” hashtag on twitter, the hashtag was tweeted in direct relation to the Gluten Free Cheerios incident on 1st October 2015 – thus matching the initial new spike in its use on Instagram. On Twitter, one of

the first tweets linked to a blog post by a Coeliac advocate in his mid-40s discussing the Gluten Free Cheerios incident, stating:

“New hashtag for those that MUST be gluten-free:
#NoCureNoChoice Please spread the word...thanks. #celiac
#glutenfree”

(Male, unknown age, Twitter, October 2015).

The above tweet claims to have created the hashtag, which is only true in terms of Twitter, but as indicated above, another user first used the hashtag on Instagram in February 2014. The first blog post to appear with the “NoCureNoChoice” hashtag links to an article about how the GFD was at the time perceived to be stigmatized by the media, with a series of television commentary, magazine articles and comedy sketches that labeled the GFD as a trend or a fad, and as not something to be taken seriously:

“@user1 and @user2 @user3 Why is gluten-free funny to you? #NoCureNoChoice I seriously would like to know:
[linked article explaining the hashtag #NoCureNoChoice]”

(Male, unknown age, Twitter, October 2015).

On the same day as the originating tweet, a user posted a second tweet, which went on to discuss the Gluten Free Cheerios incident in further depth. The blog post also contained the first full definition of the “NoCureNoChoice” hashtag, and how it related to Coeliacs’ frustrations of feeling misunderstood and stigmatized when trying to pursue the GFD:

“It’s #NoCureNoChoice (please use and share.)

It simply means...you can’t do gluten-free half ass. We have to live this way for the rest of our lives. We take enough risks every time we eat outside our home. If you make a product and you label it gluten-free, it damn well better be safe for us. Do it right for the celiac community or get out of the gluten-free business.”

(GlutenDude.com, 2015)

While the context of this food recall incident is discussed further in the empirical Chapter on Risk (Chapter 5), in this current chapter, I will now go

on to discuss the “#NoCureNoChoice” in its use as a specific CD hashtag, and its role in the quest narrative as Coeliacs share their journeys adapting to the GFD.

When looking at hashtags that co-occurred with the main #NoCureNoChoice hashtag, it was found that related hashtags were also descriptive of the various issues and stigma that some Coeliacs experienced while trying to stick to the GFD. Hashtags like #glutenfreeisnotafad (74 instances), #celiacproblems (70 instances), #invisiblefight (65 instances) were examples of this, and further expansions on the #NoCureNoChoice hashtag. This collection of hashtags could arguably be seen as some Coeliacs’ ways of communicating their frustrations with the GFD being seen as a fad diet, but also as a way of communicating just how seriously issues of cross-contamination and accidental glutening should be taken when it pertains to long-term Coeliac health.

When looking at the most active users in the Instagram #NoCureNoChoice network, I also discovered four large hubs linked to the originator of the hashtag, the Coeliac advocate and activist (Figure 20). Each of these posters had commented at least once to the original poster’s discussion of the Gluten Free recall incident, however, each of their subsequent posts went on to use the #NoCureNoChoice hashtag as a descriptor for their own struggles with the GFD. This is an example of a hashtag going viral within a small network, and then being repurposed or reused and adapted for each users’ own “quest narrative”. One of the users to repurpose the #NoCureNoChoice hashtag, was the owner of an Instagram account that belonged to a Coeliac in her mid-30s. She had interacted with the Coeliac advocate campaigning against Gluten Free Cheerios, but then went on to adopt the hashtag in her own posts between 2015-2016 (Figure 20).

In one of her posts, she uses the #NoCureNoChoice hashtag to specifically discuss the importance of allergen labeling for Coeliacs and how serious cross contamination can be for a Coeliacs’ health.

“[...] Its upsetting to see food companies marketing unsafe products as "gluten free" or accidentally contaminating their gluten free

products. I honestly get nervous when trying new products now. Just this past Christmas, I was gifted these beautiful hand painted chocolates. The website and FAQ page showed every item as gluten free but before eating them, I checked the ingredient list and allergen statement on the box, as always, and saw it contained wheat-derived ingredients. The allergen statement: "may contain wheat". They refunded the order and apologized stating they thought it would be rare that somebody consuming their products would actually be gluten intolerant. (seriously?) [...]"
(Female, unknown age, Instagram post/comment, April 2015)

In the same post, she then explains why, from the point of view of Coeliacs, gluten free food can be perceived as a medicine. The main reasoning behind this is that Coeliacs are 'prescribed' gluten free food as the only treatment for a chronic disease that currently has no other therapy or cure:

"[...] I'm very grateful for the companies that do gluten free right but what I want food companies to understand is that there is no drug to treat celiac disease. We are literally prescribed a gluten free diet by our doctors and gluten free food is the only medicine we have. Taking responsibility to manufacture and properly label that medicine is a job that should not be taken lightly. These companies don't have to accommodate us so if they aren't confident that they can, they shouldn't try to force it. I think the label "gluten free" should be treated as more of a medical claim rather than an exciting feature of a food. Maybe "celiac-safe" would be a better term?"
(Female, unknown age, Instagram post/comment, April 2015)

This comment is not only an example of the concerns that some Coeliacs have over food labeling and cross-contamination, but it is also illustrative of how, by its very nature as being 'prescribed' as part of the diagnosis of CD, the GFD has been classified by Coeliacs as "food as medicine".

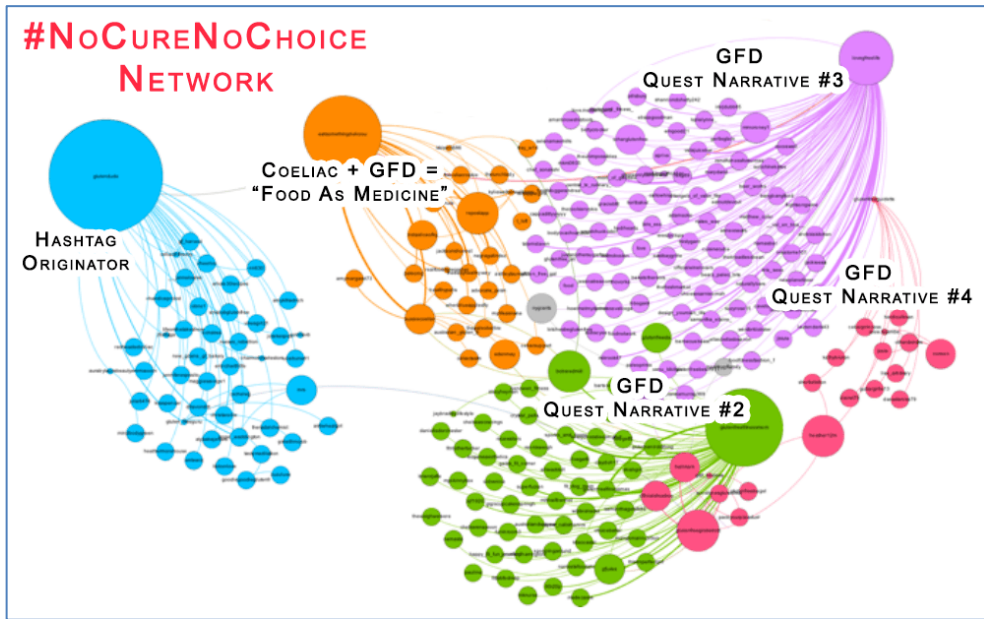


Figure 18. #NoCureNoChoice network (Instagram)

Food as Medicine

The traditional concept of “food as medicine, medicine as food” can be traced back to Hippocrates (Yoo, Saliba & Prenzler, 2010:p.530). There is a large body of work in both the sociology of food (Mitton, 2013) and anthropology of food as well as in nutritionist circles (Chen, 2009:pp.17–19), where the concept of ‘food as medicine’ has been found to be rooted in traditional healing practices. The “scientific disciplines of medicine, food science, human ecology, and environmental sciences with their ethno-scientific counterparts of ethnobotany, ethnoecology, and ethnomedicine” (Pieroni & Price, 2006:pp.1–3), have all contributed to knowledge about the use of food in various therapeutic and healing forms. ‘Food as medicine’, and the use of wild and semi-domesticated foods and their use as medicine in traditional societies including Greek, Indian, African and Chinese medicine, has also been well documented (Pieroni & Price, 2006). More recent modern medicine has also revealed evidence regarding the relationship between the foods we eat and our health (Chen, 2009).

The prescribed use of the gluten free food diet to treat CD may also be seen as a specific group of foods being used as a ‘medicine’ to treat a chronic illness. What may set the GFD apart from the traditional or holistic use of food to treat restitutive ailments, is the classification of the GFD in both UK and US law as a ‘product or food that should be prescribed as medicine to treat specific diseases’ (Gov.UK, 2017). This arguably puts it into the medical category of “food as medicine”. The categorisation of the GFD as “food as medicine” in UK law, is as a list of itemised gluten free staples that can be prescribed to Coeliacs upon diagnosis. These staples are codified and listed by government health agencies in the UK, as ‘products or foods’ that should be regarded as medicine to treat specific diseases, and thus prescribed to Coeliacs by doctors (Gov.UK, 2017). The UK government and the National Health Service (NHS) governs these prescriptions via the Advisory Committee on Borderline Substances (ACBS), who’s role it is to recommend to doctors/GPs which foods or products may be “regarded as drugs for the management of specified conditions” (Gov.UK, 2017). In this respect, doctors are able to prescribe certain foods, like the staple items of bread and pasta to Coeliac patients

who might not otherwise have access to gluten free items due to lack of local supply, or because of prohibitive costs, where gluten free foods can be up to three times more expensive than non-gluten free food items. In this context, the gluten free diet may come under the remit of 'prescribed food as medicine' for the treatment of a chronic disease, and prevention of otherwise serious health consequences, like stomach cancer or other additional comorbid diseases.

However, the classification of some food items as medicine has met some controversy in recent years. As the GFD grew in popularity as a fad diet between 2005 and 2015, access to gluten free food items has become easier in some regions, supermarkets and restaurants. This has led to critics questioning the supply of gluten free food items on prescription, without necessarily taking into consideration the full importance of the GFD as a treatment to CD. In August 2015, when a national newspaper wrongly reported that gluten free prescriptions were costing the NHS over £116 million a year, Coeliac UK wrote to the paper to insist on a correction to the correct data that:

“[...] the cost of gluten free food to the NHS was in fact £26.9 million [£180 per diagnosed patient]. This makes gluten free prescribing one of the cheapest treatments for a long-term condition in the NHS”

(CoeliacUK.org, 2015a).

Charities like Coeliac UK, and other Coeliac advocates have continued to respond to these claims with measured responses, the correct government data, and lobbying the government to continue to provide support for the GFD on prescription (CoeliacUK.org, 2015a).

Examples of Coeliacs discussing this tension were also found in the Twitter corpus for this chapter, where individuals discussed the necessity of gluten free prescriptions, and how access to this allowed them to afford to home cook, and avoid the risk of being glutened when eating out. One mother of a Coeliac posted in two consecutive tweets:

1) “My daughter is 23 and diagnosed coeliac 2 years ago. Eating out is a nightmare - she has been poisoned by gluten twice (1/2)”.

(Female, unknown age, Twitter, May 2017)

2) “eating out at so called gluten free restaurants. It can take weeks to recover! Free prescriptions is least we can do (2/2)”.

(Female, unknown age, Twitter, May 2017)

As more CCGs and health authorities scrap gluten free prescriptions or place them under review, charities and advocates have continued to campaign for awareness of the importance of access to the GFD to people who cannot necessarily afford the higher prices of gluten free supplements (CoeliacUK.org, 2015a). However, CCG and NHS budget cuts and austerity measures imposed on UK regional health authorities, has seen a 40% reduction in the amount of CCGs that offer gluten free food on prescription to Coeliacs in need (Figure 21) (CoeliacUK.org, 2017). The effect of this is also being shared on Twitter, with 7% of tweets mentioning the decline in access to gluten free prescriptions.

One example is a Coeliac in her mid-20s who tweeted on two separate occasions:

1) “The only cure for CD is a lifelong diet, but gluten free food not being available on prescription will prove difficult.”

(Female, unknown age, Twitter, May 2017)

2) “Also troubling is yet another health authority looking to cut back on the prescription that many #coeliac sufferers rely upon. #glutenfree”

(Female, unknown age, Twitter, May 2017)

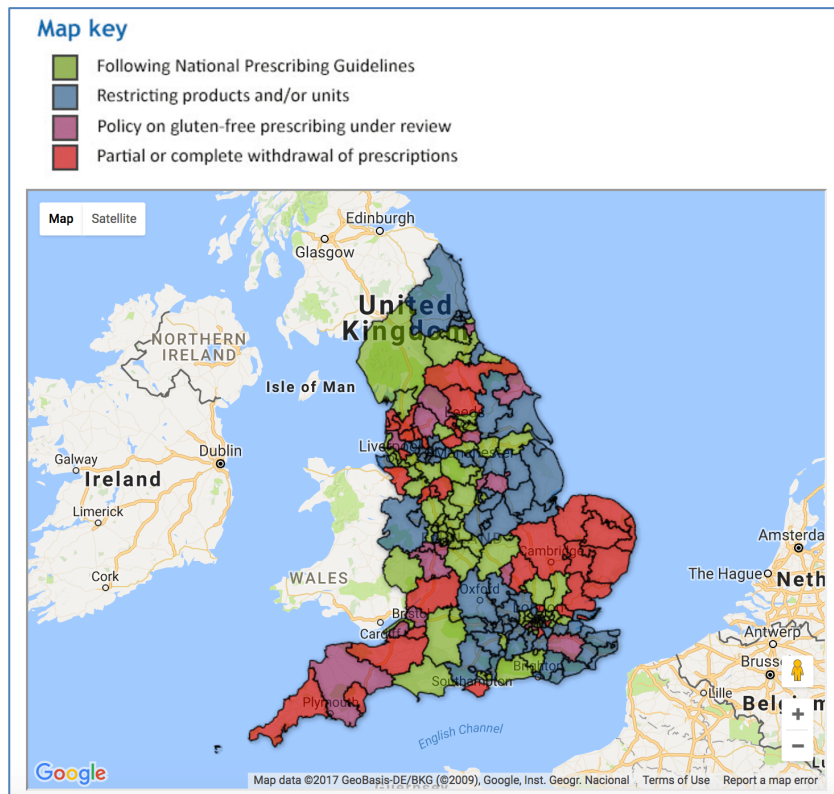


Figure 19. UK Gluten Free Prescription Map (CoeliacUK.org 2017)

As of March 2017, the UK government has also announced plans to further reduce access to gluten free food via prescription, and has entered a period of consultation with different health bodies including Coeliac UK (CoeliacUK.org, 2017). These policy changes have further highlighted the argument for gluten free food to retain its status of being viewed as a necessary medical form of therapy for the treatment of CD.

In the USA, lack of an NHS means that Coeliacs need to rely on health insurance to cover the process of being diagnosed with CD, as well as deducting the cost of gluten free food from their taxes. This was covered most recently by under the new Affordable Care Act (ACA) in 2015 (Karalexis, 2015). Like in the UK, Coeliacs in the US need an official diagnosis from their doctor, and to qualify for insurance cover, the doctor must fill them out an initial prescription, stating that a GFD is their treatment option. Upon submitting their yearly receipts and tax forms, Coeliac in the US would then qualify for a refund only if their medical expenses (including gluten free food) are more than 10% of their Annual General Income. Unlike in the UK, where tests to diagnose CD are free – in the US, while

there is currently coverage for the costs of the GFD diet, there is no guaranteed insurance coverage for what can be expensive tests needed to diagnose CD (Celiac.Org 2015). Coeliacs within the dataset for this chapter seemed to have good knowledge of this discrepancy between the US and the UK, with one woman in her mid-30s tweeting:

“In the UK if you have #celiacdisease insurance covers #glutenfree food. In the US insurance doesn't even cover all testing for diagnosis”

While CD was covered under the new ACA, at the time of writing, the new February 2017 US administration's plans to repeal this act have meant that Coeliacs in the US also face uncertainty over whether their GFD and any symptoms experienced as a result of CD, will be covered (Celiac.org, 2017). Examples of this anxiety were also found in the dataset, where a Coeliac in her early-40s tweeted about her concern for her Coeliac daughter, and the affect potentially having no insurance will have on her education:

“Erin had to drop school bc of celiac and no insurance bf ACA. [...] Defend #ACA. #carenotchaos”

(Female, unknown age, Twitter, February 2017)

Another Coeliac with comorbid illnesses also tweets about her anxiety over not being covered by insurance:

“Dear @[Senator's name] I have Crohn's, Psoriasis, and Celiac Disease. What do you suggest I do once you TAKE AWAY MY INSURANCE?”

(Female, unknown age, Twitter, February 2017)

As in the UK, Coeliac Advocates like the US national Coeliac Foundation also continue to lobby government and health services to protect the status of the GFD as “food as medicine”, as well as maintain the coverage of the symptoms and complications of CD, as covered by legislation and medical insurance (Celiac.org, 2017).

Conclusion

This chapter has revealed that, while some Coeliacs shared symptoms, they did so within the carefully delineated context of CD. This was done by the analysis of hashtags like #coeliac or #celiac, which added an element of biosocial identity or biosocial citizenship to each post. These hashtags acted to clearly demarcate some Coeliacs' communications from posts that were instead about gluten free food being used by those without CD who were alternatively using the diet to follow weight loss, body sculpting or lifestyle diets. One of the main examples of some Coeliacs re-writing a general digital environment with specific chronic illness-related information, was the way in which a trending lifestyle hashtag called #cleaneating, was completely changed by Coeliacs adding their #coeliac or #celiac hashtag to posts which also contained the hashtag #cleaneating.

By tagging posts with their biosocial hashtags, some Coeliacs are able to clearly mark-out a space for themselves within this trending topic. So much so, that a visual comparison of image data harvested from Instagram revealed the stark difference in #cleaneating posts that did not contain the biosocial hashtag #coeliac or #celiac, in comparison to posts that did include this marker. On Instagram, for example, photos shared without the biosocial #coeliac or #celiac hashtag showed a lot more selfies, body shots and gym shots, than did the photos that had both the Coeliac and clean eating hashtags. Instead, for some Coeliacs, photos of gluten free food were the overriding feature in their #cleaneating + #coeliac or #celiac posts. This shows that in terms of practicing the technologies of self-care, the sharing of photos becomes part of the 'Disclosure of Self' (Foucault, Rabinow & Hurley, 1997:pp.234–237), where for some Coeliacs, (at least in this context), the key focus of sharing images of the gluten free diet is to communicate the importance of paying attention to micro-constituents of food ingredients that make up part of the gluten free diet. This disclosure of self in relation to the gluten free diet and to the presentation of gluten free food within the context of how it is used to self-manage the disease, is in stark contrast to the non-coeliac related use of hashtags like #cleaneating, where the focus is on a non-chronic illness related disclosure of self, with a focus on body shape or selfie or healthy lifestyle images. The chronic

illness disclosure of self demonstrates that some Coeliacs are actively using social media hashtags to annotate and re-write their online environment with public health knowledge, not only with the discussion of symptoms, but also with the sharing of images which are related to hashtags linked to more popularized diets. These practices also relate to the third stoic Foucauldian technology of self – the ‘Remembrance of Self’ (Foucault, Rabinow & Hurley, 1997:pp.234–237), where individuals practice self-care by creating ‘memorisations of deeds’ and practices. Through these ‘memorisations’ or remembrances of self, Coeliacs have also shown that the use of a biosocial hashtag that is linked to a chronic illness has the power to change or re-write the digital context of a general hashtag or forum of communication, into a biosocial one.

Further analysis of hashtags linked to the symptoms of CD found that Coeliacs were using hashtags with the term ‘glutened’ in posts that contained co-occurring words related to pain, frustration and discomfort in a way that made it easy to visualise and categorise different types of symptoms experienced within specific groups of Coeliacs on social media. This revealed clear patterns of Coeliac discussion about the experience of pain, lack of energy, sickness, and finally self-investigations into what might have caused the accidental ingestion of gluten. These practices of self-investigation also reflect the Foucauldian concept of the ‘Examination of Self’ or taking stock/self-reflexivity (Foucault, Rabinow & Hurley, 1997:pp.234–237) in terms of self-care and management of health and illness.

In terms of the classification of the GFD as “food as medicine”, this chapter revealed that the overlap in the use of food as medicine and food as control in the practice of the technologies of self-care, has of course led to controversies over the viability of specific ‘free from’ diets, such as the GFD. The appropriation of the GFD by both the aesthetically body conscious, and those with specific food intolerance or autoimmune diseases has led to controversies over the availability of gluten free foods both in general contexts, and the availability of different types of gluten free food (healthy and non-healthy staples) for Coeliacs on subsidised prescription (Pietzak, 2012).

Chapter 5: Risk Communication and Activism on Social Media

This chapter investigates instances of how some Coeliacs use social media to manage and communicate risk, and then explores how some Coeliacs organise practices of activism via social media in times of food certainty. When buying food for their prescribed gluten free diet, some Coeliacs may use social media to discuss how they rely on key and trusted items from commercial companies, that have labelled items as gluten free in accordance with EU and US food allergen laws (Food Standards Agency, 2014; Food & Drug Administration, 2016). However, what happens when a product bought from a familiar and trusted source is found to be cross contaminated, and the trusted and familiar become subjects of food risk? In this chapter, I will explore how Coeliacs react to situations of cross contamination.

In June 2015, Genius Foods, a UK manufacturer of gluten free foods, issued a product recall, informing consumers that some of the products it supplied to supermarkets had been cross-contaminated with gluten on the production line (Genius Foods, 2015). Four months later in October 2015, General Mills, a US manufacturer of a the newly launched gluten free Cheerios cereal range, issued a similar product recall of 1.8 million boxes; this was also due to cross-contamination of wheat flour in the manufacturing process (Murphy, 2015). In both cases, the manufacturer used a combination of traditional media (e.g. news outlets) and social media to issue their product recall.

While previous studies of the use of social media to communicate product recalls to the public have covered the effectiveness of social media communications in differing scenarios, from prescription drug recalls (Ledford & Anderson, 2013) and disaster protocols (Dreyfuss, 2015), there are few studies that look at product recalls from the perspective of food risk and corporate communications specifically in the context chronic illness and Coeliac Disease. In contrast, this study does just that from the perspective of many Coeliacs use of social media in this regard, and by

adding to the large body of literature on food risk (Sarah Nettleton *et al.*, 2010; Green, Draper & Dowler, 2003; Hattersley *et al.*, 2014), the use of social media to communicate food risk (Rutsaert *et al.*, 2013; Stjerna, 2015) and food recall (Charlebois, Von Massow & Pinto, 2014; Gaspar *et al.*, 2014).

I explore how some gluten free food manufacturers use social media to communicate food risk and cultivate trust of their brands within the context of a chronic autoimmune disease. I also explore how some consumers with Coeliac Disease respond to food product recalls and share information about the food risk that has occurred because of cross-contamination. Finally, with the introduction to the term “Coeliac-tivism”, this study also looks at how during a product recall, when trust is temporarily broken in a food brand, some Coeliac consumers' use collective resources to confront manufacturers who they perceive are not handling issues of cross-contamination correctly. In this way, then, this chapter explores how some Coeliacs communicate their experience of risk and organise instances of community activism via Social Media.

Food risk and social media as strategic communication tool

The advent of Web 2.0 and social media has seen a change in the way that food risk is communicated to consumers (Noar, 2006). From a consumer perspective, the benefits of the use of social media to disseminate food risk information, can be: 1) faster communication and ease of access, 2) the opportunity to share and disseminate this information to an extended social network, and 3) the ability to interact with the company in question (in terms of getting more information and understanding) (Kuttschreuter *et al.*, 2014; Rutsaert *et al.*, 2015).

From a company perspective, the benefits and strengths of online communication and awareness raising can be 1) speed, 2) accessibility and 3) direct interaction with consumers. However, perceived problems areas can be 1) the risk of information overload, 2) lack of a filter, 3) low levels of trust or satisfaction, and 4) losing control of the original message trying to be disseminated (Rutsaert *et al.*, 2013).

Loss of control of the main message disseminated was found to be due to the nature of sharing and interaction tools on social media, where the context or intent of an official message can be changed via the commentary of a user in a Tweet, Facebook message or Instagram post. The inherent sharing and quoting features of most social media platforms means that users can change, interact with, and alter the text of original message disseminated by the company, a factor which may prove problematic for a company trying to disseminate a particular message. In this context, the very nature of the internet, social media, and the affordance and fluidity of the anonymity, identity, interests and location that it gives to individuals – can make it hard for consumers to fully trust the source of information shared (Mehrabi, Hassan & Sham Shahkat Ali, 2009).

Research on the sharing of food risk information via the internet has also found that as well as relying on official sources, the public tends to rely on food-related information from unofficial sources such as friends, peers and family (Rutsaert *et al.*, 2015). It has also been found that in times of online risk communication, people tend to trust those that are most similar to them, and understand the cultural and individual context of the risk within their social networks (Tulloch & Lupton, 2003:p.6; Palen *et al.*, 2009). It is therefore important to take these factors into account when analysing the sharing of information in large online communities that identify as Coeliacs.

Bearing this in mind, further exploration of the question of how much Coeliacs trust the credibility of information coming from other Coeliacs is needed – especially versus the official information from companies that have exposed them to risk via cross-contamination of the food product line. There is also the possibility that when high levels of uncertainty are experienced at the height of a food allergen recall, this may then lead to a willingness on lay people's part to challenge the advice of experts in relation to risk concerns (Lupton, 2013c:p.108). These tensions were reflected most recently in the Gluten Free Cheerios recall (discussed below), where some consumers and coeliac activists queried the way that manufacturer General Mills mechanically sorted oats that were originally contaminated with wheat. In one Facebook response to the General Mills'

recall of Gluten Free Cheerios that had been cross-contaminated, a consumer commented:

"I'm so disappointed. Until you change your process, I won't be buying Cheerios. When you use certified gluten-free oats and process them in a clean facility, then I will try them. Otherwise, I'm not touching them! It's not worth putting my health in jeopardy."

(Female, unknown age, Facebook comment, October, 2015)

I will further discuss how the above Facebook comment, and similar responses by some Coeliacs to food recall notices, show an increase in the willingness of chronically ill consumers to use their agency to challenge the authority of companies and question the status quo of industrial food practices.

First, though, a summary of the circumstances involved in the UK and US gluten free food recalls, and the dynamics of food risk communication that occurred between the food companies and Coeliac consumers involved.

The case(s) of the Genius Foods recall

Genius Foods is a gluten free food manufacturer, that was setup in 2009 by Lucinda Bruce-Gardyne, in a quest to provide tasty gluten-free bread for her son, whom had been diagnosed as gluten intolerant (Genius Foods 2015b). The company supplies gluten free baked goods to supermarkets and stores across the UK, France, the Netherland, Germany, and Australia (Genius Foods 2015b). Between December 2014 and August 2015, two gluten free food recall incidents were issued by the company. On 1st December, an alert the FSA and Coeliac UK notified that Genius Foods had recalled a batch of Genius gluten free 'Denby Pies'. These pies had accidentally been filled with non-gluten free fillings placed in them at a third party facility. When a social media query was made for mentions of the December 2014 (or #piegate) recall across Twitter, Facebook and Instagram – interestingly, only the following three direct tweeted mentions of @GeniusFoods and the recall alert were found:

1. @***User 28 Nov 2014 ".@GeniusFoods Hi, You should advertise this on social media so your coeliac customers don't get really ill? #coeliac [this tweet attached a screenshot of FSA

food recall alert mentioning recall of Genius Denby Pies]”.

(Female, unknown age, Tweet, November 2014);

2. @*****_User 4 Dec 2014 “ [...] for some feedback @Coeliac_UK @GeniusFoods I met with my colleagues on the Oxon CUK committee last night. No one knew of the recall...”

(Female, unknown age, Tweet, December 2014)

3. Coeliac @*****User 1 Dec 2014 “Really poor that you're not informing your twitter customers of this! @GeniusFoods #glutenfree pies recalled. food.gov.uk/news-updates/n...”

(Male, unknown age, Tweet, December 2014)

Further investigation of these tweets lead to a linked blog post that reported that Genius had decided not to share news of the food recall via social media, but had instead decided to only rely on the Food Standards Agency alert system to disseminate the information (Gazzola, 2014). It was questioned whether this was a wise thing to do, especially as it was argued that social media was a very effective mechanism for getting out the correct warning as quickly and efficiently as possible. Direct communication with Genius, however, found the response was Genius did not feel a need to use social media to report this particular recall, that was limited to just one item in its range of foods (Gazzola, 2014).

In contrast, in the second recall in June 2015, Genius Foods issued a product recall for 23 free-from products. Among the recalled items were Genius branded products including pizza bases and pitta breads, as well as own-label products supplied to the 5 largest supermarket retailers in the UK (Asda, Morrisons, Sainsburys, Tesco and Waitrose) (Food Standards Agency, 2015).

An official press release on the Genius Foods website indicated that the cross-contamination was down to a dry ingredient (unnamed) containing gluten, that had entered the baking process and had been identified through its regular testing procedures (Genius Foods, 2015). Under UK/EU allergen laws, a product must contain less than 20ppm of gluten to be considered safe and gluten free for Coeliac/gluten-intolerant consumers (Food Standards Agency, 2014).

The recalled products in June 2015 were tested to have fallen between 5ppm and 80ppm, levels that made some Coeliacs reportedly sick, though were levels that were in general considered to “low risk”, although not officially gluten free (Coeliac UK, 2015b). In the Genius Foods press release, they stated:

“... we have responded immediately by implementing a full recall for affected products. No other products are affected, including Genius breads and rolls.” [They indicated that they took issues of this nature “very seriously”, and] “We are working with our internal teams and retail partners to prevent any risk to our customers and prevent reoccurrence, and we apologise to any customers affected by this issue...”

(Genius Foods, 2015).

In a Q&A published on its website and communicated in response to queries via social media, Genius advised those with Coeliac disease or a wheat/gluten allergy not to eat the product. It further advised those who had done so and were showing signs of being unwell to contact their local doctor for immediate advice, or to contact Genius with any enquiries.

In contrast, to the almost total social media silence of the December 2014 recall, the food recall notice of June 2015 was both instigated and spread by Genius Foods via social media across Facebook and Twitter. This may be because the spread of the cross-contamination in this particular incident affected a wide variety of Genius Foods’ products – both the ones under its own brand label, and the ones it produced for other supermarket own-brands – hence the need to get out information as widely, quickly and efficiently as possible (Genius Foods, 2015). Consumer commentary included some acknowledgement from the previous December 2014 Tweeter of the increased use of social media communication in the 2nd recall incident:

“@*****_GF. @GeniusFoods well at least you've been more proactive about the recall this time. That should applauded. But worrying trend [of recalls] unfortunately.”

(Male, unknown age, Tweet, June 2015)

In the June dataset for Genius Foods, all mentions of the food recalls began to wane after a period of one month and two days on both Facebook and Twitter, with sporadic queries about the initial recall occurring in 3-5 posts as late as March 2016. Sentiment analysis of all social media posts found that there was a spike of 8% negative comments occurring around the initial product recall between 5th and 6th June 2015, where the majority of queries and requests for clarification were made. Positive consumer responses, praising how efficiently Genius Foods were handling the incident were at 2% of all posts. Between 7th and 10th June 2015, negative comments stayed between 8% and 9%. However, when a second announcement of further goods that were contaminated was made on 12th June, negative sentiment reached the highest at 14%, tempered by 8% positive and 7% neutral comments. While the Twitter data collected is a 1% sample of trending tweets from the public streaming API within the June 2015 to March 2016 period, and not a full data sample, covering all classifications of data, this data sample is an example of how a concentrated effort of advertising, and dealing with food recall communications across both social media and traditional platforms, can have a positive impact on how it is received. The next case, however, shows where the use of social media platforms in communicating food recall can have a detrimental effect on some Coeliac consumer and food company relations.

The case of the Cheerios (General Mills) recall

In September 2015, General Mills, the company behind the popular US breakfast cereal, Cheerios, launched a new range of Gluten Free plain, and Honey Nut Cheerios (Perry, 2015a). As part of its launch, it advertised that it had worked hard to make sure that its products would be completely gluten free, and that its manufacturing methods ensured safety for Coeliacs (some of whom had not eaten Cheerios for years since diagnosis) (Neimark, 2015). Another part of its charm offensive was to contact influential members of the online Coeliac community, whom it invited to its factory to overview the gluten free sorting process. However, while general reception was positive, a few Coeliac advocates (Coeliac-tivists) were wary of the mechanical sorting process that General Mills used to sort its oats,

from oats that were at first fully contaminated with gluten, to oats that were then mechanically classified as gluten free (Perry, 2015b). The main issue was that for the previous 12 years, Coeliacs had been warned to stay clear of oats, as they were found to create similar adverse autoimmune responses in those very sensitive to them (Sharma, Pereira & Williams, 2015). However, in recent years, the guidelines from the FDA had changed to state that 'pure oats' grown and stored in environments away from wheat, barley and rye, were deemed safe (Food & Drug Administration, 2013).

The problem that Coeliac advocates had with the Cheerios and other sorting processes, was that the manufacturers were not using 'pure oats', but were instead using very new, proprietary technology to mechanically sort very contaminated oats, so that stray pieces of contaminant grain were removed. After this process, Cheerios informed the Coeliac-tivists that it means-tested small batches (12 out of a large batch) of their cereal, and based on those results, decided that they were gluten free. Coeliac-tivists expressed concern that means-testing such small amounts meant that there would be more chance of boxes that contained above 20ppm getting through the process, and making Coeliac consumers sick (Figures 22 and 23).

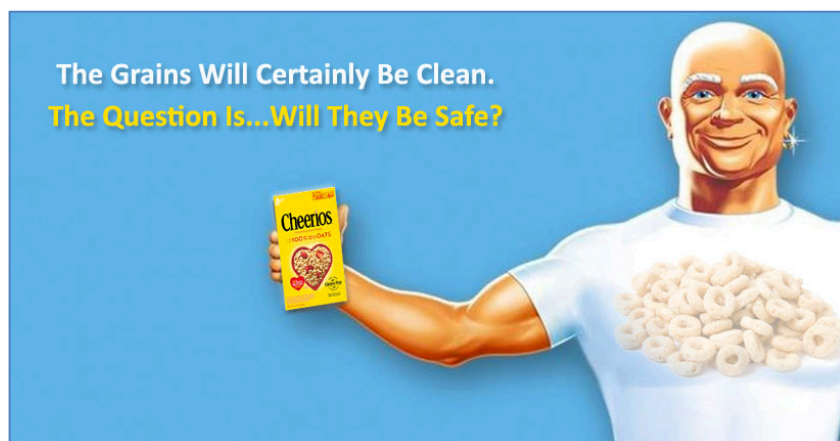


Figure 20. Coeliac-tivist questions mechanical sorting process of oats claimed as gluten free (October 2015)



Figure 21. Coeliac-tivist questions mechanical sorting process of oats claimed as gluten free (November 2015)

Thus, reception of the gluten free launch from within the Coeliac community was mixed, ranging from excited:

“I haven't had #honeynut @cheerios for over 10 years. So excited they are #glutenfree now! #cheerios #celiac”.
(Female, unknown age, Twitter, October 2015).

to cautious:

“Leaving Minnesota. Mixed feelings about the Cheerios GF Summit. Will share next week. See you soon... https://****”
(Male, unknown age, Twitter, September 2015).

From as soon as mid-September 2015, Coeliacs and those very sensitive to gluten were starting to report on social media that they were getting sick from eating boxes of Cheerios labelled gluten free. Cheerios/General Mills continued to assure customers that every one of its boxes was gluten free and that it must be the customers themselves who were especially more sensitive to oats:

1. “So I have been eating Cheerios for weeks for breakfast and it's been great. Until this latest box. I'm sick every time I have a bowl. It's mild' but it's definitely there [...] I had read up about

your process for checking for gluten and read that many had issues with that way of testing. I assured people it was safe. I now see why it doesn't work. We are a sad family now. We loved our Cheerios. Please change your testing and truly make them gluten free."

(Male, unknown age, Facebook Comment, October 2015)

2. "We are so sorry to hear you got sick. We take your health very seriously and we would like you to submit information about the boxes of Cheerios you ate to our consumer complaint line. You can reach them at: 1-800-328-1144 . We made Gluten Free Cheerios to help provide an affordable, nutrient-dense option for those with celiac disease and gluten sensitivity. Cheerios are gluten free and every box and serving are testing below 20ppm. However, we understand that for some celiacs, Cheerios will still not be an option because of the unique circumstances of the individual. We care deeply all of our consumers, including the Gluten Free community."

(Cheerios customer service, Facebook Comment, October 2015)

By this point, Coeliac advocates started to gather information, some posting messages on social media that encouraged those that had gotten sick to contact Cheerios and the US Food and Drugs Administration (FDA).

These actions fit very well within Cammerts' discussion of Foucault's three stages of mobilisation and self-mediation when social movements enact the technologies of self: Disclosure, Examination and Remembrance (Cammaerts, 2015). As noted in the literature review, Cammaerts argues that the asynchronous affordances of social media platforms as both public and private, enable social media movements to publically capture, record and archive information, discourses, as well as use this to mobilise action to exert change. In terms of Disclosure, Coeliac advocates disclosed their concerns about issues of cross-contamination via blog-posts and tweets. In terms of examination, they then called on and mobilised Coeliacs to share any experiences of symptoms of being glutened by eating Cheerios to key members of the online community, or by sending them directly to the

Food and Drugs administration. Further investigation of Examination techniques discussed later in this chapter shows how one particular member went a step further by ordering independent lab tests of products in question, which were then shared with relevant authorities. In terms of Remembrance, and the recording and archiving of protest artefacts, by 29th September 2015, some Coeliac advocates were going as far as mapping from where in the US, Coeliacs had reported getting sick from Gluten Free Cheerios (Figure 24):

“RT @[customer_name]: . @Johnnask*** mapped out people w/ adverse reaction to #glutenfree @cheerios http://t.co/**** @GFWatchdog”.

(Female, unknown age, Twitter, September 2015)



Figure 22. Mapped: Coeliacs made sick from Gluten Free Cheerios by 21st Sept 2015 (Perry, 2015b)

Sentiment analysis of posts around this time also show a big rise in negative posts directed at Cheerios, demanding to know why so many people were getting sick between September 2015 and the final announcement of the recall in October 2015 (Figure 25).

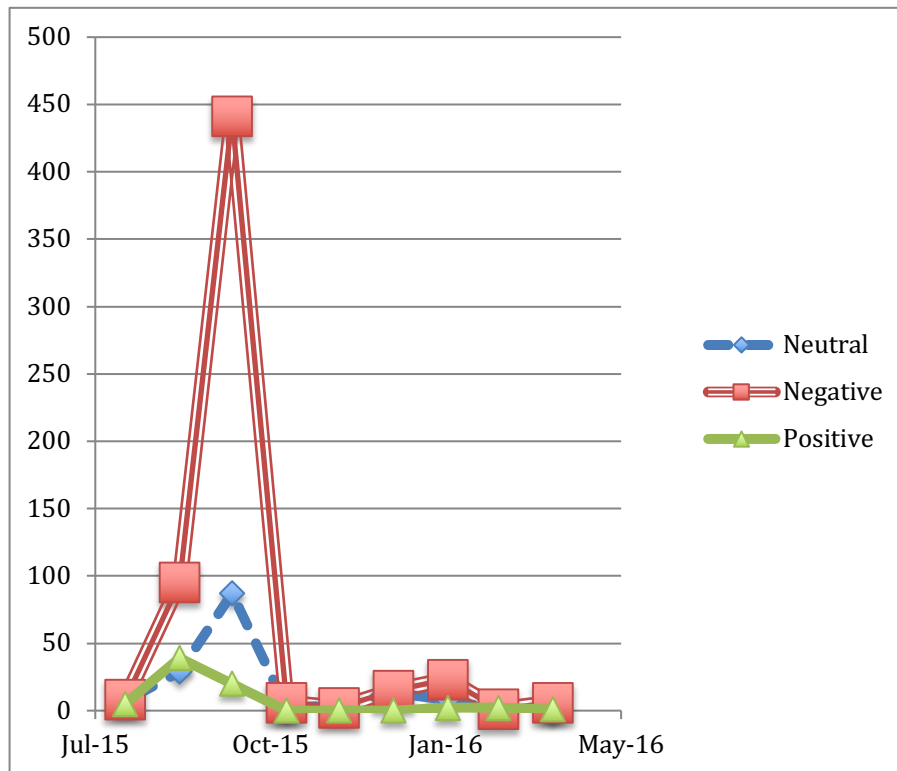


Figure 23. Cheerios Recall: Consumer Facebook Sentiment: July 2015 - March 2016

A deeper analysis of the activity behind 1) this rise in negative comments, 2) the reporting of independent findings to the Food and Drugs Administration agency, and 3) the prolonged campaign by Coeliacs with regards to the safety of Cheerios for those with Coeliac Disease will be explored in section 9 below. Ultimately, it may be argued to be a combination of online activism via a small Health Social Movement (Brown & Morello-Frosch, 2011), that was backed up by independent research that has made this a complex and active topic.

Coeliac-tivists and the Cheerios Recall

One of the strongest trends in the Cheerios recall has been the activity of Coeliacs and Coeliac advocates, who have independently gathered and posted experience and evidence-based information to convince the food authorities and food manufacturers that there was a problem with the gluten free Cheerios product. These activities seem to have affected the length of time that the recall issue has been mentioned in both social media and the general press, as well as a prolonged discussion of manufacturing

processes (October 2015 – September 2016). The kind of activity we see here, is very similar to that of Embodied Health Movements (noted in the literature review), which describes situations where both patients and patient advocates demanding better access to treatment and resources, and do so in such a way that they collectively challenge medical policy and politics, belief systems, research, and practice that include an array of formal and informal organisations (Brown & Zavestoski, 2004). In this context, Health social movements can act as an important bridge to push medicine and medical-related practices to evolve by connecting the movement's health concerns to "other substantive issues such as social justice, and access issues (Brown & Morello-Frosch, 2011). Indeed, some patients' unique status of lived experience of self-managing their disease has been argued to give them an experience that is unavailable to others, and thus lend a moral credibility to the collective group advocating for change (Brown & Morello-Frosch, 2011).

As discussed in the literature review, Rose and Howard note that such embodied experience can also be seen in the way that means that many Coeliacs cannot avoid linking their daily access to gluten free food to the health care system (2014b). Many Coeliacs may necessarily need to interact with companies and manufacturers to access gluten free food that is safe for Coeliacs to consume. This is something that the majority of healthy consumers do not necessarily need to do. Thus, making it arguable that the very nature of this interaction tends to add a unique moral credibility to Coeliacs as individuals and a group when interacting in the public and commercial sphere. This can especially be the case when things go wrong, and Coeliacs are accidentally glutened either at a local or national level via the food manufacturing or food preparation process. Examples of this unique status and use of perceived moral credibility were found in my investigation of the Facebook data around the Cheerios Recall incident, where several of the negative comments focused on the seriousness of Coeliac Disease, and thus the duty of care that companies were seen to have when supplying food that was labelled as gluten free:

“[...] It's quite a shocker that a brand like Cheerios would make such a big mistake. Mistakes do happen, but this is a big one for people

with Celiac disease that rely on safe and appropriate GF labels.”
(Female, unknown age, Facebook Comment, 24th September 2015)

This was also shown when Coeliac advocates acted to collectively mobilise Coeliacs to share their suspected incidences of being glutened by Cheerios with them. One of the Coeliacs who acted to map each incident of glutening posted, and urged people to sign an online petition, posted the following:

“There are numerous reports of sickness related to “gluten-free” Cheerios [on the Change.org petition]. If you have become sick eating these, please read [the] post from Gluten Free Watchdog. She is collecting reports of illness linked to this product and submitting them to the FDA. The FDA is aware and is listening. [...] Please sign [the Change.org petition]. Your voice matters.”
(Perry, 2015a)

More recently, writers have coined the term ‘evidence-based activism’, which describes forms of activism, where patient groups gather and build experiential knowledge and “reframe the problem to identify zones of “undone science” – thereby staking a claim to the politics of knowledge” (Rabeharisoa, Moreira & Akrich, 2014:p.115; Britten & Maguire, 2016:p.6). This arguably describes the case in the Cheerios recall incident, where Coeliacs have acted as a group to gather experiential knowledge, so that they can challenge a zone of “undone science” – in terms of what they see as undetected zones of cross-contamination, and questionable oat-sorting practices – that may be doing harm to members of their patient community. Epstein has also gone one step further to describe ‘lay expert activists’, who know enough about science to challenge professionals, but who may lose touch with their less well informed peers, unless they phrase their knowledge and activism in a way that is open to all (1996).

Further discussion and analysis of data show how this has happened to some extent with health professionals in the Cheerios network with the blogger and social media activist known on Twitter as the ‘@GFWatchDog’ (or ‘Gluten Free Watchdog’). This particular individual is also a published nutritionist, who at the time of the Cheerios food recall, seems to

communicate a balance of scientific knowledge with which to challenge authorities — as well as communicate lay-comprehensive messages to the wider Coeliac community via social media. Further exploration of her communication and calls to activism will show how this balance of experiential, scientific and communicative knowledge may be one of the key driving forces behind a fairly effective campaign of knowledge and change in the issues of cross-contamination surrounding the Cheerios recall. As Rabeharisoa (2014), and Britten and Maguire (2016) have argued, it may be that a combination of patient organisations/groups, joined with networks of expertise that ultimately adopt a reformist activist agenda – which may work to use better patient knowledge as the target to change harmful practices that affect patient groups.

Coeliact-ivism, Risk and Technologies of Self

The term ‘Coeliac-tivist’ or ‘coeliactivist’ first appeared in the Twitter corpus in 2012, when Coeliacs in the Twitter community were discussing the way that some members proactively pursued food distributors or manufacturers that they deemed responsible for ‘glutening’ them (Figure 26).

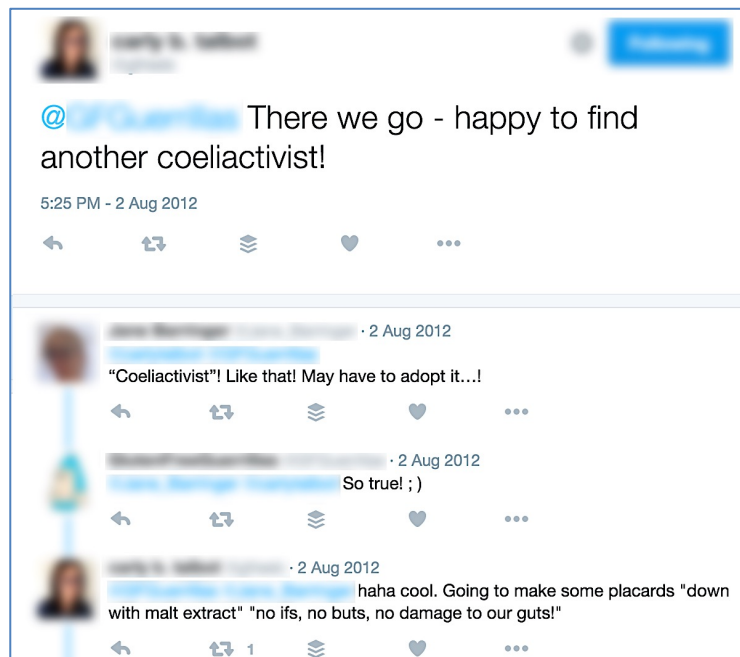


Figure 24. First Tweet conversation mentioning the term "Coeliactivist" (2012)

In 2015, the term was entered into the Urban Dictionary by a member of the Coeliac Community, and was defined as: “Coeliactivist: A person with coeliac disease or who eats a gluten free diet who is partial to campaigning or lobbying companies, organisations or individuals on issues relating to coeliac or a gluten free diet. *She's such a coeliactivist, she's always kicking off on Twitter to Domino's about how small their gluten free pizzas are*” (Talbot, 2015). While the UK spelling of ‘Coeliactivist’, brings up 17 results on Twitter, the term (and American spelling) ‘Celiactivist’ never really took off in the US, with only 3 posts found (2012-2015). However, while the term is not so widely used in individual posts, analysis of the two Genius Foods and Gluten Free Cheerios controversies has shown increased patterns of behaviour that reflect an ‘Coeliac Activist’ mind set, with individuals confronting companies they perceive to have caused or put them at risk of harm.

Because of these patterns of behaviour in social media data, I will call Coeliacs who engage in lobbying activity ‘Coeliactivists’ as a broad term for patient lobbying activity on social media. Also, for the rest of this chapter, I will refer to the term as ‘Coeliac-tivist’, to emphasise on the identity of the diagnosed *Coeliac* becoming an *activist* or advocate for the rights of people with the same autoimmune disease. This fits with the previously discussed prediction of Novas, who stated that the 21st century and the prevalence of the internet and medical knowledge found there - would allow individuals to form groups of biosociality around shared genetic or biological traits (Gibbon & Novas, 2007).

Novas and Rose describe biosocial groupings as “collectives formed around a biological conception of a shared identity” (2007). Coeliac-tivists thus acted as a “collective” by organising groups of individuals with the same autoimmune disease to directly communicate and challenge food companies involved in the food recall within the companies within the context of how that company’s practices negatively affected their health as a Coeliac community. By acting as a group of people who share the same autoimmune disease, and who were therefore potentially at risk of suffering equally harmful effects from being glutened, Coeliacs reaffirmed their collective identity, and acted as a group advocating for the safety of its

members. Such biosocial collectives can also be seen as acting as support networks for those newly diagnosed with a chronic illness, where they can ask questions about the correct way to follow the GFD, and for help in navigating any experiences of biographical disruption (Bury, 1997) while trying to cope with new diagnosis and uncertainties with regards to food allergen labelling. In explaining how 'biocitizenship' is formed within biosocial communities, Novas & Rose also described how the collective sharing of knowledge about a specific biological disease also informed how they acted as a community, and built upon and shared a collective identity and knowledge about self-care practices (2007).

One of the key themes to arise from the food recall incidents of 2015, was the sense that Coeliacs were using their collective identities as a biosocial community to campaign for better adherence to allergens guidelines within the specific context of their disease. They were doing this not as passive members of a patient community, but as active members of a community that has learnt to navigate the commercial food landscape to source food that not only is gluten free, but is safe for them to eat within the parameters of Coeliac disease (e.g. food that contains no more than 20 ppm of gluten).

Further exploration of the data around the food recall incidents will show how some Coeliacs acted as a collective biosocial community via social media platforms. I will also show how this biosocial community utilised Foucault's 3 stoic principles of self-mediation (1. Disclosure of the self, 2. Reflexive examination of the self, and 3. Remembrance of the self or deeds pertaining to the self (1997)) - to form a health movement that used practices of Disclosure, Examination and Remembrance to mobilise themselves into a group that used collective evidence of symptoms and sickness to press both manufacturers and allergen authorities for more assertive action.

Within the current Cheerios corpus, similar activity has also been found. However, this time, the activity of Coeliac-tivists seems to have progressed to even more organised levels, where consumers have been found to employ allergen testing labs, and regulatory lobbying techniques to force manufacturers to take gluten free processing procedures more seriously.

When looking at the data from the Cheerios food risk recall, one of the other interesting patterns to emerge from the company-to-consumer communication is the activities of disgruntled consumers who were unsatisfied with the information shared by General Mills. In some of the conversations coded, references to a consumer-led group called the previously mentioned 'Gluten Free Watchdog' were found. In these conversations, consumers mentioned independent tests that have been performed by the 'Gluten Free Watchdog' on Gluten Free Cheerios boxes in question, where those boxes have been found to contain more than 20ppm of gluten.

Further investigation of the Twitter (@GFWatchdog) and Facebook account behind this information, revealed that it is run by Tricia Thompson (MS, RD). Thompson identifies as an advocate for the Coeliac community who has followed the gluten free diet for 27 years, and in her capacity as a published and registered dietician and nutritionist (Thompson, Lee & Grace, 2010; Thompson & Simpson, 2014), has employed the services of an independent testing lab to test foods that were suspected not to be gluten free. In an interview about her role in the Coeliac community and the running of Gluten Free Watchdog, Thompson explained her role as a Coeliac advocate, and almost mirrors the Urban Dictionary definition of a 'Coeliac-tivist':

“[...] professional integrity means ALWAYS putting the needs of gluten-free consumers first. As can be imagined, this does not go over well with food manufacturers and gluten-free certification organizations when results are posted showing foods making gluten-free claims to contain more than the allowed level of gluten.”

(DFPI, 2014).

In terms of activity on social media as the “Gluten Free WatchDog”, what stands out is how the account utilises social media for disseminating information in a similar way to how companies and food regulators disseminate information during a product recall. Any communications with these stakeholders were also communicated via social media to the gluten free community (Twitter n= 295 tweets, Facebook n = 677 posts). In most communications, but especially in the Cheerios product recall, Thompson's

sent the results of her independent lab tests to both the manufacturers who produced the foods in question, and the US Food and Drug Administration regulator. As part of these social media communications, she used independently run scientific lab results as the basis for informing Coeliacs whether certain foods were safe enough for them to consume. An example of this is a tweet that states:

“Gluten test results for Honey Nut Cheerios posted on the public side of Gluten Free Watchdog https://t.co/****”

(Thompson, Twitter, September 2015)

In September 2015, just before the October 2015 Cheerios Recall, in a response to the increase in incidents of people reporting they suspected they been glutened by gluten free Cheerios increased, Thompson started to tweet calls to mobilise and gather information to her followers:

“If you believe gluten-free Cheerios made you sick, please contact us. We are compiling information to submit to FDA. https://t.co/t****”

(Thompson, Twitter, September 2015)

In a response to an open letter from Coeliac-tivist @GlutenFreeWatchDog to Cheerios/General Mills, the manufacturer admitted that it had failed to do any testing on the products for 17 days, and so missed the cross-contamination of the gluten free boxes with wheat flour. The following are a series of tweets by a clearly frustrated @GlutenFreeWatchDog, where she points out the error of their own testing procedures to Cheerios, and the contradictory information they shared with consumers who were complaining of illness on their Facebook page before the recall.

On 9th October 2015, @GlutenFreeWatchDog posted a tweet that stated she had gotten a response from General Mills, as to what specifically had happened for them to miss the cross-contamination:

“Important update: General Mills responds to letter from Gluten Free Watchdog community-scroll down to bottom of post https://t.co/****”.

(Thompson, Twitter, October 2015)

An excerpt of the link can be summarised as General Mills explaining how a gluten free oat flour was transported in a truck that had previously carried wheat flour, and had not be decontaminated. There was an admittance

that finished product testing had not been done for several days, and that this was why the contaminated oats had gotten into the gluten free oats supply, and had contaminated 1.8 million boxes of gluten free Cheerios. They were only able to figure out which batches had been contaminated by looking back on the days where (for whatever error), the allergen testing had not been carried out.

On 13th October, @GlutenFreeWatchDog then replied to General Mill's official response with a link to a blog post title: "Lingering Questions Remain about Gluten-Free @Cheerios Recall and Safety [...]". Following this, she posted a series of 10 of tweets that summarised this blog post, which both questioned and highlighted awareness of the reasons for the recall (perceived scientific flaws in means testing for gluten), and the context and severity of potential effects on the health of Coeliacs because of this. Following this, a Coeliac consumer posted a follow-up tweet to this series of posts in November 2015, seeking clarification from @GlutenFreeWatchDog by a concerned Coeliac, who queries:

1) "@GFWatchdog I see your Oct13 post & that @cheerios has not yet answered why finished product testing was stopped for 13 days. Unacceptable".

(Male, age unknown, Twitter, November 2015)

2) "@[customer_name] Correct. @cheerios hasn't offered an explanation why finished product Cheerios were not test at the Lodi plant for 17 run days."

(Thompson, Twitter, November 2015)

With regards to the @GlutenFreeWatchDog coverage of Cheerios recall on the day it was announced, Facebook stats of the @GlutenFreeWatchDog account showed that that specific day had the highest interactions, with 4 posts on the day of the recall gaining 150 likes, 171 comments and 255 shares. Whilst this is not vital to the overall dataset, what is interesting is that activity was again cross-platform and not isolated to one social media outlet. A cross-analysis of social media around that period also found that commentary and reference to both the Twitter posts and Facebook posts crossed over to another social media platform, where @GlutenFreeWatchDog had no presence. In this case on Instagram,

where, in comments to a post celebrating the release of Gluten free Cheerios, 10 out of 30 posts referred to the independent testing done by the Gluten Free Watchdog, as a way to back up their arguments that Coeliacs should avoid Gluten Free Cheerios (Figure 27).



Figure 25. Instagram post, with comments referencing the Cheerios recall and Gluten Free WatchDog analysis

Further examples of comments and references to the Gluten Free WatchDog were:

"[customer_name] Per the gluten free watch dog group, they clearly stated "based on the totality of information provided to #gfwd, it is our position at this time that individuals with celiac disease should NOT eat gluten free cheerios."

(Male, unknown age, Twitter, November 2015)

Overall, the clarity of social media posts shared by the Gluten Free WatchDog and the fact that the majority of them contained links to such strong scientific evidence, meant that the social media spread and influence of them was much greater. As a possible (but at that point, undeclared) result of these calls to action by Coeliac-tivists - the FDA soon launched an investigation into Gluten Free Cheerios. And after testing 36 boxes, asked General Mills to launch an urgent product recall. Tweets about this occurrence stated:

"FDA Investigates Complaints Associated with #Cheerios Labeled #GlutenFree: #GeneralMills Recalls https://t.co/****"

(Female, unknown age, Twitter, November 2015)

The link in the post is to an official statement by the USA FDA, which states:

“FDA Investigates Complaints Associated with Cheerios Labeled Gluten Free: General Mills Voluntarily Recalls Affected Lots

What is the problem and what is being done about it?

The U.S. Food and Drug Administration is investigating reports of adverse reactions associated with eating original Cheerios and Honey-Nut Cheerios labelled as gluten-free and working with General Mills to facilitate their voluntary recall of these products. We recognize the importance of this issue to people with celiac disease, wheat allergy, and gluten sensitivity, and we will continue to provide updates and advice as needed.

After learning of these adverse reactions, the FDA tested 36 samples of Cheerios products labelled as gluten-free from different manufacturing facilities and lots. Although most of the samples met the definition for “gluten-free,” one sample of General Mills Honey Nut Cheerios labelled as gluten-free contained 43 parts per million (ppm) of gluten. This exceeds one of the criteria for FDA’s gluten-free definition, that the food contain less than 20 ppm of gluten.

General Mills has voluntarily recalled 13 production lots of Honey Nut Cheerios labelled as gluten-free and 4 production lots of original (yellow box) Cheerios labelled as gluten-free due to the presence of wheat flour (an undeclared allergen). As with all recalls, the FDA will work to ensure the recall is effective and the underlying cause is identified and addressed.”

(Food & Drug Administration, 2015)

Looking at the timeline of posts, and the articles coming out after the recall, it is highly possible that the rallying of evidence from the Coeliac community, and the subsequent lobbying of the FDA led to the FDA investigation of boxes of Gluten Free Cheerios. Later tweets also mentioned that FDA testing also led to a gluten free class action lawsuit by a group of Coeliacs who had become ill after consuming boxes of Cheerios labelled gluten free (Figure 28).



Figure 26. Class Action Lawsuit as a result of FDA action from Coeliac-tivist lobbying

What was also interesting was the degree to which consumers within the Coeliac community deferred to information shared with them by the Gluten Free Watchdog. It seemed that due to her emphasis on giving scientific credibility to her claims, and sharing evidence of how those results influenced decisions made by manufacturers and the FDA, in that consumers tended to trust her information more. As a result of this, they seemed more likely to share her information amongst themselves in social media conversations, and in some cases, direct manufacturers to her information in the hopes of pushing them into swifter action.

Thus, in pushing for better transparency and adherence to purer ways of processing gluten free foods, the Coeliac-tivists have via social media advocacy, added another layer of communications in the whole food recall process. Such communication may be due to the unique relationship that Coeliacs and the gluten free community has with corporate organisations in terms of relying on consumer goods for the treatment of a chronic illness. In this area, it seems perhaps that Coeliac Advocates have arisen in response to what may be deemed as an extra layer of a duty of care to consumers who can be more directly harmed or who may feel they are more at an immediate risk when food allergen laws and protocols are not followed/adhered to.

At the time of writing, 3 months after the recall, and possibly due to the means testing technique used by General Mills, there are still reports of consumers being 'glutened' by Gluten Free Cheerios. This is also being monitored by Coeliac-tivists via Twitter, with a few more examples below:

1) "Original tweet: @[customer_name]: I got glutened by @cheerios yesterday"

(Male, unknown age, Twitter, February 2016)

2) Coeliac-tivist reply: @[customer_name] @cheerios [customer_name], please send your lot no. & "best buy" info to @GFWatchdog so she can report it to the FDA. Thanks! @cheerios".

(Female, unknown age, Twitter, February 2016)

There is also a continuing theme of risk that occurs in posts about Gluten Free Cheerios. At the time of writing (01.05.2016), a Coeliac mother, with a child who is also a Coeliac expressed her concerns:

"Honestly, I am glad Cheerios is trying. But what I don't understand is why can't they use certified oats? It was a debate for a while when they announced they were going #glutenfree. The celiac community voiced their concern over the oats not being certified and Cheerios proceeded with their original idea of sorting out the wheat. If you have #celiac disease you are advised only to eat certified oats. So issue #1. My second issue is, GM is huge, why aren't they engaging a 3rd party independent tester to ensure the sorting has worked and the food is safe. I'm not willing to let my son get glutened over GM's choice to use protocols that may or may not work all the time. The risk is too great. As a community, we need to demand safe options. I have a responsibility to ensure the safety of my kids. It's simple, if there is doubt, leave it out. Don't risk it. [...]"

(Female, unknown age, Facebook Comment, May 2015)

What became apparent is that Coeliacs were acting together as a collective community to challenge manufacturers and organisations on issues of risk via social media platforms. Looking at this data, it seems that these biosocial communities have become useful as sources of activism and information resources, in terms of how they have exercised Foucault's

technologies of self-mediation to disclose, examine and archive (remembrance) information so that they are both scientifically informed and can also use this to challenge the relevant authorities. While only a small number of Coeliac-tivists were studied in this corpus (four in total, across Facebook and Twitter), it is recommended that further study would need to be done regarding their blogging and social media activities over a longer period of time. A series of qualitative face-to-face interviews, or online questionnaires would give us more of an in-depth insight into the motivations of and workings behind such social media advocates.

However, one of the continuing threads that has arisen out of this particular instance of Coeliac social media activism, is a demand that proper methods for testing cross-contamination of gluten grains in oats, are used by manufacturers, and that means-testing of non-pure oats by General Mills of their Cheerios cereal brand meant that there would be a continued chance of boxes that contained above 20ppm getting through the process, and risking Coeliacs' health. At the time of writing, the debate seems to have widened from online to the scientific literature, with the Gluten Free Watchdog reporting a paper (published online ahead of print in August 2016) by different US gluten free cereals manufacturers, PepsiCo Inc. and Quaker Foods and Snacks (Fritz, Chen & Contreras, 2017; Tricia Thompson, 2016c). Here, they added to the debate by publishing a study that found that gluten-containing kernels of wheat, barley or rye may contaminate oats, but are difficult to detect when testing samples of the oats for gluten. This paper seemed to validate the initial misgivings reported via social media by Coeliac advocates in the previous year, who questioned the testing methods for gluten free Cheerios. Following on from this paper, also in August 2016, the Canadian Coeliac Organisation cited customer concern and scientific evidence as one of the reasons why they would not recommend Coeliacs eat gluten free Cheerios that had been given the green light to be sold in Canada (Wraggett, 2016). It is arguable that such a health-warning would not have been quite as strong had it not been for the mobilised online activism of concerned Coeliacs, and the additional Fritz et al (2017) publication — in addition to stronger FDA guidelines issued after the Cheerios gluten free food recall.

Conclusion

The analysis presented in this chapter highlights the importance of providing steps that are clear and simple for consumers to follow in a product recall that relates to food risk and the impact this has on chronically ill patients' self-management of their disease. This was done effectively in the Genius Foods recall, with the company, the Food Standards Agency, the five stakeholder supermarkets and Coeliac UK, all communicating messages to consumers. Despite the initial consumer alarm, and some negative sentiment based around uncertainty and trust of Genius Foods' products – the whole situation was effectively communicated and dealt with within two weeks.

However, the key difference with the Cheerios recall was that - previous negative interaction with knowledgeable Coeliac advocates, and their questioning of its processing practices, meant that the initial confidence, credibility, awareness and understanding of the situation was already held in a negative light. Because of this, and failure by Cheerios to quickly investigate and deal with rumours of glutening spreading via social media, enough time was given to allow more negative sentiment to gather. So, by the time the food recall came about, responses to the messages given in the recall was more negative than positive, and more people engaged an "I told you so" response.

Levels of enactment were indeed quite high in terms of people checking the batch numbers of recall boxes and reporting them. However previous Enactment initiated by Coeliac-tivists who encouraged people who were ill after eating Cheerios before the recall to report to the FDA, meant that Enactment responses had more negative responses, resulting in a class action lawsuit being brought against the company.

The question is though, if it were not for those Coeliac-tivist calls for enactment, would the recall have happened in the first place? Perhaps without this social media galvanisation, less people would have brought the cross-contamination issue to attention, it is difficult to know without further study. What stands out in the Cheerios case, however, is that effective use

of communication, shows that activists may successfully influence the outcome of a regulatory lobbying measure in their favour. Research into the background of the Coeliac-tivists, show that some of them come from a professional nutritionist background (Thompson, Lee & Grace, 2010; Tricia Thompson, 2016a), so this may be a reason why their communications are so organised (if they come from or have trained within an official health model). However, other Coeliac-tivists within the corpus do not seem to have similar backgrounds, and are mainly lay patients, with little or no medical experience. It may be arguable that having access to the official allergen guidelines of regulators, and becoming used to the wording of food product recalls has meant that Coeliacs seem to have become proficient at self-mobilisation and communication with stakeholders.

In terms of risk and social media activism, this chapter has shown how some Coeliacs can act as a biosocial group who organise themselves via Twitter and Facebook to campaign for better food safety procedures from big corporate food producers. This type of activity demonstrates some Coeliacs' ability to act together as a health social movement in the enactment of each of Foucault's 3 stages of self-mediation of models of self-care: Disclosure, Examination and Remembrance (Cammaerts, 2015). By sharing knowledge of both food recall incidents investigated in the case study, Coeliacs were able to: 1) disclose to each other key information to enable them to avoid harm; 2) to examine evidence shared by the manufacturers as to the cause of the mass cross-contamination of gluten free food: and were able to 3) archive evidence of being glutened, as well as any misinformation being shared as a result of the recall.

These type of practices also demonstrate a reconfiguration of expertise in matters of health – where some Coeliacs can act in groups to assimilate expert knowledge both as a) individuals who have researched the ins and outs of levels of cross-contamination that affect Coeliacs, and as b) biocitizens who have embodied experience of the symptoms of cross-contamination. These type of online practices also bring notions of patient 'expertise' to the foreground – especially in the adoption of specific scientific techniques to argue the case for better food safety practices. This was shown by a specific Coeliac advocate, the "Gluten Free Watchdog",

who resorted to proving her case, by utilising similar scientific allergen tests used by authorities via an independent laboratory. This enabled her to argue that her and others' claims of cross-contamination could also be backed up by scientific data and thus be taken more seriously. In one such post, she writes about how gluten free samples are tested, so that the evidence can be used to lobby manufacturers/authorities about cross-contamination issues:

“Samples are tested in duplicate using the standard sandwich R5 ELISA (R7001 Ridascreen Gliadin) and extracted with the cocktail solution (Art. No. R7006, official R5 Mendez method). [...This is because...] ...the R5 ELISA is included in the FDA's Question and Answer page on the gluten-free labelling rule as one of the methods the agency will use for rule enforcement if testing a product becomes necessary...”

(Tricia Thompson, 2016b)

One further example of this, is a slogan on the Gluten Free Watchdog's website, which reads: “Data you need to eat: confidently, safely, freely, smartly” (2016b). This heavier reliance on data, and the sharing of scientific-based knowledge via social media, demonstrates the emergence of a new type of evidence-based online activism where some Coeliac advocates are reconfiguring what it means to be an 'expert', and indeed what evidence is utilised when lobbying for change.

In this way, Coeliacs are able to organise as a collective and biosocial group, whose actions were empowered by protecting the health of those with their specific disease. In so doing, they managed to engage with corporations and government allergen authorities to make sure that their voice was heard, and that action taken in rectifying the problem behind the cross-contamination in the food recall, was taken with specific regard of their autoimmune disease. These online and social media actions seem to have then had a longer lasting effect, a year later, when in August 2016, gluten free Cheerios were introduced to Canada. At this point, the official Canadian Coeliac Organisation released a public direction to Canadian Coeliacs:

“The Canadian Celiac Association (CCA) recommends that people with celiac disease or gluten sensitivity DO NOT consume the gluten-free labelled Cheerios products at this time because of concerns about the potential levels of gluten in boxes of these cereals. The CCA is receptive to evaluating any additional information that General Mills is willing to disclose.”

(Wraggett, 2016).

This message was shared by Coeliacs across US and Canadian social media networks, with some arguing that it was in part, in response to the reporting of sickness incidents that occurred, as well as the discussion of scientific findings found by both activists and the FDA:

“Personal opinion: not Celiac safe. We had adverse reaction.

“Concerns raised in Canada over gluten-free Cheerios” (Twitter, August 2016) and “Gluten-free Cheerios? NOT recommended by the CCA [inc. URL to blog post]” (Twitter, August 2016). In the linked post commentary on the CCA statement remarks that: “[...] The Gluten-Free Watchdog and other sensible leaders in our community are also on board with this stance[...].“

(GlutenDude.com, 2016)

This chapter thus demonstrates that especially in the Gluten Free Cheerios recall incident, some Coeliacs are actively using mobile tools and social media to bring a new meaning to Foucault’s notion of ‘technologies of the self’, and his 3 stoic principles of self-mediation (1. Disclosure of the self, 2. Reflexive examination of the self, and 3. Remembrance of the self or deeds pertaining to the self (1997)). By mobilising as a community, Coeliacs were able to utilise already existing practices of self-disclosure of symptoms, and reflexive examination of gluten free food consumption, to collect relevant data that they could archive, map and assemble to lobby the relevant food allergens and food standards agencies to further investigate food supplier practices.

The study has shown that their concerned social media response to gluten free food recalls indicates an insistence on the need clear and simple

consumer guidelines in these recall incidents. The level of attention paid to detail and the amount of evidence of symptoms collected and shared between many Coeliacs on social media during these periods, shows that they take the responsibility and self 'governmentality' of care very seriously. This demonstrates that some Coeliacs have actively used technology to reconfigure what it means to be an expert patient in matters of health and illness, and the management of chronic illness in particular.

Chapter 6: Coeliacs, Social Media and Gamification

This chapter provides an illustrative example of how the gamification of social media analysis and patient knowledge with regards to the symptoms of CD can be used to create an app that visualises the concept of CD. I deal with Pols' (2013a) discussion about how we can make use of patient knowledge relating to how they manage their chronic symptoms, and utilise that knowledge to help new and continuing patients with Coeliac Disease. I argue that a study of these Big Social Data practices can reveal to us basic patterns of self-care, that can in themselves be re-imagined as patient knowledge to further help other patients/individuals. I also consider examples where the gamification of health knowledge has helped younger and continuing patients (Khaled, 2014; Hamari, Koivisto & Sarsa, 2014; Phillips, 2016). Finally, I discuss how once such knowledge is visualised and turned into a games-based learning app to help Coeliac patients learn how to practice basic levels of self-care and independence post-diagnosis, it can also be recognised by other social science and medical researchers as contributing to both the social science and gastroenterology literature.

Turning User Data on Social Media into Gamified Learning Tools

So far in this thesis, research has begun to explore how Coeliacs are using social media, and how they keep visual and status diaries of their practical experience. These individuals are also building knowledge of managing their gluten free diet, from going through the process of diagnosis, learning how to adapt to the gluten free diet, and sharing experiences of the symptoms from being accidentally glutened. Building on the data from Chapter 4, where I look at how Coeliacs expressed different levels of self-care and identity in their pursuit of managing the GFD post diagnosis. Here I explore the concept of using game-based visualisations to relate the care of CD to Coeliacs and others interested in playing health-themed games.

Gluten Fighters

I developed the Gluten Fighters game (Martin, 2014c) which is based on the simple games-based principles seen in the literature review. I wanted to see if I could use a fantasy game as a way to illustrate how basic gaming principles like a fantasy world, and role-model character based on a superhero, could help to visualise the practices of the GFD in a way that Coeliacs could engage with (Lieberman, 1997:chap.6). The story in the game focuses on a character called 'Coeliac Sam' and her other Coeliac friends who 'fight' back against chefs who had promised them that their restaurant food was gluten free and not cross-contaminated, but had instead served them food that had been glutened and made them ill anyway. This game story was an attempt to visualise the scenarios that I had come across in my data from Chapters 4 and 5 in this thesis, where Coeliacs had tweeted or posted on social media about being glutened while eating out, despite being assured that their food was 'coeliac safe', and prepared separately. To reflect the frustration felt by Coeliacs, I created a game scenario of what would happen if the Coeliacs in question could take matters into their own hands and 'bat' the glutened food back at the chefs who had promised them it was safe for them to eat. This scenario would turn into a rather gentle, but still empathic 'fight', where the angry superheroes batted back glutened muffins towards the chefs in question.

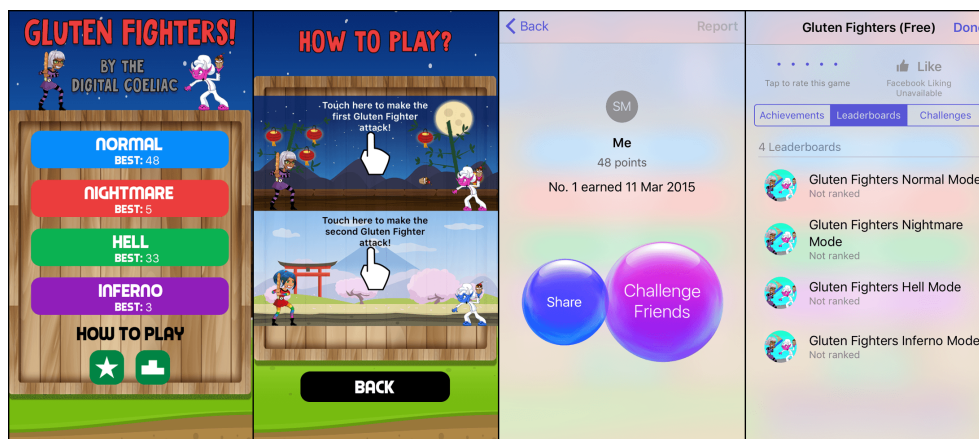


Figure 27. Gluten Fighters game and achievement interface

My initial thoughts for designing the character were that Coeliac Sam would be of the pre-teen age group, with general superhero qualities like a cape, and edgy outfit, and that their ethnicity would also reflective of the diversity of people worldwide who are diagnosed with Coeliac Disease. Therefore, the ethnicity of Coeliac Sam is a bi-racial girl of indeterminate race, with green eyes, and with purple hair to match her superhero outfit. This was also based on observations in the literature of calls in recent years for strategies to be developed to help more South Asian and North Indian Coeliac patients in the UK to adhere strictly to the gluten-free diet, where uptake of the Gluten Free Diet is quite low (Holmes & Moor, 2012).

To widen the demographic of who played the game, I also chose to make the character a girl. This reflects analysis of an increase of 35% of girls and women who are playing games on their smartphones (35%) (Rubin, 2007). This also mirrors the increased inclusion of diverse female superheroes like Wonder Woman and Bat Woman in comics and in today's market (this is in comparison to the mainly young male audience catered for in the past) (Rubin, 2007).

I finally settled on designing the character of 'Coeliac Sam', a pre-teen girl with brown skin, glasses and a cape, whose main role is to go through a fictional world, searching for gluten free food labeled with the official gluten free cross-grain label used by Coeliac UK and other Coeliac organisations around the world. The name "Coeliac Sam" was also chosen to connect to

my personal experience of living with Coeliac Disease (see Introduction, Chapter 1). Portraying *Coeliac Sam* as a super heroine was seen as an effective way to potentially portray the positive self-management of Coeliac Disease to Coeliacs. It was hoped that such a perspective would help some Coeliacs perceive themselves as the superheroes of their own guts and immune systems, and that playing such a character would help them feel a little bit better about being proactive in self-care.

Within *Gluten Fighters*, I created 4 levels in the game, that were themed on Dante's levels of hell (again a reference to the hashtag #glutenhell used by Coeliacs who had accidentally been glutened). Each level of the game becomes harder, with the hardest level meaning that the game player needs to help 4 different superheroes bat back glutened food to four different chefs (e.g. the equivalent of eating out 4 times a day at 4 different food venues, and being glutened at each one). I also utilised classic gaming features like instant feedback, leadership boards, achievement levels discussed by Munson et al. (2014:pp.601–605), with the ability for players to repeat each level of the game and get better with each try, so that by reaching different achievement levels, they would feel more positive about advocating for their own gluten free diets.

Gluten Fighters was launched in August 2014. However, despite marketing it via Twitter, Facebook, blog posts and Instagram, the amount of downloads for the game was small, and the overall impact was very small, with just 100 downloads between 2014 and 2017. While thinking about why users did not seem to be inspired by the game, I went back to Munson et al. and Lieberman's discussions of using gamification features to promote health-changing behaviour (see the Literature Review for this thesis, Chapter 2). Upon a closer reading, I realised that a key factor that I may have missed was giving potential game players the ability to empathise with a game character at a level that allowed them to go through the basic stages of searching for gluten free food for their diets, and seeing how the symptoms of being accidentally glutened actually affected the superhero they were playing. Going back to Lieberman, I realised that *Gluten Fighters* did not allow Coeliacs to properly empathise with the characters in the game in terms of:

“video games [should] represent appealing role-model characters, [and] ***provide scenarios that involve making health decisions and carrying out self-care skills, and epic realistic consequences in response to players’ decisions and actions***”

(Lieberman, 1997:chap.6)”. (emphasis mine).

In an aim to bring about a more empathetic game, where Coeliacs better identified with the everyday actions of the characters, I returned to my data with regards the experiences of symptoms and selfhood shared by Coeliacs on social media, and crafted a second game featuring Coeliac Sam, that brought out the practising of these health decisions and self-care skills, and the consequences of being glutened in a more pronounced way. By keeping Coeliac Sam a superhero of her gut, but making the game more interactive, it was hoped to empower Coeliacs and younger children into feeling they could have a positive role of being ultimately responsible for looking after their own gut health.

Coeliac Sam: Learning Basic Gluten Free Diet Concepts with Games

The creation of the second gaming app, and thus the new ‘Coeliac Sam’ game (Martin, 2014b) was to see how I could further utilise the initial results of the social network analysis of how Coeliacs shared patterns of self-care, but this time visualise the concept of searching for food to manage the GFD in a more interactive way. In this way, I brought active pursuit of the GFD into the foreground, while keeping game interface components like health points and leaderboards within the background of game. The creation of Coeliac Sam that focused more on actions of self-care was also an experimental exercise in seeing if a games character could be re-imagined with the task of engaging in Foucauldian acts of self-care, self-government and responsibility for chronic illnesses like Coeliac Disease.

As noted already, in terms of acts of the self-care of illness, Foucault argues that individuals in society moderate or self-govern themselves as subjects of consumerism through what he labels the practices or technologies of the self (Foucault, 1988). For Coeliacs, the need to access

and buy gluten free food so that they can manage their life-long gluten free diet, means that their roles as consumers, and their reliance on external sources for this food is at the forefront of their practice of self-care. By creating a games character, whose sole aim is to find safe gluten free food to self-manage her health, it was hoped to re-imagine this Foucauldian concept of self-care, and responsibility for the ill self.

By giving the character the identity of someone with Coeliac Disease, I also aimed to visualise Gibbons and Rose's concept of Biosocial Citizenship (2007). In terms of being a 'Biosocial Citizen', by her name alone, "Coeliac Sam" can be identified as belong to the biological group of people with Coeliac Disease. Her attempts at trying to stay healthy by finding safe gluten free food in a world where the majority of food has gluten in it, also makes her a part of the social and cultural experience of Coeliacs experiencing the same issues.

Within the game, as *Coeliac Sam* goes around collecting gluten free muffins, she also collects 'health points' as her gut grows stronger (Figure 31). The adversaries that make up the world of superheroes are here in the form of 'monster' cupcakes and pizza slices that are filled with gluten, and have small teeth that gnaw away at the Coeliac small intestine/gut when Coeliac Sam comes into contact with them. My design of these adversaries was based on Coeliacs tweets discussing how they managed the biographical disruption that they experienced when first having to go on the GFD after a lifetime of eating gluten and wheat, and how they coped with being tempted by gluten-filled cakes and pizza when hungry, and calling them ' #glutenmonsters' that would cause them pain (Figure 30). This expression of reimagining the food that they once loved as monsters that would harm their health, was a reflection of previous qualitative studies in the literature that questioned how newly diagnosed Coeliacs coped after diagnosis, and got a similar response (Rose & Howard, 2014a; Hobday, Law & Howard, 2015). I aimed to answer my research question by using games mechanics and the visualisation of quantitative data to express these findings, and disseminate them to see if Coeliacs or those interested in gut-related diseases would engage with this mode of gamification.

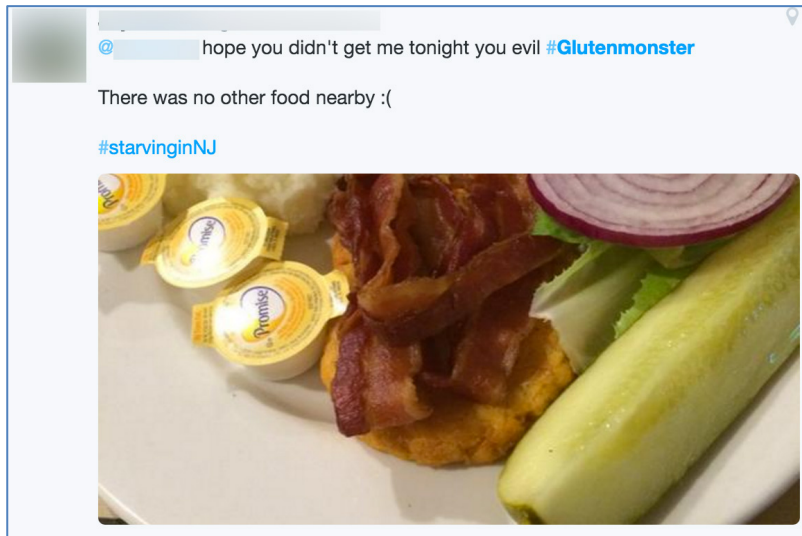


Figure 28. 'Gluten Monsters' (#Glutenmonster) mentioned in Coeliac Twitter corpus



Figure 29. Coeliac Sam app: Gameplay

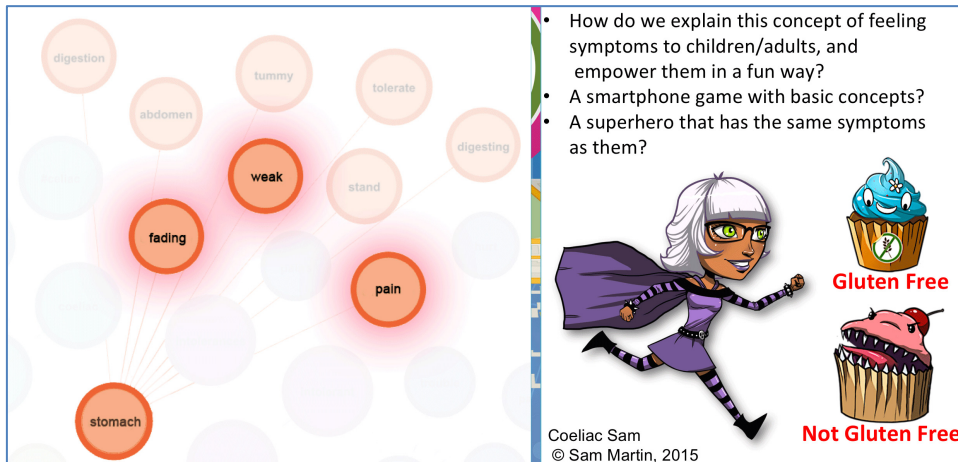


Figure 30. Hashtag analysis of Coeliac Symptoms

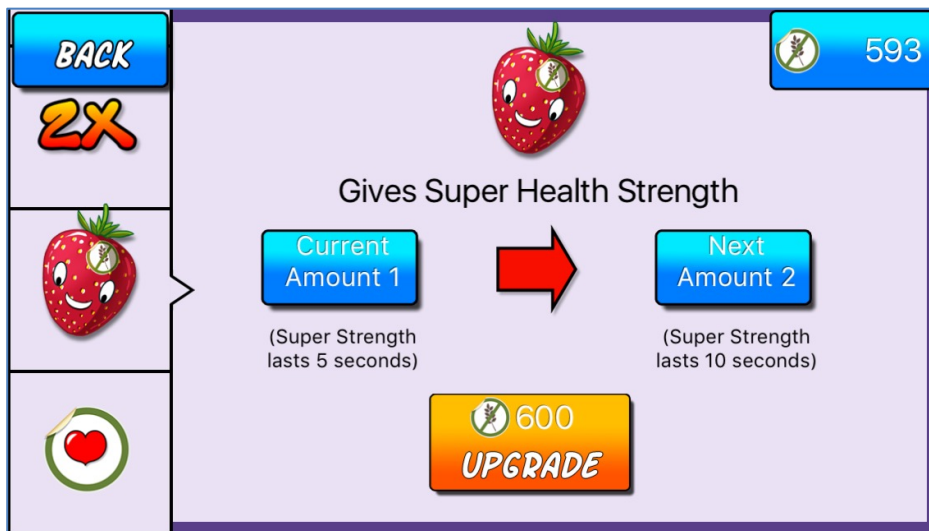


Figure 31. Coeliac Sam: Super Fruit power-ups: remedies for being glutened



Figure 32. Coeliac Sam: Game Over - 'Glutened'

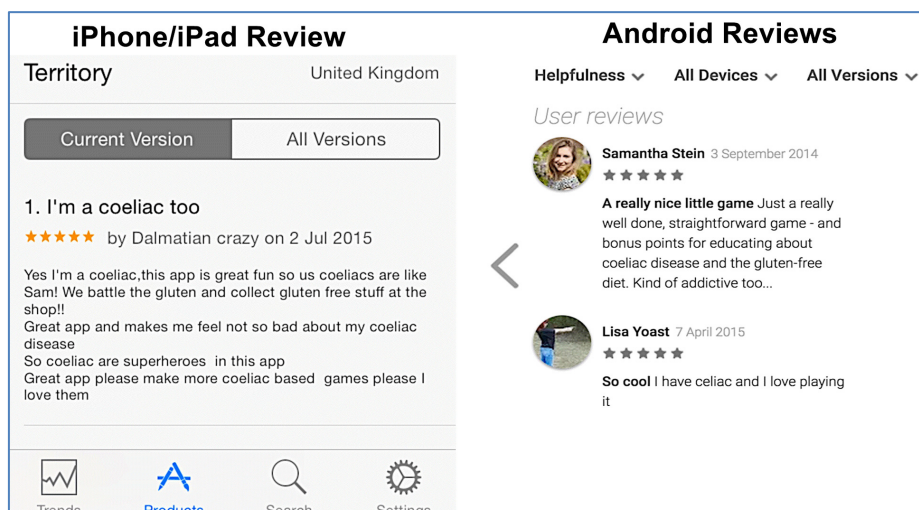


Figure 33. Coeliac Sam Review/Feedback

Drawing on social network analysis from the Twitter corpus evaluated in Chapter 4, I visualised how Coeliac Sam would experience the symptoms of being glutened. Here, I looked at the top 10 words that Coeliacs used to describe how they felt when glutened, these were mainly words to describe fatigue and a lack of energy. In this regard, I programmed animation into the game, so that whenever Coeliac Sam touches a gluten-filled pizza or muffin, she seems to visually fade away and flash in and out of focus on the screen until she touches a resource that helps her gain back her strength (Figure 34).

In terms of recovering from being glutened, I again drew on analysis from my Twitter and Instagram corpus, where several users (55% of 40,000 Instagram posts, and 65% of 75% Tweets in between May 2013 – 2014), reported resorting to healthy fruit and smoothie remedies, and fruit flavoured yoghurts that contained probiotics to help their guts heal after being glutened. To reflect this, I introduced 'super fruit power-ups' in the form of 'super strawberries' into the game, so that any time Coeliac Sam's energy becomes low after being glutened, these 'super strawberries' give her some extra time to heal (Figure 33).

Each time Coeliac Sam digests too much gluten she 'crashes', and the 'game over' screen pops up, giving the user a run-down of the number of 'health points' and gluten free food she's accumulated. It also gives a continuous count of the highest score the player achieves throughout the life of the game as it exists on the user's phone. This was a subtle way of

keeping a continuous count of progress made in Coeliac Sam's gluten free diet, which is as continuous as the life-long gluten free diet followed by Coeliacs (Figure 34). The decision was made to briefly explain the thinking behind these visualisations and animations in the game in the description of the app in the App stores upon release, so that users would understand that the game was aimed at younger users with Coeliac Disease. This was mainly because I wanted to see if users gave feedback that showed they understood the premise of the game, and hopefully that they would share if playing it helped them feel more proactive or empowered about managing their chronic disease.

To this end, Coeliac Sam was launched as a free app game in the Health & Lifestyle and Food & Drink categories on the Apple and Google Play and Amazon Play stores for both iOS and Android smartphones in 2014 was launched as a free app game in August 2014, with just over 2000 installs across both iOS and Android phones (between 2014 and 2017). In just over a year, feedback from users showed that they found some positives from playing the game. Although there were no overall negative reviews, this may be because users had not felt inclined to write or send a negative review. Overall ratings of the game across iOS and Android platforms, however, were between 4 and 5 out of 5 stars. One such review was from a British user (reviews are itemised by region in app store analytics), who seemed to immediately identify with the character of Coeliac Sam, and communicated how it felt her feel more positive about her Coeliac Disease (Figure 35). In her review she says: "Yes I'm a coeliac, this app is great fun so us coeliacs [sic] are like Sam! We battle the gluten and collect gluten free stuff at the shop!! Great app and makes me feel not so bad about my coeliac disease So coeliac are superheroes in this app Great app please make more coeliac based games please I love them". This review shows that Coeliac Sam seems to have been accepted as a Coeliac, as a game-based projection of biosocial citizenship, where her trials and struggles and health point goals are a reflection of those of the players that engage in the game. This was also reflected in reviews on Google Play and Amazon Play stores, where users gave feedback with regard to their view of it as an educational tool about Coeliac Disease and managing the prescribed gluten free lifestyle. As a result of one of these reviews, by a Coeliac who

also blogged about her experience of living with Coeliac Disease, I was also asked to give a short interview for her blog, where she asked me several questions about the research behind the app, and how I hoped people would use the app (Samantha Stein, 2014).

While this was a positive result for an explorative study into gamifying and visualising the concept of the self-care of Coeliac Disease, it was still uncertain what real impact this had on the social science or medical literature in terms of the effectiveness of app solutions in terms of addressing sociological and health problems. Both the Gluten Fighters and the Coeliac Sam app remained in the wilds of the Apple and Google Play app stores, until July 2017, when a commissioning editor for The Lancet contacted me to ask for details to review both apps for the Gastroenterology supplement for their August edition (Zajanckauskaite, 2017). This was a simple review of apps that not only quantified the management of gastroenterological problems, but also visualised these issues in an educational or gamified way.

What was helpful about this short Lancet review was that it looks at the effectiveness of my use of both types of gamification models to visualise the self-care of CD. With Gluten Fighters, it looks at the simple use of game mechanics in terms of instant feedback from the characters in the game knocking back glutened objects at each other. It also recognises that while this is an entertaining way to visualise self-care of CD, it is less interactive and less educational in comparison to how the second Coeliac Sam game gives players a way to learn and understand what it means to have CD and to self-care for the GFD. Zajanckauskaite notes:

“Gluten Fighters is a health-themed educational game app, designed to teach children the basics of coeliac disease. In this prototype app, Coeliac Sam and her friends fight against demon chefs who throw gluten-filled muffins at them. The aim of the game is to stay healthy by knocking the muffins back. Whilst entertaining, and even addictive, the original app is no match for its offshoot version Coeliac Sam, which offers a much better understanding of what it means to have coeliac disease. In the later version of the game the player is taught to avoid food with gluten, as well as how

to identify gluten-free food, something that the Gluten Fighters lacks. Coeliac Sam gets stronger and healthier when she collects gluten-free food, which has the cross grain label on it, and loses strength when she makes contact with gluten-filled products such as pizza and muffins, which aren't labelled gluten free. Although it's fun and of course well intentioned, Gluten Fighters is clearly just a stepping stone to Coeliac Sam. ”

(Zajanckauskaite, 2017).

This review pulls to the forefront, Lieberman's argument that having characters of games engage in health-related activities helps to bring a better emphasis on, and engage players in practising more positive levels of self-care (Lieberman, 1997).

Conclusion

This chapter has shown that with the deployment and uptake and feedback of the Coeliac Sam game, that games of this kind could be useful in terms of visualising the concept of self-care of CD and the gluten free diet. However, the basic games mechanics of Coeliac Sam has meant that it was not possible to conduct a more thorough investigation into whether playing a game like Coeliac Sam could have any positive and long-term behavioural changes into attitudes of adherence to the gluten free diet. It is proposed that a future study would involve a control group of different age groups, who are both Coeliacs and non-Coeliacs, who would play the game and then report back their thoughts on the game character's adventures, and how this makes them think about experiences with Coeliac Disease. Due to time, budget and programming constraints, the app was designed as an endless platform game. This means that the Apple, iOS version, only has 3 levels that run continuously (while the Android version has one continuous level). The app also does not have the added challenges of having Coeliac Sam search for different kinds of foods in different environments, or the experience of facing different adversaries in the form different food types or social situations.

Looking at the initial customer feedback from the Apple, Google Play and Amazon app stores, and the Lancet review it seems that to some degree

my experiment with the initial prototypes of the Gluten Fighters and Coeliac Sam apps seems to have worked to: 1) Enable more positive perceptions about the costs and benefits of adherence to the gluten free diet (the new behaviour), in relation to the reduction of painful symptoms and improvement of overall health, and 2) To help individual and social perceptions of cost and benefits of a change in behaviour or adoption of the gluten free diet, and gradually help alleviate food-related psycho-social stress for young people Coeliacs (Howard, Law & Petty, 2011; Rose & Howard, 2014b). The brief Lancet review also seems to have answered my initial questions about the need to use a more interactive and engaging format to illustrate practices of self-care, especially in terms of “carrying out self-care skills, and epic realistic consequences in response to players’ decisions and actions” (Lieberman, 1997).

What this chapter contributes to the emerging literature of gamification and health, is an exploration of the question of what we as social scientists can do with our analyses of the self-care of chronic illness via social media. As discussed in the Literature Review to this thesis (Chapter 4), Pols argues: “How can we articulate the knowledge that patients develop and use in their daily lives (patient knowledge) and make it transferable and useful to others?” (2013a:p.73). I have tried to answer this by visualising the analysis of the big social data practices of Coeliacs, and by reformulating them into gaming tools that may help new and continuing patients visualise and engage with acts of self-care in new and virtual ways. By extracting the patterns and co-occurrences found in the communication of patients in social media data, I have been able to turn social science enquiry into a format that articulates patient knowledge using games-based mechanics and interactive self-care practices.

Future plans for expanding this type of game include the introduction of different dynamic characters and levels for the user, as well as more diverse challenges to teach younger players about handling different real-world situations. While Coeliac Sam has not been able to give a more thorough insight into the behavioural effect of games on adherence to the gluten free diet in the first instance, it is arguably a good example of what can be done in terms of gamification of social media research results.

In terms of using games based learning tools to help support Coeliacs' adherence to the prescribed life-long gluten free diet — I suggest that there is a need to reflect on critical design and adoption considerations when deciding whether a game is an appropriate method for creating, displaying or organising health information. There is great potential to utilise this data via e-Health toolkits and apps for improving digital health-based resources, and education of individuals about chronic disease. Interactive, character-based games like Coeliac Sam can be developed further into quite versatile formats, especially in terms of interactive and illustrated books for the touch screen capabilities of the iPad and the Kindle, as well as some more learning-based apps that perhaps teach users how to manage and monitor other illnesses, such as diabetes and other autoimmune diseases.

Chapter 7: Visualising CD and Comorbidity on Social Media

In this chapter I build on the exploration of symptoms in Chapter 4 and the gamification of CD in Chapter 6, to create a digital research tool that would enable social scientists to explore the potential of social media data to study the embodied, visual and daily experience of those with CD and comorbid illnesses. In so doing, I reimagine this aspect of health-based social research in a way that gives a visual insight into how people self-manage Coeliac and comorbid chronic disease(s) in particular. In many ways this is an example of a 'live method', as Back and Puwar call it (2012).

When building this tool in the form of a smartphone app - these live methods entailed the use of the call-and-response technique discussed in the Methods section of this thesis (Puwar & Sharma, 2012). This consisted of a social media collaboration with users of the app, getting them to identify parts of the app they felt needed to include more information that would represent their comorbid illness(es). The result was an m-Health smartphone app called the Spoonie Living app (Martin, 2015), which can be used by Coeliacs and those with comorbid illnesses to visualise their symptoms. The smartphone app acts as a photo editing tool, that uses gamification principles to prompt Coeliacs to visualise their symptoms and comorbid illnesses, with the aim of getting them to visually tag their experiences and share them via social media platforms like Instagram and Twitter. The app is designed to allow Coeliacs to add a sticker overlay to their everyday photos, that express the hidden symptoms they are experiencing, expresses their biosocial identity as a Coeliac, or their co-identity with other comorbid diseases. The 'stickers' in question act like virtual badges that are added over the top of photographs, so expressions or warning signs like "Glutened!" "Caution! Symptoms in Progress" or "Caution Brain Fog in Progress" can be placed over the top of a normal photograph or image, and then shared to a social network (Figure 36).

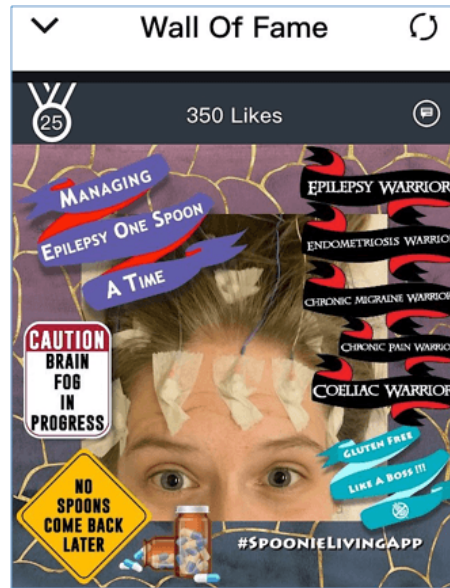


Figure 34. Spoonie Living app Stickers: Symptoms + identities of CD + comorbidity

The Spoonie Living app can also be used by social science researchers to conduct small visualisation studies on participants with health or social issues, as a way of using context-relevant meta-tagging to express their symptoms/issues. By context-relevant meta-tagging I mean how social media users use contextual hashtags and keywords to tag their posts and images, which may in turn be found by other users searching for posts that contain those keywords (Zappavigna, 2014). Context-relevant meta-tagging has also been used to define 'ambient affiliation', or in other words different types of social media communities that interact around specific affiliated hashtags, keywords or topics (Zappavigna, 2011).

Thus, the Spoonie Living app has been developed with a simple design, which means that, if it was to be used in a different research project, then its chronic illness stickers can be swapped with images that represent a more specific group of people or patient activities (other than those with CD). For example, the visual stickers in the app could be redrawn to be used in a visual diary for asthma sufferers, or alternatively for a study visualising the self-reported activities of heart transplant patients. Overall, the Spoonie Living app was built as a tool that could be easily used by both patients and researchers in a way that acts as a digital and visual bridge between the contextually chronic agential snippets that are created via

patients/users' smartphones and the social media/communication platforms they already use to share their daily self-care with.

The term 'Spoonie' originated from a post written by Christine Miserandino entitled "The Spoon Theory" (Miserandino, 2003), where she used the concept of spoons to explain how an individual suffering from the symptoms of a chronic illness hypothetically measures their ability to carry out daily tasks by counting "spoons" of energy (or lack of energy) levels. Spoons represent the emotional and physical energy of someone managing the embodied effects of a chronic illness. Each day is started with a fixed number of spoons, and every action (however 'normal' it may seem to someone without a chronic illness), uses some of those spoons of energy up. The more demanding the task, the more spoons it requires.

Thus the terms "running low on spoons" or "straight out of spoons", are used on social media when someone with a chronic illness is indicating that they are feeling unwell and running low on energy due to the symptoms of their chronic illness, e.g. stomach pains, fatigue and aching joints due to being glutened, dizziness, nausea, chronic pain or other challenges (Miserandino, 2003). One "spoon" represents the energy needed for the 'morning routine' of getting out of bed, getting dressed and having a shower, and later - to shopping, working, cleaning, and then eventually running out of energy (or spoons!).

Since that original blog post, the term "spoonie" and the hashtag "#spoonie" have been used by chronically ill individuals on sites like Instagram over 600,000 times (Instagram.com, 2016) and Twitter over 712,000 times (Symplur.com, 2016) to connect with other people living with chronic illnesses. Using the concept of 'spoons' as a measurement of the dips in energy levels experienced with the symptoms of chronic disease, the term "Spoonie" and variations of it have been used in various forms to share the embodied experience of living with long-term illness. Such symptoms can include stomach pains, fatigue and aching joints due to being glutened, dizziness, nausea, chronic pain or other challenges (Miserandino, 2003). Figure 37 shows a photograph summarizing each of the mundane tasks that a spoon would represent. Here, one spoon

represents the energy needed for the 'morning routine' of getting out of bed, getting dressed and having a shower, and later - to shopping, working, cleaning, and then eventually running out of energy (or spoons!).



Figure 35. The mundane tasks that a spoon of energy might represent.
(Kathleen Hoffman, 2014)

One explanation as to why the term 'Spoonie' seems to co-occur in the social media posts discussing CD (2013-2016), is that CD has itself often been classed as a 'hidden disease' where others cannot see the physical and thus visible symptoms of (Rose & Howard, 2014b). The 'hidden' nature of CD has also been discussed in studies that have reported the frustration of Coeliacs who are at times not believed when they tell others that they have a long-term chronic illness that others cannot visibly see. In these cases social anxiety and stigma can be experienced, where they are labeled as 'fussy eaters' (Dovey *et al.*, 2008; Tharner *et al.*, 2014), or as following a 'fad diet', when in fact ingesting gluten is physiologically harmful (Schroeder & Mowen, 2014).

Another reason why many Coeliacs may feel more affiliation with the #spoonie hashtag, is due to the symptoms of being glutened in some cases overlapping with the symptoms of other chronic illnesses, like Crohns disease, IBS (Irritable Bowel Syndrome, a disorder affecting the large intestine with symptoms of cramping, abdominal pain, bloating, gas, diarrhea and constipation) or Fibromyalgia (a condition characterized by chronic widespread pain, and fatigue, as well as including gastrointestinal

problems). In terms of Coeliacs who also deal with the symptoms of an additional or comorbid chronic disease, they may feel more of an affiliation with the #spoonie hashtag, as they are not defined by one disease, but instead have found a way to talk about their comorbid symptoms under one umbrella term. This overlapping of symptoms has also been recognized in the literature as one of the reasons why it can take much longer to get the correct diagnosis of CD due to the cross-over of symptoms with other chronic illnesses (Tonutti & Bizzaro, 2014; Dixit *et al.*, 2014).

A comparative study of the symptoms of fibromyalgia patients with the symptoms of CD, also found that (outside of gastrointestinal issues) symptoms such as a higher incidence of fatigue, depression, memory loss and gluten sensitivity, are symptoms that coexist/overlap to a great extent (García-Leiva *et al.*, 2015). Other factors that influenced the study's focus on Coeliacs who self-cared for more than one illness, was a study by Fox and Duggan, which found that individuals with more than one chronic illness were more likely to share their own personal health experiences online (11%), versus those with one chronic illness (9%) (2013). These figures show that people are more likely to share the increased burden of symptoms with their peers, when self-caring for more than one symptom, with 8 in 10 saying that they were hoping to reach a general audience of peers and other internet users, compared with just 1 in 10 who said they hoped to get feedback from a health professional (Fox & Duggan, 2013).

As discussed in the Literature Review (Chapter 2), the research into the genetic susceptibility of Coeliacs to other chronic illnesses, has found that those diagnosed with CD in the third decade are more likely to have other autoimmune diseases, or comorbidity (Fasano, 2006). The literature shows that 1 in 8 people are more likely to have another chronic illness alongside CD, with some direct genetic factors linking CD with diseases such as Diabetes and Crohns Disease (Mazzarella *et al.*, 2008; Hermann *et al.*, 2003).

The thinking and framework behind the Spoonie Living app stems from the extensive literature and practice of visual methods, and its more recent application to social media practices and the visualisation of chronic illness

(Yi-Frazier *et al.*, 2015). This illustrative exploration will also add to the emerging literature by addressing Ziebland and Wyke's argument, that images should be studied beyond being a design issue in terms of representing illness, and should be studied within the context of how patients visualise and sometimes share the critical moments their chronic self-care over the internet (2012:p.237). It is hoped that a study into how a digital tool like the Spoonie Living app is used by people with chronic diseases like CD and comorbid illnesses will give us further insight into how individuals visualise self-care via social media.

Visualising CD

While analysis of the literature has found a recent study of how sampled individuals with Type 1 Diabetes share images of the disease via Instagram (Yi-Frazier *et al.*, 2015), there is currently no research that investigates how Coeliac sufferers with comorbid disease(s) share and visualise the experience and self-care of this. Chapters 4 and 5 of this thesis have already shown that images have been a continued presence in the Twitter and Instagram datasets collected. What this current chapter will add to the social sciences literature, is an exploration of how such images are used to specifically visualise the embodied experience of symptoms in relation to CD and other comorbid illnesses.

Gamifying the Mundane: Coeliacs and the Gluten free Diet

Within the context of the self-care of Chronic Illness, the tasks of taking medicine, living with symptoms, or indeed trying to keep to a restrictive diet, can be solitary ones (Weiner and Will, 2015). It is here that the gamification of existing platforms can involve sharing experiences virtually rather than with people who are present in physical time and location. The definition of Gamification can be in two senses. One, the use of games mechanics and principles to setup an activity or practice as a game that can act to change behaviour (Munson *et al.*, 2014). Or two, the more general term of turning a mundane practice into something enjoyable, that represents a game in the physical or virtual sense (Weiner & Will, 2015). Wiener and Will discuss this

second form of gamification in relation to patients turning the use of blood pressure measurement devices into a game, so that they can cope with the potential anxieties of measuring high blood pressure (2015). While Chapter 6 of this thesis also shows how general gaming formats, and the utilisation of fantasy role-models inside games with a health-based focus, like the games Coeliac Sam and Gluten Fighters, that I have developed, can go some way to helping Coeliacs engage in more positive and imaginative patterns of self-care.

Analysis of the data collected in the Instagram and Twitter corpora for this thesis has also shown that many Coeliacs express their self-care by making activities such as finding and making gluten free meals into creative photo diaries, and turning the construction of hashtags into games. The following examples will show how some Coeliacs have turned the mundanity of the self-management of their disease into a format that affords them creative and perhaps therapeutic ways to manage and share new and accumulated knowledge.

One example of how Coeliacs have used creative practices to gamify the general adoption of the gluten free diet can be found in Figure 38. The term “gamify” is used here in the looser definition of gamification, described by Weiner and Will to also mean the turning of the mundane into a game-like or fun activity - with either health or educational benefits (2015). Here the experience of enjoyment or fun, or “gamifying” is used as a self-help tool to help people engage with data, make behavioural changes, or gain understanding. (Weiner & Will, 2015). The image in Figure 38 shows examples of Coeliacs creating photo diaries of gluten free food, where they have artistically arranged food into magazine-style configurations, and used both colour and perspective to construct stylish narratives of their daily gluten free food intake on Instagram. A second example of gamification from within the project’s Instagram corpus, is of meme image poetry, where users overlay images with poems or words that express their experience of symptoms of chronic disease. Figure 39 shows a poem written by a Coeliac about her experience of the symptoms of being glutened, and her attempts at using different remedies (i.e. ginger tea, peppermint tea, and multivitamins) to try alleviating them.

A third example of the gamification of self-care was found in my Twitter corpus in early 2015, when the film *50 Shades of Grey* (based on the popular series of novels, (James, 2011) was released too much media attention and popular critique. At the time, discussion about the film was trending across social networks, and in keeping with this the Coeliacs within the UK network I was monitoring decided to hold a competition around a community-based hashtag they created. This hashtag (#50shadesofCoeliac) was created as a way to parody their sometimes-frustrating experiences of trying to manage the gluten free diet. The hashtag was shared almost 150 times, and Figure 40 shows how Coeliacs used the hashtag #50shadesofCoeliac to create humorous and clever word-play and sexual innuendo to parody the trials, tribulations and mundanity of finding safe gluten free food as a Coeliac eating out.

If we look at this from within the context of gamifying the daily preparation of food via creative photography, image poetry or the sharing of hashtag challenges, then the very act of making a game out of hashtags, or being creative with the way that the consumption of gluten free food is shared, may gradually arguably alter the perception of the individual of being able to cope with the daily adherence to the gluten free diet. Within the context of gamifying practices, Perruzza and Kinsella have also noted that engaging in creative arts may have important value to the chronically ill, in terms of giving them a feeling of perceived enhanced control, allowing them to build a sense of self through the creative expression of their illness, and thus transforming the illness experience (2010). It is in this sense that it might be said that the way some Coeliacs have reconfigured general social media platforms to share self-care practices has the potential transform the mundane and solitary into the gamed and creatively therapeutic. The creation and testing of the Spoonie Living app is an attempt to engage with these gamifying activities, and analyse further how the visualisation of these playful hashtags can be used to further study self-care practices.

While indeed these practices can be classified as 'gamifying the mundane', there may also be room for argument here, that these same practices also fall under Foucault's principles of the Technologies of Self. By this, I mean

that the act of Disclosure of Self may be read in the way that Coeliacs use gamifying principles such as photography and playfulness with hashtags to reveal their daily experience of self-care or self-management of their disease on the gluten free diet. Examination of self, may again be interpreted in the way that photographs of home remedies are shared to communicate how to recover from being accidentally glutened. And finally, 'Memorizations of Deeds' may also be a way to describe how photographs of food are used to both capture their daily diet in a visual food diary, as well as a visual sign-post to others of new places that serve gluten free food options when eating out.

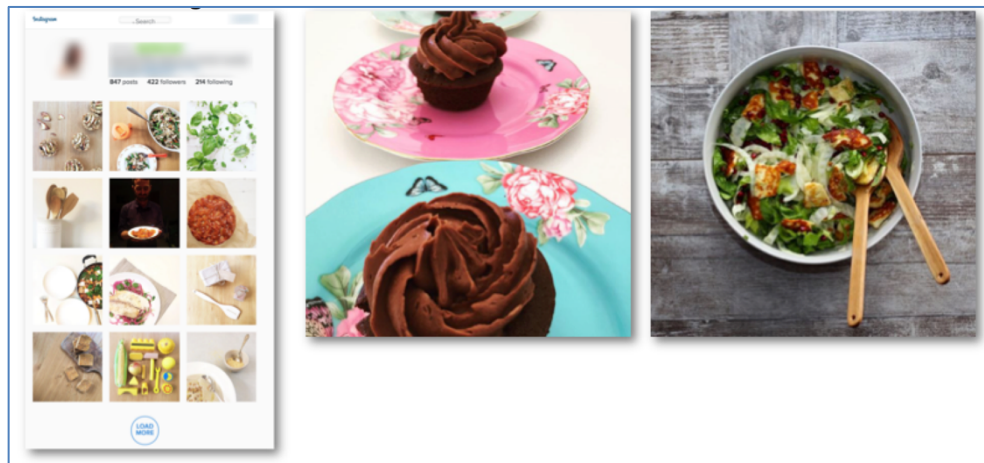


Figure 36. Coeliac photo diaries on Instagram

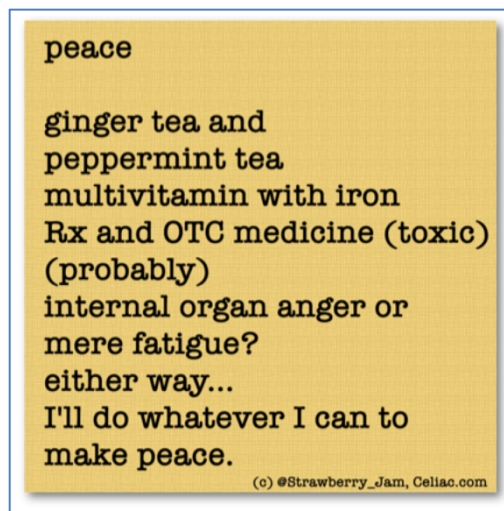


Figure 37. Coeliac Meme Poetry: Gamifying the mundane on Instagram



Figure 38. #50ShadesofCoeliac - gamifying the mundane with popular film culture

Coeliacs and the #Spoonie hashtag

Within this context of Gamification, one of the key factors in deciding to create the Spoonie App as a research tool, was the strong pattern of co-occurring hashtags containing the terms “Coeliac” OR “Celiac” AND “#Spoonie” (35%) when looking at reports of comorbid illnesses reported by Coeliacs in a combination of the May 2014, June 2015 Instagram (700 posts) and Twitter corpus (3,000 posts). Figure 41 shows a sub-sample of the 153 Instagram posts in this dataset. Here, the nodes represent 153 individual posts that mention both the terms ‘Coeliac’ and ‘Spoonie’ (22%). Out of these 153 posts, a total of 38 specific autoimmune diseases were co-mentioned with CD. Twelve posts contained hashtags similar to the term ‘Spoonie’, which were used by users as blanket terms for their comorbid chronic illness(es). Examples include tweets from the dataset with hashtags: “#spoonieliving #spoonielife #autoimmunedisease #invisibleillness #chroniclife #chronicillness” (orange nodes). Nine posts contained overlapping symptoms across comorbid diseases (blue nodes). More specifically, it was found that where Coeliacs discussed comorbid symptoms that shared similar symptoms with CD (e.g. brainfog, stomach issues, anxiety or depression), the symptoms were talked about collectively, and assigned hashtags that acted as umbrella terms for collections of comorbid illnesses.

What this data sample shows is that some Coeliacs are not only talking about and identifying with CD as a singular disease, but they are also talking about comorbid symptoms. As further investigation of the Spoonies network will show, by using the Spoonie hashtag, Coeliacs are also taking part in larger biosocial networks, which include ‘Spoonies’ with different diseases, or those that have CD and other comorbid illnesses. Far from exclusive groups being created around specific biosocial identities, the use of the Spoonie hashtag by some Coeliacs, and the discussion of the sometimes-overlapping symptoms of different autoimmune diseases, show that biosocial identity around chronic diseases can sometimes be a more fluid identity. Such activity is perhaps evidence of broader social media networks existing around chronic illness as a whole, where the narrative of different kinds of social illness is shared across illness communities.

that CD has itself often been classed as a 'hidden disease' where others cannot see the physical and thus visible symptoms of (Rose & Howard, 2014b). There is also the case that the gastrointestinal, chronic fatigue and further symptoms of CD can also overlap with the symptoms of other chronic illnesses, such as IBS (Irritable Bowel Syndrome), or Fibromyalgia (a condition characterized by chronic widespread pain, and fatigue, as well as including gastrointestinal problems). While this overlapping of experienced symptoms is recognised in the literature (García-Leiva *et al.*, 2015), it seems that Coeliacs and other Spoonies have also come up with a colloquial description for this overlap, with the term 'Spoonie' as well.

The diagnosis of comorbid diseases, like Diabetes and Crohn's Disease as additional chronic illnesses to CD, also remains a genetically susceptible factor in Coeliacs diagnosed in later life (Fasano, 2006; Hermann *et al.*, 2003; Mazzeella *et al.*, 2008). This prevalence for comorbidity is also reflected in photographs shared via posts collected in all the Instagram and Twitter datasets for 2013, 2016. Here it was found that 45% of posts also mentioned other chronic illnesses, with Diabetes, Crohns Disease, Irritable Bowel Syndrome (IBS), Postural orthostatic tachycardia syndrome (POTS) a condition in which a change from the supine position to an upright position causes an abnormally large increase in heart rate, called tachycardia; Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Lupus, Arthritis, Fibromyalgia, and Hashimoto's Thyroiditis being in the top 10 of co-mentions.

While in recent years, there has been an increase in the quantitative study of user data created via visual social media, in terms of rates of use, and frequency of hashtags (Kaufer, 2015), there have been fewer studies that used mixed methods to study how patients are visualising their embodied experience of chronic illness. There have been singular studies looking at how the experience of chronic pain is shared and articulated across blogging platforms like Tumblr (Gonzalez-Polledo, 2016), and a study into looking at how Instagram is used to visualise the self-care of Diabetes (Yi-Frazier *et al.*, 2015). However, there have been no studies that look at the visualisation of comorbid chronic illnesses, or which have developed a

research tool or m-Health app that plays an active part in measuring such visualisations.

Digital Photovoice: Visualisation of Coeliac comorbidity

In recent years, the increasing use of technology and social media in every day cultural, social and business life, has also been met with an increasing sociological call to respond to this “pervasive production and harnessing of social data” (Wilkie, Michael & Plummer-Fernandez, 2015:pp.79–80) with the use of live methods and a rejuvenated sociological imagination in terms of updated research practices (Back & Puwar, 2012; Marres, 2012a). Back argues that a re-imagination of methods and devices used to study digital cultural practices is needed to bring about a fresh and directed focus and insight into how social practices evolve and are affected by the digital age (2012:p.31). The use of participatory research via the mode of photography is seen by Back as a particular way that the fast and often visual form of digital cultural practices can be paused to study the “ebb and flow of social action” for closer sociological inspection (Back, 2012:p.31). More recently, Lezaun et al. (2016), have also discussed the positive potential of the use of participatory use of basic technological platforms, in a way that can produce new documentation of the digital in the social processes of life.

The Spoonie Living app falls within the format of such participatory experiments, in that it is developed as a device for real-time or ‘live’ investigation into finding out how Coeliac Spoonies with comorbid illnesses visualise their experiences. The way that the app is used within such participatory research is also a digital extension of Photovoice. Photovoice is a participatory action research method that traditionally involves giving a group of participants cameras, enabling them to capture, discuss and share stories they find significant (Wang & Burris, 1997). The use of Photovoice enables participants “to record things relevant to their life which health professionals and researchers may not have previously had access to” (Williams, Sheffield & Knibb, 2013:p.1171). This is especially relevant for studying chronically ill individuals who may, due to illness and decreased accessibility, have fewer options for participating in group studies. The design of the Spoonie Living app is based on the use of simple ‘live’

smartphone photography, with the addition of chronic illness specific stickers (or overlays) to express symptoms or feelings. Individuals can use these stickers to make the images they share immediately identifiable as being related to their experience of chronic illness. Thus, a user experiencing symptoms might take a photograph with the app, or upload a previous image from their phone's image library, and then add stickers to the image via the app. S/he would then have the option of sharing the image via different social media platforms.

For the purposes of the illustrative example explored here, the main platforms used were Instagram and Twitter. This was mainly because Instagram and Twitter were the main social media platforms where the presence of the use of the Spoonie hashtag was found in initial data analysis. For the purposes of the research I wanted to see if the utilisation of hashtags used by comorbid Coeliacs within the networks studied, would also feel comfortable using hashtags when sharing visualisations of their symptoms via the Spoonie Living app. By creating stickers that included hashtags and colloquialisms that had already been observed from within this community, it was hoped that they would find it easier to use a tool that also used terms that they were familiar with, in an already established social media community. In this context, the deployment of the tool across both Twitter and Instagram also enabled the research parameters to be further explored.

Within the Spoonie Living app, the use of image overlays was influenced by the common use of internet memes within image sharing practices within the context of chronic illness (Yi-Frazier *et al.*, 2015). The use of text over image has long been a feature of printed publications, such as comic strips and cartoon editorials, and has noted by Pinar (Pinar, 2014:p.384) to have a specific multimodality in terms of bringing into focus a certain author narration of what is going on in the image presented. As the user interfaces for social media have become varied or sometimes restrictive in space and style (such as the 140 character restriction of Twitter), the use of text over image as a way to communicate more expressively and extensively outside of restrictive formats (Araujo *et al.*, 2014; Malik, 2014). Likewise, Don (2013), has also described this kind of image over text or

image overlay narration as a type of “interior monologue captioning”, as a way of representing what the author/producer is thinking/feeling.

The use of this type of “interior monologue captioning” (Don, 2013), was found within the context of chronic illness in images shared by Coeliacs from within the Twitter and Instagram corpus. Here, Coeliacs were using a Coeliac-specific form of the image macro by using captions to emote a vernacular narrative of how they felt about the symptoms of CD. A reading of some of these images could be read as “interior monologue captioning”, where the first person narrators voice of the Coeliac expressed their frustrations/feelings/observations of being glutened (Figure 42).

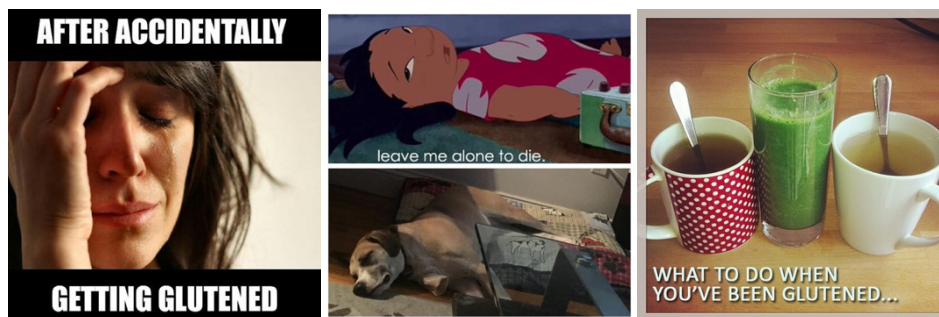


Figure 40. Coeliac Image Memes: Visual expression of being Glutened

However, when looking at images that contain co-hashtags “Spoonie” and “Coeliac” from the 2014-2015 dataset, it was found that 45% of images contained more subjective photographs of individuals themselves, as well photos taken where there is a co-presence of the user (a limb or point-of-perspective). This is compared to 20% of images that contain re-used internet memes with monologue captioning (Figure 7). It would thus seem from this particular sample of posts, that users of image-based social media platforms are still using the present and co-present formats of selfies to express or visualise their comorbid illnesses, but minus any visual tagging. In terms of co-presence, and subjectivity, this notion of co-presence or partial presence in photographs, and how this is different from selfies, is a topic discussed by Zappavigna (2016), and will be covered later on in this chapter. To see if giving users chronic illness specific tools to visualise their illnesses would help them put these selfies and co-present photos into more context, the Spoonie Living app was built and deployed in a small case study of initially 40 users, over a period of 3 months.

Visualisation of Embedded, Sensory experience of chronic illness

One of the main issues with studying the self-management and symptoms of CD and chronic illness occurring alongside it, is that the experience of these diseases can often be difficult to articulate. While social media has indeed provided platforms for self-expression in both visual and text formats, previous studies have found it problematic to direct users to use digital sharing tools in a way that focuses on the specific topic at hand (Drew, Duncan & Sawyer, 2010:p.1682; Yi-Frazier *et al.*, 2015). Studying these experiences and how people express them both with words and images via social media, has thus meant that attempts to understand and interpret the meaning and significance tend to rely on the social researcher's immersion in the sites of other people's experiences (Pink *et al.*, 2015:p.36).

So far in this thesis, studying experience of chronic illness has depended on analysing the big data outputs of Coeliacs, in order to identify concepts Coeliacs and Spoonies have associated with sensory or emotional experiences of living with long-term conditions. The next stage is to use this analysis to better facilitate the visualisation of chronic illness experience with a sample group of research participants (Pink *et al.*, 2015: 36). In this way that the use of the Spoonie Living app, a research toolkit that focuses on visualising a particular set of experiences within the chronic illness context, can help to better understand how individuals visually communicate their symptoms.

With the use of live methods to conduct live research via Instagram and Twitter, with feedback from participants to the researcher as to the appropriateness of tools in the app, the aim is to find out how this form of experimental design would operate to fine-tune a more multi-morbidity focused analysis. It is also hoped that the results of this live qualitative study would uncover areas that showed how the "application of [digital] visual methods and how they worked in combination to confirm, complement, elaborate and contradict data generated through other methods" (O'Connell, 2013:p.36).

Illustrative Study: Spoonie Living App

The Spoonie Living App itself was based on a simple image sharing app template, that was re-designed and modified to include chronic illness specific stickers, and an internal wall and commenting system, that also enabled the sharing of complete images to Instagram, Twitter, Tumblr and other platforms. When analysing data about the source of tweets and Instagram posts for this thesis, it was noted that over 70% of posts were made with an Apple smartphone or tablet. Because the majority of individuals within the data corpus self-identified as using Apple-based technology, it was decided to build the Spoonie Living app using the Apple Xcode platform, with a combination of Swift, XML and SQL.

Participants were recruited via a series of tweets and posts calling for participation in the project on Instagram and Twitter, while the description of the app on the iOS Apple Store included a call to action on. I used the text analysis tools on the web-based Netytic.org platform to identify 40 participants from my initial Instagram and Twitter datasets (700 Instagram posts and 3,000 Tweets). I did this by identifying messages where each individual had used the hashtags #Coeliac or #Celiac together with the mention of another comorbid illness e.g. #diabetes or #ibs. I then sent a direct message to participants via Twitter and Instagram, briefly explaining the project, and inviting them to participate. In terms of gaining informed consent for their participation, I used the self-selection or opt-in method of complete disclosure, as used in the Mappiness app project (MacKerron & Mourato, 2013:p.994). This worked by an opt-in notification when users first open the app. Once prospective participants had downloaded the Spoonie Living app from the app store, upon opening the app, they are shown a pop-up screen that informs them that by using the app they will be participating in my research project.

Once they have read more about the study, they are directed to give their informed consent to take part, by clicking on the 'I Agree' button (they are also given the option to leave the study at any time (see Figure 43).

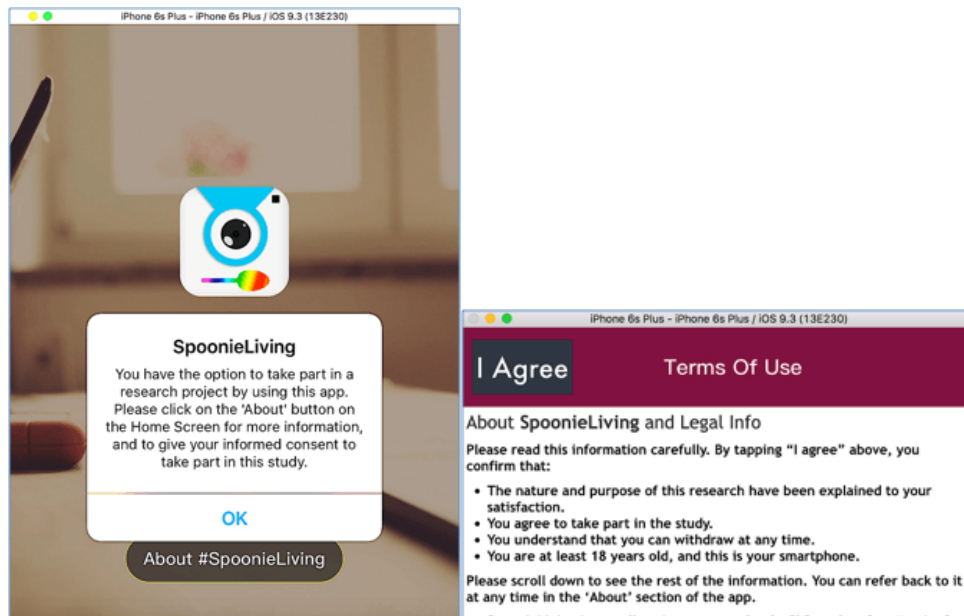


Figure 41. Informed consent message and form - wording based on Mappiness study (MacKerron & Mourato, 2013:p.994)

To get more participants for the study, I also posted a separate tweet and Instagram post, with the message “#Coeliac or #Celiac with an additional illness? Please help test my student project, an app visualising #ChronicIllness. DM for more details.”. Once potential participants contacted me, I instructed them on how to use the app, and directed them to add the hashtag #spoonielivingapp to any posts that they wanted me to share via the app’s Instagram, account. I also made it clear that any posts with the hashtag #spoonielivingapp would be posted live on the app’s Instagram page. The use of the hashtag #spoonielivingapp, and its mention as a tool for sharing via social media both in the initial study, and in the main description of the game on the app stores, was also an attempt to ‘gamify’ the use of hashtags. By this, I mean that by using the #spoonielivingapp hashtag to alert me to their use of the app on their own social media accounts, and it being an implicit permission for me to advertise their images on the app’s official Instagram page, it also acted to gamify the app’s use.

By the second week of the study, the use of the hashtag on Instagram seemed to turn into a competition. Users would not only link their images with the hashtag, but would also send me private messages, and use Instagram’s own integrated person-tagging feature to make sure I was

alerted to their sharing of the app's images on Instagram. In addition to this, as their friends became aware of the app, they also downloaded it, and started to add the hashtag and tag-links to the app's account on their posts. While this had the potential to confuse matters in terms of me sticking to the control group, it was also interesting to see that by using simple games mechanics in terms of feedback and the 'reward' of being featured on the app's official page, users seemed to naturally respond to the gamification of a hashtag being used to promote the visualisation of symptoms (Munson *et al.*, 2014:p.602). The #spoonielivingapp hashtag itself also managed to act as a gamified link between the app as a singular device, and linking it to the broader use of chronic illness related images and hashtags on social media in general.

I also informed them that any images that were posted to the app's internal wall were not for public sharing, but would remain as private, and used for analysing how users used the chronic illness stickers to create private content. If they found that they did not want to share the image publically, they were encouraged to either email/message me the images directly, or share them via the private internal wall on the app, and use the comment feature in the app for the diary entry.

Within the sample group, the 40 participants with CD and other comorbid illness(es) were instructed that they had a 6 week period (2nd May to 12th June 2016) to take photographs that showed the impact that dealing with comorbid symptoms had on their health-related quality of life. They were asked to add some descriptive text, in the diary format common to most posts shared by the Spoonie community on Instagram and Twitter. No instruction was given on what they should write alongside each photograph entry, so that there was as little interference as possible from me as the researcher — this "allowed participants to record their own perceptions of their [health-related] quality of life" (Williams, Sheffield & Knibb, 2013:p.1172). Out of the 40 participants who agreed to take part in the sample group, 22 users from this selection returned results and reported their experience of using the Spoonie Living app via shared images via various social media platforms.

The age of participants ranged from 18, 55 years old. This age range allowed the full range of multi-morbidity illness that co-occurred with CD to be studied. Programmatic constraints (such as the API constraints described below) meant that only four main platform choices were available to share directly from the app, which included Instagram, Twitter, WhatsApp, Facebook and Email (although there was an 'Other' button that allowed further sharing via other apps, like Tumblr, correct formatting was not guaranteed). This was due to individual API restrictions on the sharing of images directly from third party apps. More specifically, a recent change to the sharing allowances via the Instagram API, meant that previous allowances of pushing through pre-programmed hashtags to automatically appear from an app in an Instagram post were now banned (Instagram.com, 2015b). This meant that I had to rely on users remembering to add an associated hashtag to their Instagram posts, which we will later see produced a few problems in terms of keeping track of images produced by the app when the app became popular. However, although additional semi-compatible apps could be added via the 'Other apps' sharing feature within the Spoonie Living app - this feature was not guaranteed to work with all apps.

To make access to the app as easy as possible, the app was published live on the Apple Store, with a brief description that it was primarily the function of a research project that helped users with comorbid Coeliac and other diseases, visualise their illnesses. Because of the live access and subsequent sharing of information about the app, the original sample pool of 22 users grew to just over 230 Twitter followers, and 382 Instagram followers between May and October 2016. Thus information about the existence and use of the app was shared, reposted or re-tweeted amongst a wider social media network, especially by users with a large amount of followers. By the beginning of October 2016, there were just over 1,000 downloads (1,037) of the app across both Apple (iOS) and Android phones., and 500 traceable image posts/shares both on social media platforms and within the internal app sharing feature itself. Out of these 216 wildcard users, a further 65 were found to have CD alongside their other chronic illnesses. Over the 6-week period of the initial case study (May to June 2016), a total of 105 user images were anonymously tracked.

Tracking images was originally planned to be via a content hashtag '#spoonielivingapp'. From within the control group, this was fairly easy to do, but needed to be done quite quickly, as after an average 3-week period, some users opted to delete images previously shared. Thus, screenshots of images had to be done speedily to keep a full record. Where users from within the sample group did not use the designated hashtag, reasons given in feedback included that the hashtag was too long, users forgot, or the closed/secure platform the image was shared on (e.g. WhatsApp) did not allow the public tracing of hashtags.

In terms of the lesser use of the hashtag in the non-control group (who were not part of the original 40 participant study, but who posted images on Instagram and Twitter using stickers from the app), this may be because users had downloaded the app without fully reading the description on the app store, or did not want to be part of the research and instead were using the app as a general chronic illness based image filter, instead of as a focused part of the research project. Thus, it was found that wildcard users were not always posting images with the control hashtag, but were instead using other hashtags that they felt better identified their condition, or that were short enough to fit into 140 character tweets describing the photo they had created.

Overall, the Twitter platform character restrictions were found to play a main part in the non-use of the hashtag, with 37% of tweets containing the hashtag, compared to 72% of Instagram posts retaining the hashtag. It is arguable that this may be down to the longer character allowances of Instagram, which users may have felt allowed them more room to stick to the allotted #spoonielivingapp hashtag.

Visualising Comorbid practices of Self care

In terms of the visualisation or remembrance of technologies/practices of self-care (Cammaerts, 2015), one of the key findings to emerge from this research, is the way that Coeliacs visualised the different techniques they used to self-care for both CD and their comorbid illnesses. Shared images where the management of symptoms were shown, seemed to take on an

'either-or' context, where Coeliacs seemed to either share photographs of remedies for being glutened, or shared photographs of medication used to treat their other comorbid illnesses, not both. If sharing medication for other comorbid illnesses, there would be a photograph of the tablets taken (e.g. anti-inflammatory pills for arthritis), or the documentation of symptoms such as accelerated heart beats via a monitor for the tachycardia symptoms of disease (Postural Orthostatic Tachycardia Syndrome) (Figure 44). The text accompanying the image would also detail the symptoms of the key illness being managed at the time. In these instances, a Coeliac-related sticker might also be added to the image, or where this did not occur, the presence of CD might instead be referenced in the hashtags associated with the post.



Figure 42. Spoonie Living App Stickers + Quantified Tachycardic Symptoms of POTs

These variations in the referencing of CD in the presence of comorbid illnesses, show how the complexities of self-care are expressed, either visually or within the text and meta-tagging of illnesses via social media. While the way that the symptoms of illnesses present themselves cannot always be straightforward, or clear-cut, chronically ill individuals find ways to navigate this through varied means of self-expression, presenting the most prominent symptoms experienced at key points in time. It is also notable that at the time that two users within this chapter's sample group identified themselves as Coeliacs, outside of a few reports in the literature

of a small amount of comorbid Coeliacs who also had POTS (Gibbons & Freeman, 2005), the nature of the association was unclear (Tursi *et al.*, 2004). There was also no supporting literature where an exploration with regards to an association between CD gluten-related dis-orders and POTS has been performed before (Penny *et al.*, 2016). However, at the time of writing, one study by Penny *et al.* (2016) was published, noting that a large number of POTS sufferers had self-imposed a gluten free diet on themselves, in the belief that it helped them with symptoms. When clinically tested, results revealed that overall, 4% patients with POTS had serology and biopsy-proven CD. This was significantly higher than the local population prevalence of CD of 1%, and thus shows a potential association between CD, gluten-related disorders and POTS (Penny *et al.*, 2016). While my social media analysis using the Spoonie Living app only covers a small sample of the Coeliacs presenting with POTS, it is good to see evidence of this link also represented in recent clinical literature.

Other examples of the complexities of visualising comorbid Coeliac symptoms also occurred when users tried to visualise the overlapping gastrointestinal symptoms of having both Coeliac and IBS. Here, when the user was unsure whether it was accidental exposure to gluten, or an IBS response to another food ingredient, they opted to use both IBS and Coeliac stickers, while at the same time mentioning how borderline their symptoms were in the text of their post. They also expressed surprise at this sudden emergence of symptoms, as the gluten free diet had otherwise been beneficial to them, but they could not be sure exactly which disease was currently causing them pain. The image from this post is not shown here due to the users' request to stay anonymous. However, the users' experience is indeed in line with the current literature about the prevalence of IBS-type symptoms in patients with CD, where it was found that individuals with both IBS and CD still often reported IBS type symptoms (Sainsbury, Sanders & Ford, 2013). Here it was also found that in some cases, these symptoms sometimes overlapped with CD (2013:p.360).

This reflection of the visual complexity of Coeliac and comorbid diseases was also seen where Coeliacs used the stickers within the app to express their biosocial identity with more than one of their illnesses. These

particular posts usually included a co-present selfie (self-portrait), with a line-up of illness identity stickers placed around the photo of the individual (Figure 45). These kind of images show that users with comorbid illnesses are also keen to express not just one, but several biosocial identities with all these illnesses. In the case of comorbidity, they are not just a Coeliac or a Diabetic but seem to visually tag their biosocial identity with multiple diagnoses, as well as express the ability to discuss the symptoms of these comorbid diseases indiscriminately.



Figure 43. Spoonie visualising identity with CD, IBS and Chronic Pain.

In one case, it was found that a Coeliac with both Diabetes and Arthritis used different stickers to represent different aspects of her illness in different photographs, all depending on who in the Instagram Spoonie community she was talking to. On one day, she used relevant stickers and hashtags to discuss her issues with finding suitable gluten free food while at work with other Coeliacs; and in another post, used context specific stickers and hashtags to discuss her daily insulin injections with a Diabetes sufferer. Finally, in a separate post, the same user used chronic pain and arthritis stickers and hashtags to discuss the side effects of the painkiller Prednisone with other arthritis sufferers. Thus, by using different symptoms appropriate hashtags and stickers from the Spoonie Living app, users seemed to be able to share these agential cuts, or snippets of their

symptoms to easily navigate between the communities that they interacted with.

As noted earlier in Chapter 2, Frank's notion of 'chaos narratives' have often been used to explain the situation of patients that have unexplained medical symptoms, who experience illness, but remain undiagnosed (Frank, 2013). In the current study, an example of the chaos narrative can be said to be present, when users of the Spoonie Living app contacted me to request the creation of a "Chronically Undiagnosed" or "undiagnosed Spoonie" sticker. When requesting a sticker called "chronically undiagnosed", users explained that they felt this would be a good representation of the 'in limbo' stage they sometimes found themselves in mid-diagnosis. This can be where an individual is experiencing symptoms, and being tested in the hopes of a diagnosis, but as yet does not have a name for their illness. In terms of the diagnosis of comorbid illness(es), one such example is where I was contacted by a user who explained that while she had been diagnosed with CD, depression and rheumatoid arthritis, she was currently experiencing symptoms that were under investigation, but had yet to be diagnosed. In this respect, she thought it would be a good idea to have a sticker created that said "Undiagnosed Spoonie", that would better represent those going through the diagnosis process. After this sticker was created and published on the app, I found that 5 out of the 40 users in the initial sample group also used this sticker, to reveal that they were also going through periods of diagnosis for additional autoimmune diseases, from Fibromyalgia, to Diabetes, PTSD and Arthritis (Figure 46).

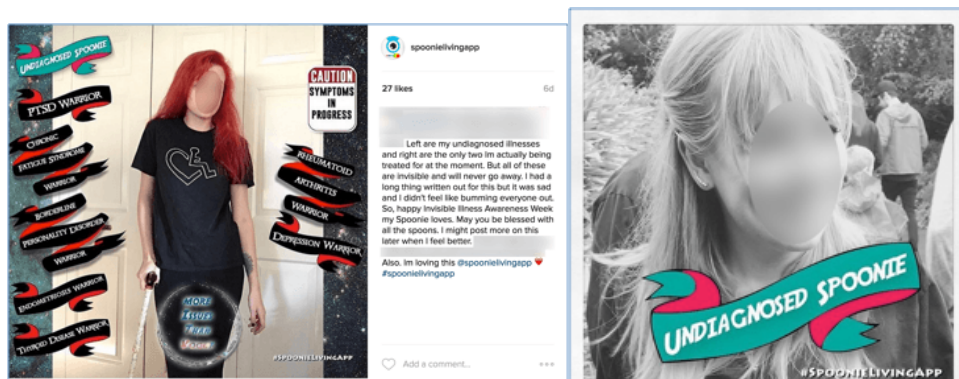


Figure 44. Listing diagnosed and undiagnosed comorbid illnesses

It seemed that the presence of this sticker for the process of diagnosis indeed acted as an opening for other comorbid Coeliacs (and later those with other illnesses), to visually express the complex processes of being diagnosed with one or two chronic diseases, while also being investigated for additional symptoms that fit within another disease spectrum. This also tallies with reports in the literature that highlight the increased chance of being diagnosed for additional autoimmune disease, once diagnosed with CD (Fasano, 2006). This also shows that while individuals with comorbid illnesses also identify with their particular groupings of comorbid disease, where acute symptoms are under investigation, they also identify with the on-going process of acquiring an additional biosocial identity. And as signaled to me by some users, also require some form of visual representation when sharing visual experiences.

While the use of the sticker #undiagnosedspoonie might be good for on-going processes of diagnosis, it brings to the foreground the various issues in the chronic illness community, where self-diagnosis without recourse to a medical expert can be problematic when verifying the treatment and representation of chronic illness online. The issue of self-diagnosis itself is a contentious issue both within the Coeliac and Gluten Sensitivity community, where both lay and scientific arguments as to the presence and treatment of CD vs. whether or not Non-Coeliac Gluten Sensitivity (NCGS) is a bona-fide genetic condition or not, is part of a continuous debate (Catassi, Gatti & Fasano, 2014; Fasano *et al.*, 2015b). While I will have tried to keep my research unambiguous and within the confines of the #coeliac and #celiac hashtags used on social media, it is acknowledged that the issue of the self-diagnosed use of the #coeliac or #celiac hashtag cannot be ruled out as being as some part of my vast dataset.

The creation and use of the hashtag #undiagnosedspoonie pulls this issue back into the frame as part of this present case study. Of the five users who used the sticker here, I checked with each one, either directly, or via their extended social media profiles, as to whether they had been officially diagnosed, I am fairly confident, as well as from the text of their posts, that they have been diagnosed primarily with CD. Awareness of the

complexities of diagnosis is also addressed via Coeliac charities and advocacy groups, such as Coeliac UK, who have also created a web service that allows those who question whether they have the disease to go through a self-assessment process. In a campaign aimed at improving rates of diagnosis of CD, and reducing the average period from the onset of symptoms to diagnosis (13 years) — the campaign aims to reduce the years of unnecessary suffering and endless visits to the GP by getting individuals to complete an online self-assessment form. The results of this are assessed in order to advise individuals of whether their embodied experiences/symptoms require them to get further medical advice from a physician (Coeliac UK, 2016).

In terms of uses of the app outside of the six-week testing period, without an investigation into the medical histories of the 1,000 plus downloaders of the app, I cannot be completely sure that those using the #undiagnosedspoonie sticker are in the process of being diagnosed, or have actually just self-diagnosed. The question of self-diagnosis has long been a contentious issue within the chronic and long-term illness communities. Those that reject the ability to self-diagnose argue that some chronic illnesses are too complex to be self-identified, while those that accept self-diagnosis argue that an individual's lived experience is as or more important than standard clinical assessments (Sarrett, 2016:p.30).

In terms of self-identifying with self-diagnosed chronic illnesses, the use of Novas and Rose's context of bio-sociality or biocitizenship for a sense of belonging to a specific chronic illness groups can be seen in two ways here. Novas and Rose described 'informational biocitizenship' as the process of becoming an expert patient, in gaining as much knowledge as possible about one's condition after diagnosis has occurred (Rose & Novas, 2007:pp.439, 463). However, Sarrett argues that this is reversed in the self-diagnosis of conditions such as autism, where, often, an individual will flip the process by learning about their perceived condition, and then decide the label that they feel appropriately describes their lived experiences (Sarrett, 2016:p.30). In contrast to this, it was found that overall, users of the Spoonie Living app discussed the process of working together with medical professionals to find the course of the other

symptoms experienced alongside CD. As one individual commented alongside her image (and as part of a blog post about her hospital appointments and tests): "... getting closer to a diagnosis, finally after 10 years. Looking at Fibro, ME, [...] Maybe!". A further investigation of the posts and images co-occurring with hashtag #undiagnosedspoonie would also be beneficial to a further understanding of how those with both comorbid and undiagnosed illnesses express how they cope with different stages and symptoms of the chronic disease process.

Visualising the Invisible: Hidden Chronic Illness and Visibility of Self in Photos

When analysing images taken by Coeliacs with comorbid illnesses in this illustrative study, I found that, in many photographs, individuals were either present, co-present, or not present, depending on the context/focus of each post. As noted in Chapter 2, there is growing interest and analysis of different levels of presence, co-presence and non-presence of individuals in submitted photos on social media. Zappavigna notes that the term 'visual co-presence' describes an ambient 'sharing' experience most typical with visual social media platforms like Instagram, where the part played by the photographer is presented within the image (2016:p.18).

Mizuko and Okabe (2005), and later Zappavigna (2016) argue that social media seems to have influenced the way that individuals express a form of 'intimate visual co-presence' in their shared images. This is in terms of a relational occurrence that arises out of the sharing of subjective photos with others in the temporal and portable nature of social streaming technologies. Zappavigna calls this style of personable visual co-presence photography: "you could be here with me", where social media users include a part of themselves or experience in the image, in a way that invites viewers to imagine themselves into the frame/experience (Zappavigna, 2016:p.2). In terms of the sharing of experiences of a chronic illness, this type of visual co-presence may make the experience of the image even more intimate as the user invites the viewer to share in their experience of painful or frustrating symptoms. Analysis of photos in the Spoonie Living app project has found that sometimes this form of visual co-presence is used both as a

form of expression and as a form of release, much in the same way that the traditional diary has been used as a way of expressing that which has gone unsaid in everyday life (Murthy, 2012:p.28).

Users of the Spoonie Living app were found to practice visual co-presence in many different forms (Figure 47). They used their camera phones to maintain a) full visual co-presence (e.g. a selfie, a self-portrait photograph); b) partial co-presence (a limb or other body part in the frame, or the photo taken to intimate the subject's presence, e.g. a cup or plate in the foreground); or c) no presence (no intimation of presence, but the use of an inanimate object, or landscape view, with the sticker overlaying and conveying a message).

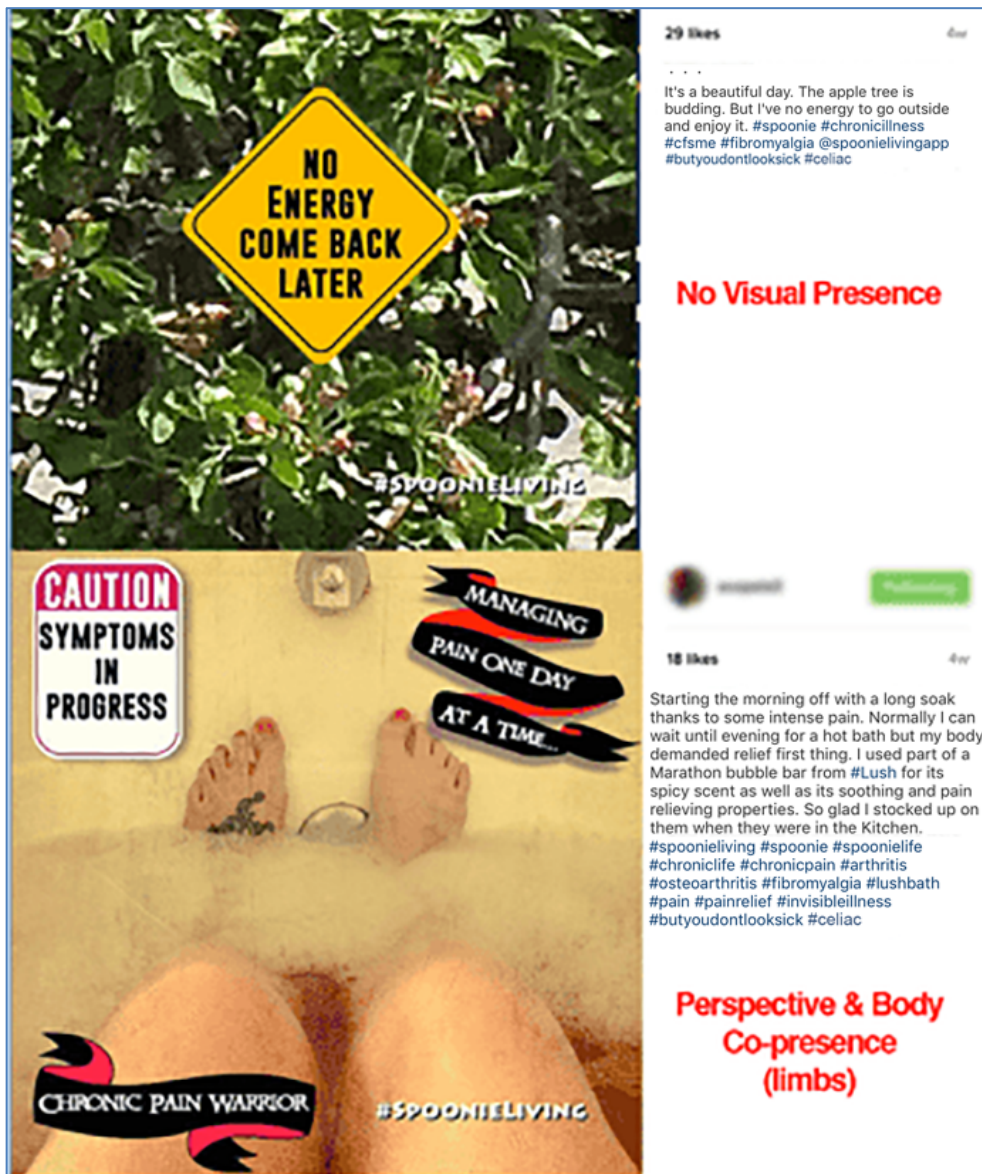




Figure 45. Varying degrees of visual co-presence in #spoonie photographs

In cases where there was no presence of the individual in an image, these 40 images contained pictures not taken by the users themselves, but were internet memes (pictures with concepts or catchphrases that circulate via the internet) (Yi-Frazier *et al.*, 2015:p.1375). In these cases, the stickers from the app were used to overlay trending posters or memes that carried informational messages about specific comorbid diseases (Figure 49).

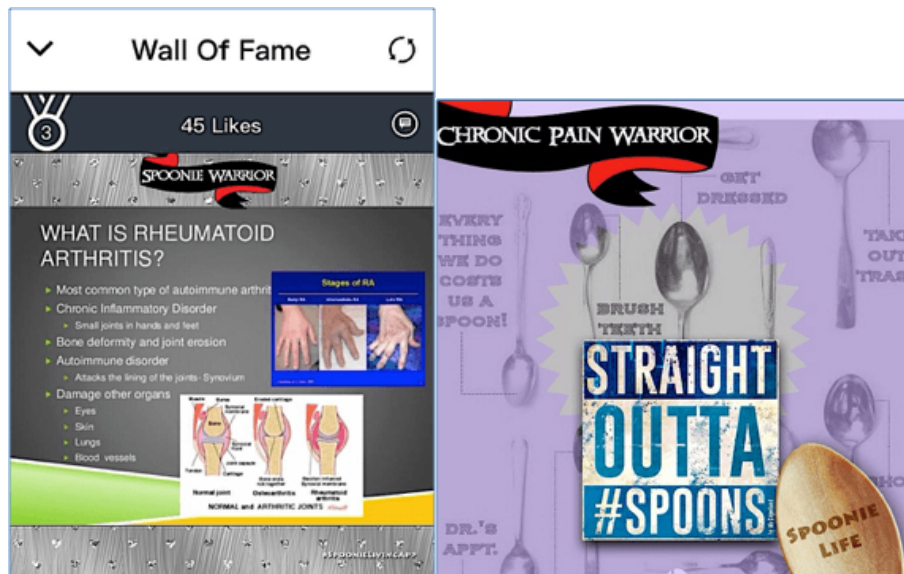


Figure 46. No co-presence: Internet Meme with plus app stickers

Despite the occasional use of stickers over internet memes, the most common form of sharing was with photos with the individual themselves visually co-present in each frame. This mainly occurred when individuals shared a photo of themselves or a situation where they tried to show the visual expression of pain. The majority of these photos were in the form of a selfie, and are usually paired with a textual post, which paraphrases: “this is what the pain of my symptoms look like” (Figure 50). While memes can include faces, a lot of the time those faces are not usually the faces (or bodies) of the individuals using them to express a certain emotion, concept or feeling (Mosenzon, 2014).

What was found as participants used the Spoonie App, was that they often put their physical features or facial expressions in photos where they strived to articulate what could be best described as the ‘invisible’ symptoms of chronic illness, like pain and discomfort. Here, the levels of subjectivity may be argued to be greater than that of a general meme image, where aspects of visual co-presence are more pronounced as chronically ill users express themselves. One example is that of a comorbid user who also has chronic pain issues and POTS (Postural orthostatic tachycardia syndrome, a chronic condition in which a change from a seated/lying position to an upright position causes an abnormally large increase in heart rate, called tachycardia – see Glossary) (Raj, 2013).

In one post, she took a photo of her face contorted in pain, as she paced her room, waiting for her medication to ease the pain she had been in all night. The use of the emotive stickers ‘Caution: Waiting for Meds to kick in’ was used to overlay the photograph in Figure 50, as well as the sticker ‘Spoonie Warrior’, which acted as a good blanket sticker to cover the experience of multiple symptoms from her chronic illnesses, at that point in time. While the text in the tweet she shared was minimal (due to space restrictions), the text in the longer Instagram post expressed a greater degree of subjective reflexivity:

“It’s one of those mornings. So much pain, especially in my hips, and nausea is unbearable. I can’t get comfortable so I’m just up pacing my apartment waiting for my zofran and meds to start working. I’m sure my downstairs neighbor loves me right now. This is the tortured face of #chroniclife.”

(Female, unknown age, Instagram post/comment, April 2016)

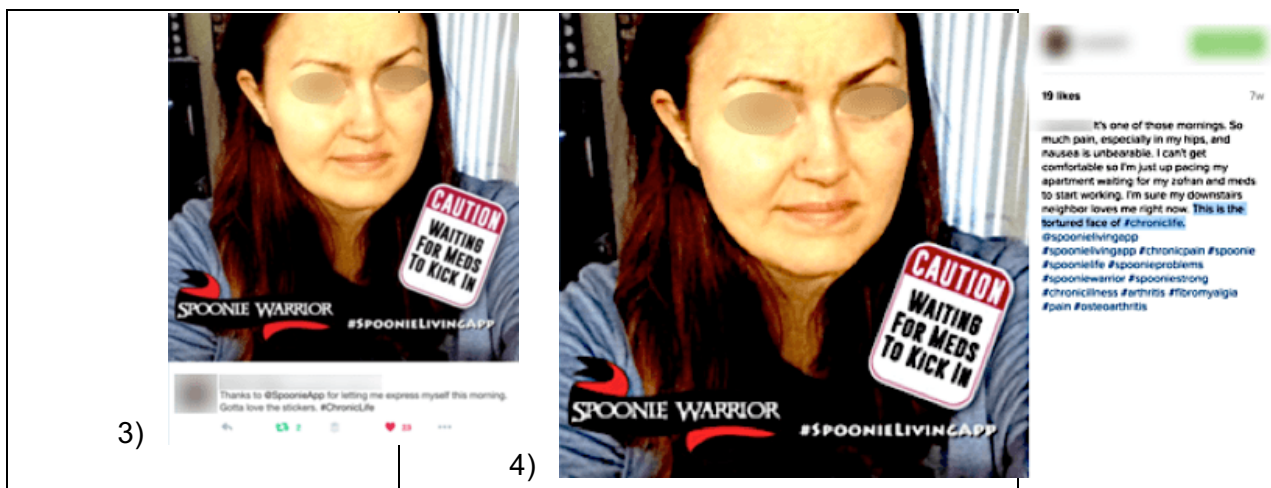


Figure 47. #Spoonie visualisation of comorbid chronic pain on both Twitter (less words) and Instagram (more text description)

Thus, as shown in the examples in Figure 50, in 10% of cases there were instances of the same picture being used and adapted to fit the delivery format of different social media platforms have also occurred, where a photo with an overlaid sticker has been used to communicate the bulk of information on the more restricted Twitter platform, in comparison to the same photo being used with 2 paragraphs of text explaining the experience of symptoms in much more detail on Instagram.

Stickers with the term 'warrior' were used to express the symptoms of 5 comorbid chronic illnesses in the app, in most cases, where the comorbid illness had symptoms needing acute pain or lifestyle management, like arthritis, diabetes, lupus, fibromyalgia or IBD. The use of these stickers in the app was based on previous contextual word-pair analysis of text tweets and Instagram posts, which found that in 30% of posts, the term 'warrior' was used in the context of someone having to push through the sometimes-debilitating symptoms of chronic disease to maintain a relatively average level of mobility and quality of life. It was found that Spoonies would often refer to themselves as 'fighting through one day or one symptom at a time', and then add #[illness]warrior as a hashtag at the end of their post e.g. "My current view: chronic pain/ celiac flare up. #celiacdisease #chronicpain #spoonie #celiacwarrior".

Instances of no visual co-presence occurred in some cases, where individuals shared images that were taken from the gaze of the camera's viewfinder, and the app stickers were used to show what the user is thinking as they experience the symptoms of being glutened (e.g. brainfog or low energy, as the camera gazes outwards at a garden, or a landscape). One such user used an image of a tree that she was looking at from her bed, while recovering from being glutened. Here the image of the tree was used to communicate her wish to be outside enjoying the spring weather instead of being unwell and indoors. The text used with this image was: "It's a beautiful day. The apple tree is budding. But I've no energy to go outside and enjoy it. #spoonie #chronicillness #cfsme #glutened". The sticker used was 'No energy, Come back later' (Figure 51).



Figure 48. Photo using no visual-co presence.

At other times, the app was used to express triumph, with regards to the positive aspects experienced when self-managing CD, such as the proud display of a gluten meal that has been cooked by a user who has needed to learn how to cook for herself, due to being unsure about eating out, with regards to the risk of being accidentally glutened. In these instances, the photos were tagged with positive stickers, like a popular colloquial phrase found in the posts of the 2013-16 Instagram corpus: “gluten free like a boss!”, or the term “kickass coeliac” (Figure 52).



Figure 49. Spoonie photos tagged with positive Coeliac stickers.

Overall, it was found that there were less co-presence in photos about finding gluten free food while on the move (only 8% of posts about gluten

free food had a person in them), and more subjective visual co-presence when users expressed their emotions over being glutened, or other co-occurring symptoms of their illness (65% had a person, or the partial presence of a person e.g. an arm/leg/hand/selfies).

One final aspect of co-presence and issues of temporality was found in the use of “before and after” photos when users described how they managed with the biographical disruption of illness. Here, individuals used the digital collage feature of the app to compile images that either:

- 1) showed self-portraits of them before diagnosis and some years after diagnosis (Figure 53); or
- 2) Used general photos shared days/weeks/months previously, but then updated them with chronic illness stickers to better visualise how they were actually feeling within the context of their illness when the original photo was taken (Figure 54).



Figure 50. Reminiscing on self-prior to biographical disruption of chronic illness.

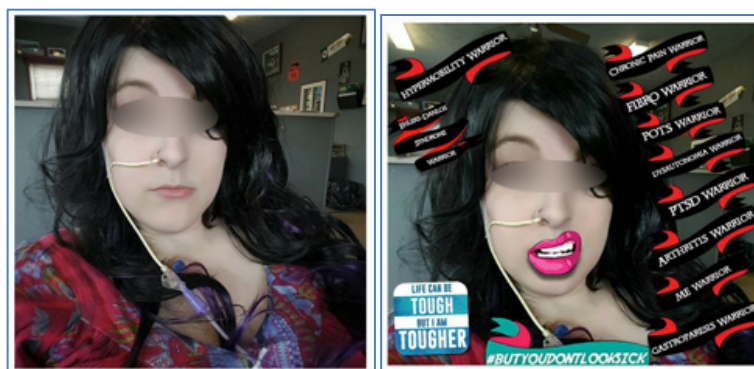


Figure 51. Previous image to reveal hidden nature of comorbid chronic illnesses.

Where the photos shown were years apart, individuals contextualised their embodied experience by discussing the effects of chronic illness on the both body and the psyche. Here, foremost emphasis was the effect that the more severe symptoms of chronic pain and discomfort had on their visual appearance in forms of aging and appearance of healthiness, and ultimately the effect that symptoms has had on their Health Related Quality of Life. One example is of a lady in her late 30s, who says:

“This is me about 18 months prior to my #myalgicencephalomyelitis & #fibromyalgia diagnosis. It's pretty much the only picture I like of myself. It's from the days I ran around with friends, traveled, drank like a sailor & caused a bit of mayhem. Now, I shy away from cameras, crowds, people in general. Even doing YouTube requires so many spoons. I look like a fat chick with no eyebrows [...] Now my life is much smaller, I barely make it past eight each night or have insomnia [...] But, I am blessed beyond measure [...] I have faith in a loving God, a family who have my back, a badass #bff & #ibff plus a community of very inspirational women! #plannercommunity #spoonielife #spoonieforlife #celiac #cfsme #awareness #chronicillnesswarrior”.

(Female, unknown age, Instagram post/comment, April 2016)

Thus, like the above post, the discussion around some of these images, talks about how the toll of experiencing chronic pain and other symptoms of chronic illness can be both ageing on the body, as well as enact a psychological change on the personality of the individual. Used in this way, these images can be used to contribute to an understanding of the visual perception of both observable and hidden elements of the embodiment and experience of chronic and comorbid illness, as well as allow comparisons between past and present practices (Mizen & Wolkowitz, 2012:p.2).

Live Methods & Call-and-Response

As part of the ‘live methods’ aspect of my research process, I wanted to explore how accurate the analysis of co-occurring hashtags was in formulating the visual stickers for the app. One way to do this, was to use the collaborative method of *call-and-response* (Puwar & Sharma, 2012). In

speaking about experimental collaborative practices in the use of Live Methods in social science research, Puwar and Sharma describe call-and-response as a process of communication “which activated a chain of reflexive responses between the researchers, the creative practitioners and their cultural productions (cf. Minh-Ha, 1991)” (2012:p.54). It was through this method, that Puwar and Sharma argue that the researchers became less directors (with a one-way flow of direction and influence), which enabled the project to go through a beneficial process of transmogrification as a result of collaboration and use of this multimodal approach (2012:p.54). Indeed, using this approach enabled me to find out from my sample group of users if the pre-selected set of stickers I had created from my hashtag analysis indeed fit their experiences of dealing with Coeliac comorbid disease.

Within the Spoonie Living app project, I instigated call-and-response through a process of tweet, email, and direct messaging interaction, where individuals requested stickers they felt better represented their experiences. Upon receiving these responses, I involved users in the design process of stickers, by tweeting sticker designs in progress, and, where needed, asking for further input. Live tweeting some aspects of the design process seemed to more fully engage users from my sample group, and encouraged them to request additional stickers if needed (Figure 54). Once this process was finished, I implemented user requested stickers in updates of the app, so that users within my sample group, and later, the wildcard group, could go on to use them and better visualise their embodied experiences.



Figure 52. Work in progress tweets during call-and-response sticker collaboration

To maintain a 'lively' methodological process, when possible, I also updated the general images on the description page of the app on Apple's App Store, so that they included examples of user submitted stickers. While due limited time and resource reasons, this process was only implemented during the 6 weeks of the project, it was found that the call-and-response method was quite beneficial in increasing the use of the app. As each new series of chronic-illness related stickers was advertised on both the Twitter and Instagram platforms, and each new update saw a steady rise in the number of user sessions and output of images created with new stickers (Figure 55). Territories in which the app was downloaded also match 4 out of the key 5 territories of diagnosis of CD (US, UK, Canada and Australia — Figure 56).

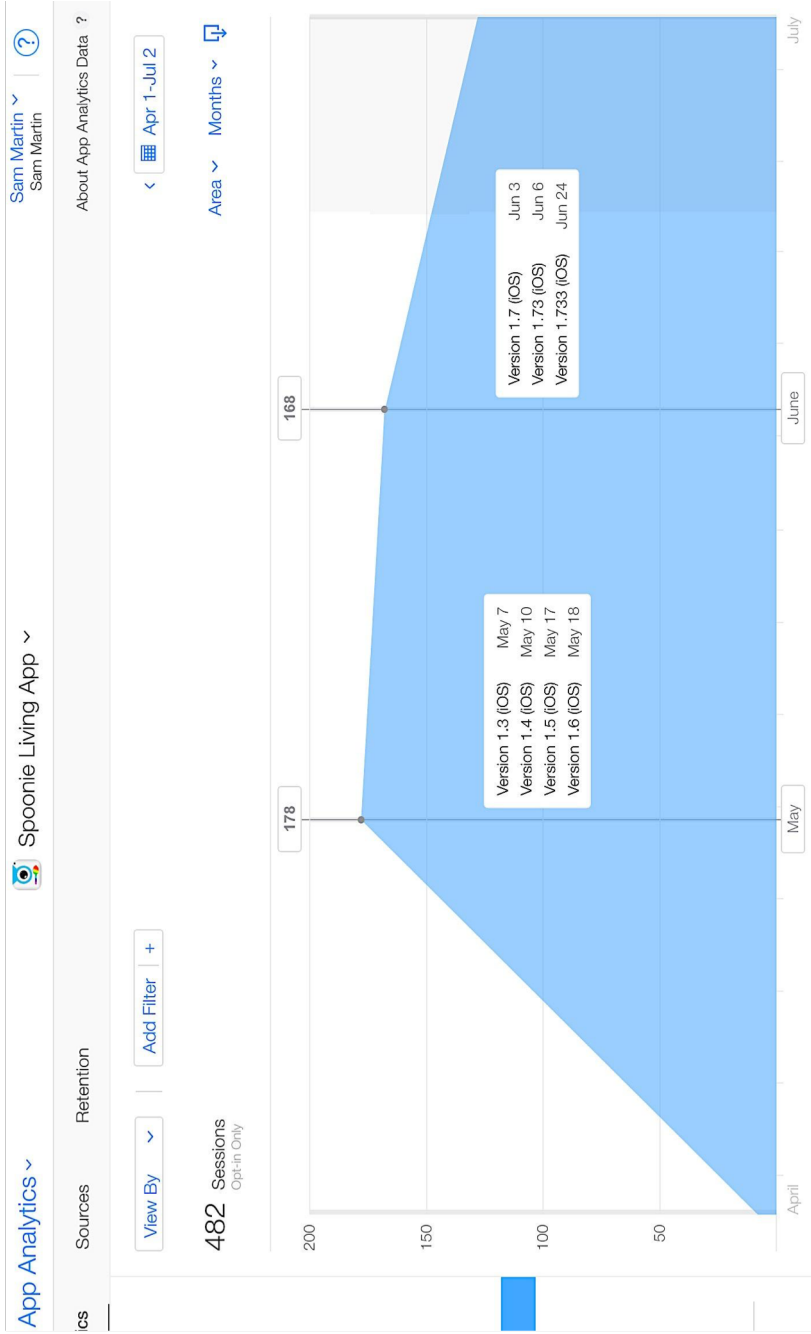


Figure 53. Increase in app user sessions per app update (Apr-July 2016).

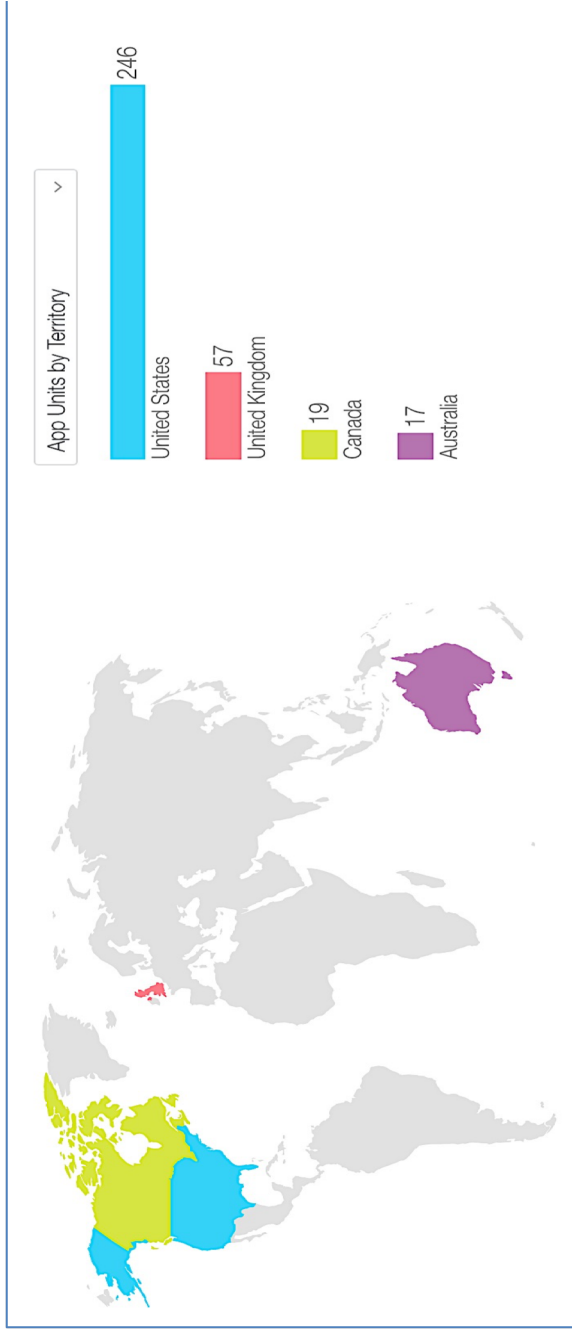


Figure 54. App Territory downloads (Apr-July 2016).

Through the course of collaborative dialogue with the user participants, 3% of the 40 user sample group informed me that they would like to use the app on platforms outside of Instagram and Twitter, and chose Tumblr instead. They explained that they preferred the freedom of a blog style format, than the image-based format of Instagram, or the text restricted format of Twitter. After further consultation, I added this feature to the app sharing menu, and after an app update, they went on to use the hashtag #spoonielivingapp on Tumblr. Perhaps as a result of this update to include visualisation output to Tumblr, I received further unexpected email communication from the Tumblr Spoonie community via the host of a blog called “Spoonie Living”. The owner of the blog requested permission to share the Spoonie Living app with her followers. Here she featured the app in a blog post, with a link to my research blog and link to the app page, all clearly outlining the parameters of research (Figure 57). In effect, this created an unsolicited and extended number of 20 wildcard users, who used Tumblr to share their visualisations of chronic illness.



Figure 55. Tumblr adoption of Spoonie Living App (May 2016)

As a result of this activity and discussion and use of the app on Instagram, the app was again reviewed by a Spoonie on a WordPress blog, where it was featured as “Instagram for the Chronically Ill: #SpoonieLivingApp” (Grace Shockey, 2016). Here, the app was reviewed as a useful visualisation tool for Spoonies to visually express themselves, where the ability to express comorbid illnesses is addressed: “I give [the app] credit

for the wide variety of illnesses that [it] cover[s] in [it's] stickers: Gluten Free stickers, Epilepsy, MS, Lupus, Coeliac, Chronic Pain, Diabetes, Fibromyalgia, Transverse Myelitis, POTS, Crohn's and Colitis, Stoma Superhero Stickers, IBD, IBS [...]" (2016). Overall, the review was favourable, and interesting in the way it viewed the Spoonie Living app as an alternative Instagram for Spoonies, where the wall facilitated a private community. This provided good initial confirmation that the app was intuitive enough to be used as a standalone device or as a bridge between itself and other social media platforms. It is worth noting here, however, that because I did not select this particular group, none of them presented with comorbid CD together with another chronic illness. This lack of Coeliac comorbid data may prove that my social media focus on Instagram and Twitter data for Coeliac comorbidity using the #spoonie hashtag was correct. However, in terms of Coeliac comorbidity and other chronic illness representation on the Tumblr platform, the result may warrant more investigation on how this is discussed/represented on Tumblr. Ultimately, the new parameters uncovered show the challenge of using live and public digital social methods becomes more apparent, in the sense that when a tool is adopted by wildcard users outside of the group, keeping hold of the reigns and parameters of sharing becomes more difficult.

Gender usage

Results from the sample study confirm data in the literature about the role of gender both in comorbid Coeliac diagnosis, and the use of social media platforms, with a higher number of female participants in comparison to male participants (Megiorni *et al.*, 2008). In terms of the Spoonie App, just 12 out of 300 Twitter followers in the sample group were men. In comparison, 85 out of 653 Instagram followers were men. When looking at the percentage of women and men who identify as having CD, as well as other autoimmune disease, the differences are also strong, with 72% (n = 470) women, and 8% (n = 7) men sharing their use of the app across Twitter and Instagram. This also reflects broader studies of CD, where it was found that more girls and women were found to be diagnosed with CD, than young men or boys (Megiorni *et al.*, 2008). While there has been some speculation as to whether this is mainly to do with men having been

found to be more reluctant to see a doctor than women, due to social and cultural pressures, overall, it has been found that women are more diagnosed with CD than men (Dixit et al., 2014). In terms of overall social media usage, these findings also match recent reports of usage between genders, where, it was found that of all internet users, 22% of women (n = 139 million) are active on Twitter , compared to just 15% of men (124 million), and on Instagram, 20% of women (80 million) are active, again compared to 15% of men (70 million) (Vermeren, 2016).

In terms of the differences found in the way that women share information in comparison to men, Vermeren found that in general, when sharing personal information, men were found to use social media to gather information to boost influence in terms of career and hobbies, while women were found more likely to use social media to make more social connections like staying in touch with family or friends (2016). When looked at from the perspective of sharing information about chronic illness, the percentages match with the literature about the gendered use of social media overall, with only 10% (n = 97 out 953 users) of men in total having self-selected to share their use the Spoonie Living app over social media. The smaller percentage of male users of the app also follows the gender patterns of worldwide levels of diagnoses for autoimmune disease, where, approximately 79% of 8.5 million individuals diagnosed with an autoimmune disease worldwide were found to be women (Abdelaziz, 2007). This data shows that usage of the Spoonie Living and Coeliac Life apps are more or less normalised with correlating data matching diagnosis of chronic illness and CD, as well as gender usage of social media for personal purposes overall. A larger and more wide-reaching study will need to be done to see if this is reflected across all chronic illness communities based on social media.

User Feedback

During the course of the 6-week trial of the app, users submitted feedback by email or direct message facilities on the Instagram or Twitter social media platforms. To do this, I used the following two main strategies: 1) I requested feedback on user experience of the app, and 2) I asked how

each individual used social media to discuss the self-care of their chronic disease(s).

Out of the sample group, 12 out of 40 users supplied feedback. Where it was asked how they used the Spoonie Living App to communicate their illness, 43% (n = 17) said it helped them to better visualise their feelings about managing comorbid illnesses. Interestingly only 14% (n = 6) reported that they used the app to visually tag photos of food from restricted diets like the gluten free diet, stating that they preferred to visualise actual symptoms and triumphs of the embodiment of their illnesses. Users seemed to want to use the app to articulate that which is often unspoken with hidden illnesses, more than they wanted to visually tag their meals. This was also reflected in 75% of total 494 images tagged by users as shared within the app's internal image feed, which contained selfies or co-present parts of individuals. In this case, more stickers were used when things went 'wrong', so Coeliac users used more stickers like "Glutened" or "BrainFog", or "Coeliac Superhero" when they'd had a harrowing day of coping with symptoms.

In this way, the Spoonie Living app seemed to be used as a tool that acted as sharing coping mechanisms, a way of expressing the 'less visible' (whereas ironically, the physical presence of gluten free food is perhaps the more visible aspect of CD). This theme of visualising the 'invisible' was also continued with the amount of images shared by users who used image stickers like "Coeliac Warrior", "Chronic Pain Warrior" or "Diabetic Superhero" to express a sense of pride (22%, n = 109 out of 494 shared images) or communicate the amount of inner-strength (21% n = 104 out of 494 shared images) they used to get through difficult days where symptoms were at their worst, or they had won through against odds.

An example of text accompanying a post shared on the internal wall reads:

“Living with celiac disease is a love/hate relationship because you know your eating healthier for your body but you also have to be very mindful each and every day. It is hard work and takes a lot of discipline and practice but I will fight and do my best.

#coeliac #coeliacdisease #coeliacwarrior #lovehate”.

(Female, unknown age, Instagram post/comment, May 2016)

When questioned about finding support through visualising their symptoms, 56% (n = 22) of users from the comorbid sample group reported that they found connecting with other peers with chronic illness helpful. While the rest (43% n = 17) reported that social media only helped them sometimes, preferring face-to-face contact in local groups than relying solely on social media. 30% (n = 12) of sample users reported that they used social media to share their feelings more than 5 times a day, while 43% reported that they shared at the most 6 times a week. It was found that those that reported sharing more often were from the 18-25 years age group, while those that shared less were from the 30-55 years age group.

Overall, it was found that just over half of the individuals (52.5%, n = 21) in the sample group used more subjective and emotive stickers and co-visual camera angles and viewpoints to communicate symptoms. This suggests that, at least in the attempt to visualise pain/discomfort, there seems to be on balance, a focus on the digital embodiment of feelings and experience of illness in photos shared. Within the sample group it was found that when comorbid individuals visualised overlapping symptoms, they visually communicated the experience of symptoms as a whole - rather than assign specific symptoms to specific diseases. While this could be down to the way the stickers were designed, it is noted that users had full choice of the range of stickers to use, and while in some cases, some used the disease identity stickers together with symptom stickers, 35% (n = 14) separated images of identity from images expressing symptoms. In contrast, it was found that 12.5% (n = 5) of individuals used stickers specifically denoting biosocial identity, like “Coeliac Warrior” or “Diabetes Superhero”, to symbolise positive identity, pride and feelings of positivity whilst maintain chronic disease. However, It was also found that when sharing instances

of the type of gluten free foods they eat/prepare, or find on the move, comorbid Coeliacs within the sample group were more likely to visualise the food itself, rather than themselves eating the food. This arrangement of food may be slightly influenced by the more prevalent style of food photography shared on visual apps like Instagram, and recipe sites on the internet and social media (Araujo *et al.*, 2014).

Despite it being communicated to users that the first prototype of the app would only be available to the sample group via the Apple iPhone and iPad (due to restrictions of time, funds and Android programming skill), as the app became more popular, and more comorbid stickers became available, users also demanded that it be made available to them on Android platforms. As well as being a fairly normal result of growth of use and increase in user demand - this could also be argued to be an example of users feeling empowered by technology and the openness of the research to critique its boundaries/restrictions. Such call-and-response dialogue also helped with ironing out bugs in the app, where I found that $\frac{1}{4}$ of my user-group were unable to use the app on the larger version of the iPhone (iPhone 6+), mainly because the stickers were designed for smaller screens. The open process of dialogue and the users' voluntary sharing of screenshots, were good indicators the problems occurred. This also meant that I was quickly able to address the problem, and republish the app anew, with all bugs fixed, and a happy and importantly more active section of the user group now able to engage with and use the app in the study (Figure 58).

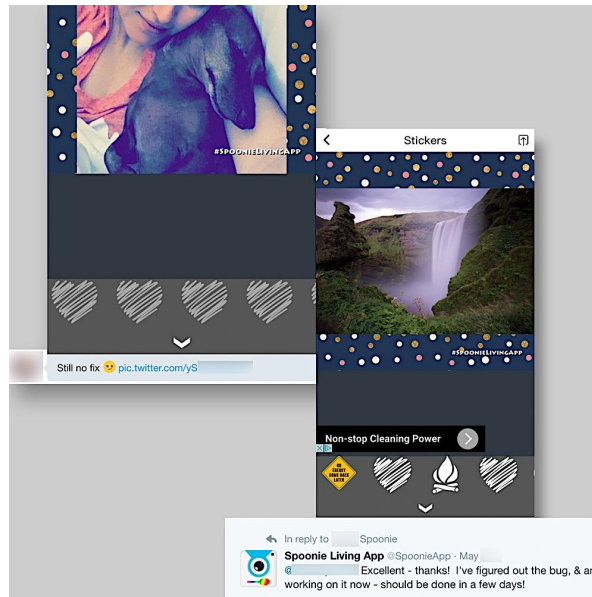


Figure 56. Live Methods + Call-and-Response: Fixing app bugs on live Twitter stream

At all times, I communicated with users via the mediums they felt most comfortable with, whether it was live tweeting, or via personal direct messaging. It felt that by communicating in this way, and ultimately publishing results and fixes in a more general mode, the user engagement and participation flowed well throughout the project.

Private vs Public Visualisation: User Experience

From an ethics point of view, the sharing of photos across the direct messaging aspects of social media platforms Instagram and Twitter, as well as the internal mechanisms of the app, highlighted a few potential problems to be considered in future studies using the app. Despite the use of the Spoonie App to share photos publically across social media networks, Instagram, Twitter and Tumblr, it should also be noted that public sharing was not for everyone, and that care was taken to preserve the privacy of users. Over the course of the six-week period of the app being used by social media participants, it was found that some users felt more comfortable using the app's inner photo wall, rather than sharing via social media. This hidden layer of visualisation became apparent, when in all, some 50 images were posted on the app's internal wall, with only 65% of them showing up on users' existing social media accounts. Of note on Instagram, were users who did not post public images with the app, but

instead used Instagram's Direct Message feature to send photographs specifically for the research study. These photographs showed images with stickers depicting their private struggles with symptoms, that they did not want to share on their public accounts.

For other users of the app, neither Instagram nor Twitter were used, but more private inward facing apps like SnapChat and WhatsApp were used for internal image sharing. Users explained that they did this because they preferred to use more private apps, instead of the broadly public-facing platforms like Instagram or Twitter. Two users requested that the app be adapted to be interfaced to be used via private channels, like SnapChat. It was found that users only shared what they felt comfortable sharing, regardless of whether or not they had public accounts. Some users had more than one social media account, what they called their 'normal' account, away from what their family and friends could see, and then their 'spoonie account', where they felt they could talk freely about their experience of chronic illness without being judged by people they knew in their local environments. On these occasions, I would receive requests to share images, but asked to take away any obvious links back to the user. This type of user behaviour, that blends the boundaries between the private and the public use of images depicting the self-care of chronic illness, seems to support the argument that researchers must not assume that all that is openly shared via accessible Big Data APIs is an accurate example of shared digital social life (Mahrt & Scharrow, 2013).

One occurrence linked to the sanctioned sharing of otherwise private images, was when one member of the user group requested that I share an image on the Instagram wall, however, a few weeks later, in the comments section of the shared photo on Instagram, it was reported by a Spoonie friend of hers, that she had died from a stroke suffered during complications arising during a routine operation. In this case, her family shut down the original Instagram account of the deceased individual. However, instead of this being the final phase - the Spoonie living app image that the user had sanctioned to be shared, was immediately copied and reposted by another Spoonie via her own private Instagram account. This post was in the form of a memorialisation message to alert fellow Spoonies within the

community that she had sadly passed away. The Spoonie Living app stickers the user had shared to self-identify with her comorbid illnesses, were now changed from a living testimony to her comorbid illnesses, to a memorialised statement of the comorbid illnesses she had passed away from. They were instead used to tell her overall story of symptoms suffered as a Spoonie, and also to acknowledge that long-term chronic illness can also have terminal consequences.

At this stage, I had to take the ethical decision as to what to do with the original image of the deceased user of the Spoonie Living app, which at the time was still live on the app's Instagram wall, especially as the family had already closed down her account. There was an interesting incident, where the husband of a deceased lady contacted the friend who had created the private Instagram memorialisation message with her Spoonie Living App image, expressing his thanks for the 50+ messages of support from the community. He then requested that the private image stay up as a reminder of his late wife, and also requested that any public images be taken down. In acknowledgement of this, I took down the public image of the deceased individual, and have anonymised it in the data archives for this thesis.

This kind of occurrence also raises questions as to what is to be done with remaining online data when someone dies. It is argued that the increase in Instagram photo-sharing practices when someone dies echoes a broader shift in commemorative and memorialisation practices, where there seems to be a movement away from formal and institutionalised rituals to informal and personalised, vernacular practices (Gibbs *et al.*, 2015:p.255). Since the emergence of Web 2.0 and social media platforms, various issues have arisen with companies like Facebook and Google finding the need to respond to calls for the control of the accounts of the deceased or online memorialisation with policies these situations should be managed (Gibbs *et al.*, 2013). The ethical issue which arose in this thesis' particular use of Instagram was what to do with the public echo of the shared image of a now deceased user, whose family wanted any social media memorialisation to remain private. In this case, I think taking down the public image in respect of the family's wishes was the right course of

action. However, it is suggested that situations where the family has no input, and where the memorialisation becomes a living symbol or avatar of the person and their illness need to be carefully considered and handled on a case-by-case basis (Gibbs *et al.*, 2013; Klang, 2013).

These hidden layers of both private and public communication of the symptoms of illness must also be taken into account when using social media and m-Health app technology to study chronic illness. It seems that despite the public-ness of smartphones apps in general (outside of the encrypted kind) - there will always be some issues that individuals with chronic illness are unwilling to share. A circumstance also recently found by Yi-Frazier *et al.* in another Instagram study:

"Despite these important findings, it was clear that this intervention was not for everyone, and care should be taken in terms of selecting who might benefit most from this type of program. [...] Many of the reasons for declining focused on being a private person, or not wanting to share about diabetes using social media.

(Yi-Frazier *et al.*, 2015:p.9)

Issues of privacy are legitimate concerns, and despite the last decade being an age of sharing everyday life via public technology, the needs of those who want to use technology to share their chronic illness issues privately, should also be taken into account (Yi-Frazier *et al.*, 2015:p.9). During the case study, where it was unclear if photos found on social media without the #spoonielivingapp hashtag were meant to be private or public, I contacted the user, and asked for explicit consent to share photos on the app's public Instagram wall. Only those photos that had direct permission, or were specifically tagged to notify me that they were public were shared. These occurrences again highlight the blurred boundaries between the private and public sharing of photos, even when the tool used is linked to an inherently public network. What happens when a user expresses a wish to have most images in a social media project made public, but not others? Especially when they request that their images are counted in some way in the researcher's final analysis, but not publicised as evidence of use on an inherently public site? Overall, based on my initial ethics approval for data accumulated and analysed as part of this project - I have in these cases

strived to anonymise all identifiable usernames and links in published works to keep the identity of participants private.

Conclusion

The illustrative study in this chapter has shown that the use of inventive, live participatory digital methods can be used to uncover visual and qualitative insights about how comorbid Coeliacs and individuals with other chronic illnesses visualise their self-care. This uncovers additional data that singular quantitative analysis of conversational textual and hashtag data does not. It elaborated on the argument that to be able to understand how social life is shared and enacted on digital platforms, what is also needed is “a conceptual understanding of the specificities of digital devices and the data they generate” (Ruppert, Law & Savage, 2013:p.4). To this end, it was noted that users’ conceptual understanding of the different constraints of different social media platforms informed how and what kind of chronic illness information they shared, and why. For example, when discussing the management of symptoms in particular, users in the sample group were prone to rely more on the visual elements of the Spoonie Living app when the platform restricted the amount of information shared via word count, than when it did not.

Thus, on Twitter, where there was less space for explanation, users used less words and effectively relied on the image to do the talking for them, by mainly communicating symptoms or identity via image stickers, with little text. However, on platforms that afforded more space for elaboration, users tended to use the same photo to elaborate on the details of self-care to deal with the urgency of symptoms, and additional methods of pain control. As Ruppert, Law and Savage argue: “digital devices and the data they generate are both the *material* of social lives and form part of many of the apparatuses for *knowing* those lives” (2013:p.3).

In terms of working with the Spoonie Living app’s sample user group, I used live methods and call-and-response dialogue via both Twitter and Instagram platforms, by getting users to question and critically examine the tool they were asked, rather than just using what has been given to them by

an 'expert'. Instead, they were asked to critique it, and request where needed, additional stickers that better reflected their daily experience of illness. This helped to challenge and test my previous analysis of the co-occurring hashtags that were shared when users posted about Coeliac and comorbid disease. By crafting the tool of study while it was in live use, such collaboration also gave the sample group the chance for more autonomy and exchange of ideas between themselves and the researcher. This is different because, the Spoonie Living app can act as both a tool for social research, but also serves as a mode of visual expression for the users, both in the study process, and long after the study has stopped.

Limitations of this use of the app include the tool being used by non-Coeliacs both during and after the control group were testing the app. Although I was able to monitor usage from within the app's internal image wall, at some points the data began to be mixed with the posts of other users who did not have CD. It is suggested that any similar studies using the app as a tool should be released within isolation, and not live on the app store, so that data is not potentially skewed. Another limitation was that because (due to Instagram API limitations) the designated hashtag #spoonielivingapp could not be programmatically hardwired into the sharing feature that allowed users to share the app on social media, when images left the app, the requested hashtag was not always used. This made them harder to track via Netlytics and the Digital Methods Initiative hashtag network harvesters, potentially meaning that some images were lost in the social media ether. These limitations reflect Sugiura's caution about the use of new digital methods in the social sciences, that "Whilst the digital space is exciting, [...] new methods and devices for capturing data produce new methodological problems as well as opportunities" (Sugiura, 2014:p.644). A suggestion for the next iteration/version of the app, would be for each image shared to be saved in the backend of the app, on a secure server. In this scenario, all username and identifiers would be stripped to maintain ethical anonymity. Users within small group trials, would be asked their permission for their images to be saved as part of the research project. This would also help mitigate the situation where some images were tagged with the correct hashtag on Instagram or Twitter, but were then prematurely deleted by users if not collected on a daily basis. I

was able to retrieve about 98% of images shared via social media by tracking the hashtag via, for example the Netlytic tool, but found that some images were later lost when I went back to retrieve them.

Finally, this example of exploring Instagram images has shown that the use of digital live methods can indeed provide us as researchers with an opportunity to think about how we reimagine the stream and flow of information shared in its different formats, and how to capture and understand the different and innovative ways that users themselves are adapting basic platforms in order to articulate their experience of life through the digital. Back & Puwar argue: "The use of digital devices [...] offer the opportunity to augment sociological attentiveness and develop mobile methods that also enable the production of empirical data simultaneously from a plurality of vantages" (2012:p.34).

Here, it is hoped that research toolkits like the Spoonie Living app, can also go some way to re-imagining the collection of empirical data that has been visualised by patients, in a way that compounds both the image and text format. It is arguable that this compounding of the visual and textual allows the user/participant to better mold their visual expression of illness within a context that is in keeping with their biographical flow (Williams, 2000b).

Chapter 8: Conclusion

The aims for this thesis were to investigate the following research questions:

- 1. How are social media used to self-manage CD?**
- 2. How might modes of gamification be used to explore and visualise the self-management of CD and comorbid illness?**

In turn, this thesis has addressed questions about how such social media practices may be framed within Foucault's notion of technologies of self. These questions were addressed in terms of how some Coeliacs shared self-care and their formation of online activist movements in moments of uncertainty about food safety. The sharing of risk strategies, and the proactive online protests against issues of cross-contamination in the Gluten Free Cheerios incident, also revealed a certain reconfiguration of patient expertise on chronic health in terms of navigating questions of risk via social media. I also addressed the question of how the live flow of big social data around these practices could be re-imagined, explored and visualised using innovative digital methodologies and tools. It was found that the creation and use of the Spoonie Living app, while in its early stages, helped to assist in the social science analysis of Coeliacs and other chronic illness patients in regards to the way they visualised their self-care.

This thesis has met these aims, and answered these questions by using analysis of the social media practices of Coeliacs as they shared and visualised their self-management of their illness. This was also achieved by the development and deployment of three e-health apps that have been used to re-imagine data as well as act as a visualisation tool for comorbid patients. As a reminder, in what follows, I provide a chapter summary of how each chapter contributes to answering my research questions.

Chapter Summaries

In answer to my first research question of how social media can be used to self-manage CD: the research in this thesis demonstrates that individuals suffering from chronic illness can be both creative and innovative in how they share their embodied self-care practices via social media. Many Coeliacs have found creative ways to gamify the mundanity of self-care by using creative hashtags specific to their experience of, and self-identity with their illness. While both Instagram and Twitter have been utilised to share experiences and information, the use and function of the hashtag on both these platforms have also been creatively adapted by individuals for the sharing of the embodied self-care of chronic illness. This was found to be most apparent in Chapter 4 on Symptoms, Self-care and Subjectivity, with the creation and use of the #NoCureNoChoice hashtag, as well as in the third empirical chapter, with Coeliacs' adoption of the #Spoonie hashtag. In both cases, these hashtags were found to have been used as biosocial identifiers, as well as providing evidence of the practice of Foucauldian self-care/enactment of technologies of the self. The chapter on how Coeliacs use social media to negotiate risk while on the GFD (Chapter 5), also demonstrates how, in addition to these risk aversion practices, groups of Coeliacs could be quite proactive at utilising Twitter and Facebook to self-organise online activist and lobbyist groups during periods of mass food recall, where gluten free staples had been accidentally contaminated.

While there is much in the literature of the sociology of health and illness about how individuals narrate their journeys from diagnosis to the management of chronic illness, I have added to this literature by investigating how these narrations are carried out across different social media platforms, in both text and image form. Throughout the thesis I have demonstrated that discursive practices around the self-care of CD are spread across different social media platforms (e.g. Twitter, Instagram, Facebook and Tumblr), as well as expressed proactively by Coeliacs to forge complex biosocial identities. From the results of this research, it is arguable that together, these discourses have enabled Coeliacs to utilise knowledge to help them avoid the risk of accidental glutening, as well as form collective health movements to deal with issues arising from unsafe

food preparation processes and mass food recalls. I have also demonstrated through the experimental development/deployment of the Spoonie Living smartphone app (Chapter 7), that visual knowledge shared by those with chronic illnesses on social media, can be reimaged and reflected back to new and continuing users to help keep them informed about positive self-care practices, as well as visualise their symptoms.

Overall, what the research thesis adds to the sociology of chronic illness literature, and social sciences literature, is a unique insight into how Coeliacs and those with other chronic illnesses are creatively utilising and adapting social media tools to tell their own illness narratives and quest narratives. I have shown that many Coeliacs are doing so in a way that not only fits within their everyday lives, but also in the form of the gamifying and visualisation of mundane practices like following the prescribed, life-long GFD. I have also shown that by engaging in these digital health practices, Coeliacs and the chronically ill are also expressing how they come to terms with the biographical disruption that a diagnosis can bring. By interacting within chronic illness communities, and sharing chronic illness specific hashtags like #NoCureNoChoice, and #Spoonie, individuals have been found to be creating communities based around biosocial citizenship and biosocial identity via social media, in the way that both Rabinow (2005) and Novas and Rose (2007) envisioned.

When discussing the methodology in this thesis in Chapter 3, I noted how I was mindful of how drawing from different theoretical approaches and perspectives, would leave myself open to criticism in terms of the potential ontological and epistemological tensions/problems with theoretical eclecticism (Williams, 2011:pp.xxi–xxii). I do, however stand by my reasoning that with the current literature around the use of social media in the self-care practices of the chronically ill being in its early stages. While indeed, I have used the approaches of biosocial citizenship, the illness quest narrative, and Foucault's Technologies of Self through which to analyse the Big Social Health Data practices of the chronically ill, it is arguable the approach of using different theories to explore the complex issues that have arisen, has given the analysis of these practices a broader and more flexible scope from which to explore.

From this context, while Foucault's concept of Technologies of Self (1984) have been utilised to study different practices of self-governmentality both offline, in Crossely's study of Body Techniques of self-care within a gym community (2004), and online self-mediation in Cammaert's study of community activism (2008, 2015), to date, the research in this thesis is the only study known to draw on Foucault to study online practices of self-care with CD and chronic illness. The application of Foucault's Technologies of Self to Coeliac practices fit well throughout all three illustrative chapters, where the strongest thread in all my illustrative explorations was Coeliacs' sharing of different methods of self-governance in regards to finding safe food for the Coeliac diet.

In the chapter on symptoms and subjectivity (Chapter 4), while the main theme was the reporting of symptoms via social media and how this reflected the affect this had on individuals' health-related quality of life, the overall theme was how Coeliacs cared for or alleviated their experience of symptoms when they occurred. This theme was continued into the chapter on risk and activism (Chapter 5), where again, notions of risk were seen as the onus of the Coeliac to navigate, request information of likelihood of cross-contamination when eating out, and investigate which remedies to take when glutening symptoms occurred. Finally, the chapter on the visualisation of symptoms and comorbidity (Chapter 7) also uncovered a thread of self-governmentality, where individuals at times shared images of self-care of the flare-up of comorbid symptoms. This is important, because the research in this thesis pulls the work of Foucault directly into the digital and social media world of chronic health and illness practices. It shows that the application of these concepts can be applied not only to the sharing of embodied experiences of chronic illness via social media, but to how practices of self-governance also link with the increased use of social media to reconfigure notions of patient expertise, both in how this expertise and knowledge is shared and utilised to meet individuals' daily and politically activist needs.

The research findings in the first part of the chapter on symptoms and subjectivity (Chapter 4), also show how the use of biosocial hashtags can

alter the look and content of a trending hashtag into one where the focus turns from the perceived physical, body-sculpting results of the GFD, to a focus instead on the micro-constituents of the gluten free food, and how it relates to treating Coeliac Disease. Concepts of biosociality could thus be argued to be having a plausible impact on patterns of data output as they are shared by Coeliacs who use the everyday for the specific treatment of illness.

The chapter on risk and Coeliac activism (Chapter 5) revealed that some Coeliac advocates were creating large online maps to visualise the data of self-reported incidents of Coeliacs who were continuing to get sick from food items that were then declared safe after a gluten free food recall. These mapped incidents were also used as part of a large archive of evidence that was presented to authorities to demonstrate the negative effect that these food items were having on the Health Related Quality of Life (HRQoL) of Coeliacs who had trusted that issues with the food items had been resolved, but were still suffering symptoms of being glutened. This chapter also shows how this concept of self-governmentality, and the importance of having safe food for Coeliacs to be able to responsibly manage their own diets, was also a strong factor in their lobbying of food manufacturers to carry out safe allergen testing practices. The main thread running through this chapter could be summarised with the rhetorical question: "How can we look after our health, if the food you supply us with is processed using scientifically suspect allergen testing practices?" Here, the issue was not: should Coeliacs be responsible for self-care. Rather, it was a demand that they be supplied with safe resources to do so. In this case, the data in the chapter on Risk also highlights the potential tension between Coeliacs and corporations, where Coeliacs must rely on corporate retails and manufacturers to operate safe processing practices so that Coeliacs can use the food produced as a type of medicine for their GFDs.

Finally, the research in the Risk chapter also shows how collective utilisation of the technologies of self in social media activism also has the power to influence government policy and corporation practices. The collective lobbying actions of Coeliacs between July 2015 and August 2016 seem to have widened the debate around mechanical testing/sorting

practices around making non-pure oats safe for Coeliacs to eat. The utilisation of Foucault's 3 stoic practices of technologies of self: with regards to the [social media] practice of Disclosure, Examination and Remembrance of evidence of Coeliacs being glutened by gluten free Cheerios declared safe by the manufacturers, seemed to be enough to induce further investigation of the issue by the Food and Drugs Administration. This public debate of the issue also seems to have widened the debate enough so that rival manufacturers published a scientific paper questioning the use of mechanical sorting practices, and the safety means-based testing in irradiating gluten for cereals aimed at individuals with CD (Fritz, Chen & Contreras, 2017).

With regards to concepts of Biosociality and Biosocial Citizenship (Gibbon & Novas, 2007; Ene, 2009), the research in this thesis shows that, as well as CD being used as a form of collective group identity in practices of activism in the chapter on Risk, it was also shown how complex notions of biosociality and biosocial citizenship can become when it comes to visualising comorbid diseases (Chapter 7). This chapter showed that Coeliacs were able to be quite flexible when identifying and visualising the symptoms or presence of comorbid diseases, in some cases, placing a timeline on the advent of diagnosis or symptoms with before and after photographs, or the order in which they placed disease-related stickers in relation to current diagnosis, or on-going diagnosis. This visualisation of the complexity of identity with disease is important, as it potentially opens up the field of research in terms of finding out how individuals with comorbid illnesses understand and identify with their illnesses/symptoms. Better knowledge of how individuals perceive the comorbid self-management of these diseases may in turn help to better inform how different specialist units collaborate or work together to help patients self-care for their disease post diagnosis.

While there have been studies of health-related hashtags, and how they utilised by individuals on social media platforms, the implications of my findings on how the use of biosocial hashtags can work to change the context of trending lifestyle hashtags is fairly significant. This is because it highlights and expands the already existing tension between Coeliacs who

use gluten free food for treatment of their illness, and individuals who use the GFD for weight-loss and lifestyle enhancement (Schroeder & Mowen, 2014). To date (January 2017), there have been no studies that specifically look at how hashtags around healthy eating are visualised, and how these hashtags are taken up by the chronically ill to demarcate their own use of the diet for their chronic illness needs.

In answer to my second research question, Chapters 6 and 7 focus specifically on how the use and gamification of hashtags can be utilised to explore how modes of gamification be used to explore and visualise the self-management of CD. In Chapter 6, I explore how the results of social media research into Coeliac-related hashtags can be utilised to visualise the concept of CD into two different gaming formats. The first, in the form of the Gluten Fighters app, which explored using games mechanics to visualise how Coeliacs might imagine reacting to being glutened when eating out at a restaurant. And the second in the form of Coeliac Sam, which used a super hero in a more personal visualisation and demonstration of how to manage the GFD. My initial findings of the need to use a more personal and interactive format to elicit a more empathetic response from game users, was further qualified by a review in the *Lancet* (Zajanckauskaite, 2017), which focused on how users might experience using the app from a gastroenterological perspective. It was suggested that the practice of finding food, and experiencing the accumulation of health points was a proactive way of encouraging positive user engagement with their diet. This small chapter also worked as the basis for the further development of the visualisation of health-related hashtags in Chapter 7, where I used the analysis of previous hashtags on symptoms to explore how the creation of a new social research tool (the Spoonie Living app) could be used to analyse and tag the visualisation of symptoms and comorbidity via social media.

Because an initial search for a tool that would help me study this kind of activity could not be found, I decided to utilise my skills as a user experience designer and burgeoning app developer to see if I could build a tool that could enable such research. This soon resulted on the development and deployment of the Spoonie Living app. I created this

patient visualisation and research tool with the aim of better understanding how smartphone apps with an image-based chronic illness theme could assist Coeliacs with comorbid illnesses to visualise their symptoms and the affect this had on their quality of life. Individuals' use of this tool demonstrated that they could utilise various descriptive and emotive virtual stickers to not only visualise and communicate symptoms and self-care, but to change the mood and context of photographs that, without the stickers, would just seem like every day selfies.

The use of chronic illness stickers was found to have a profound impact in revealing the hidden symptoms and thoughts around chronic illnesses, where users at times took previous photos from their Instagram timelines, and added descriptive chronic illness stickers on top of them, to describe how they were actually feeling at the time photographs were taken. This demonstrates that the creation of an additional health-based layer of visual dialogue to photographs can help individuals communicate the embodied experience of chronic illness. The choice and use of stickers by individuals using the Spoonie Living app also suggested more complex forms of biosocial identity occurred with comorbid diseases and the experience of comorbid symptoms. In some cases, overlaps in the gastrointestinal symptoms of CD and both Irritable Bowel Syndrome (IBS) were visualised, where similar symptoms were expressed being attributed to both diseases, where it was unclear if there had been any accidental ingestion of gluten, or if the body was having an irritable bowel reaction to another food ingredient. While the GFD was often associated with a reduction in symptoms, individuals with both IBS and CD still often reported IBS type symptoms. These factors were in line with the current literature about the prevalence of IBS-type symptoms in patients with CD (Sainsbury, Sanders & Ford, 2013).

Where biosocial identity or biosocial citizenship was expressed with these stickers, individuals were also able to demonstrate different stages of diagnosis, with currently diagnosed stickers on one side of their selfie, and on-going or undiagnosed illnesses represented with chronic illness stickers on the opposite side. During collaboration with users, who requested more representative stickers for their comorbidity, these identity stickers were

also used together with stickers that visualised a sense of pride or strength and perseverance despite battling daily with multiple conditions, in the form of stickers like “Spoonie Warrior” or “Coeliac Super Hero”. While this chapter looked at how Coeliacs with comorbid conditions visualised the complexity of the embodied symptoms of their illness, it also demonstrated how technologies were being used to visualise the practices of self-care. This was shown in the way that Coeliacs shared photographs of the various remedies they used to recover from being glutened, as well as images of the other medications they took to alleviate or monitor the symptoms of comorbid illnesses. What was also interesting, was that during the call-and-response process of collaborating with the users of the app to come up with more appropriate visual sticker overlays for their images, users requested additional stickers that would help them express their different methods of self-care.

These visual stickers came in the form of images of, a syringe to represent insulin injections for diabetes, pill bottles for the pain management of arthritis, motivational stamps for images that showed success in finding gluten free food while on the move, as well as stickers that reflected the process of care of comorbid conditions, e.g. a sticker that said “Waiting for Meds to Kick in”. These user requests also demonstrated a great deal of user knowledge about their specific comorbid conditions. Some users sent message requests for newly representative stickers where they took time to go into the details of how and when they were diagnosed, as well as information of what was involved in their self-care, and how they balanced this with everyday activities. There were indeed some instances where I learnt a lot more about the self-management chronic illnesses like Crohns and POTS (Postural orthostatic tachycardia syndrome) from both messages and the text shared alongside images from the app, than I ever would via a simple search engine query. In this respect, the Spoonie Living app both helped to provide richer data for my case study, as well as demonstrate how those with comorbid illnesses were actively using social media and smartphone platforms to reconfigure and share their expertise of self-care of chronic illness in particular (Rose & Novas, 2007).

By aiming to both explore and develop innovative digital methodology to create and deploy a social science research tool, I also hoped to enable Coeliacs and those with comorbid illnesses to visualise their self-care and health-related quality of life. I did this by utilising the research results from the previous chapters on symptoms and risk, to create a smartphone app that used Coeliac and chronic disease specific digital stickers to enable users to visually annotate their experience of illness and self-care. To demonstrate its flexibility, the tool was also built to be easily utilised by other social researchers in projects focused on the visualisation of the self-care of illnesses like Diabetes, Asthma, HIV and Arthritis. Because the main component of the tool is based on stickers that act as visual overlays that enable a user to express how they are feeling, these stickers could be easily replaced with a project specific selection of stickers or images based specifically around diseases like Diabetes, Asthma, HIV or more. The way in which the use of call-and-response collaboration with users was constructed can also be easily replicated by researchers, with the setup and management of open Instagram and Twitter groups, while inviting users to collaborate via direct messages, emails or via the app itself. The way that users communicated with me via the call-and-response method demonstrated that while the utilisation of quantitative data mining and data analyses of social media can give a good base for structuring community apps focused on chronic health, a period of collaboration with test users is also key to understanding to a greater degree, their embodied experiences and needs in terms of self-representation and visual communication. To this end, using a mixed methods approach helped me triangulate the results of my quantitative hashtag and conversation analysis of Coeliac and comorbid posts on Instagram and Twitter. Using the call-and-response method uncovered previously unseen issues and factors that helped to challenge, complement and elaborate on my previous findings.

The process of using the tool to explore the comorbid diseases that occur with CD also led to a better understanding of how Coeliacs interacted with users within other social media communities used by the chronically ill. While the conversations about CD stayed more or less focused on Coeliac symptoms or the ups and downs of the GFD, the more complex interactions and overlaps of the symptoms of comorbid illnesses seemed to broaden

the reach of these conversations to other members of the chronic illness or 'Spoonie' community. It was found that when sharing the images created with the app via Instagram, comorbid Coeliacs were also adding the hashtags #spoonie #spoonielife or #spoonieliving to their posts, these posts were then also getting comments and likes from other chronically ill individuals, who identified with one or more of their comorbid illnesses. This demonstrated that, the visualisation and communication of comorbid illnesses via social media could attract commentary or discussion from others that also identify with parts of the original poster's biosocial identity. In terms of biosocial identity or citizenship then, being a Coeliac and belonging to the Spoonie community is more complex. One is a member of the Spoonie community through the definition of having a hidden illness, however, when it comes to the constituent parts of which of your illnesses are interacted with, this also depends on which parts individuals identify with. Like citizenships of regions, states and countries, biosocial citizenship can be of one overall region, such as Europe, or in chronic illness terms, being a Spoonie. However, identity can also be of specific countries or states within that region too, as can different levels of identity with the particular groupings of comorbid diseases in the Spoonie community, like Coeliac and Diabetes, or Coeliac and IBS or Arthritis.

The chapter on visualising comorbidity (Chapter 7) also demonstrated the different variations of presence and co-presence of individuals who share images of themselves when visualising their experience of their disease. When talking about symptoms of comorbid illness, the rates of co-presence were pretty high, with 65% of images showing the individuals' face or visible feature. This also occurred when people described their lives before and after the diagnosis of illness, or where on initial use of the apps, they took previous photos from their timeline and used the app to add stickers about what they were feeling in terms of their illness at the time the photo was taken. This shows that the app enables people to add an extra layer of visual detail to photos to reveal the often hidden symptoms or illnesses that were 'present but hidden' when originally taken. This also gives us visual insight into how embodied symptoms affect the health-related quality of life of the individual, especially where stickers like "glutened", "managing pain one day at a time" or "caution symptoms in progress" are overlaid onto

photos taken at the time of the experience of comorbid symptoms in conditions like CD and Arthritis.

Chapter 7 also highlighted the need to be continuously aware of ethics procedures at each stage of the research process, especially when it comes to the sharing of personal images that focus on chronic illness, and often-vulnerable patients. While the call-and-response process meant that I had the chance to collaborate with and learn from users of the app, it also brought me into situations where users with private Instagram accounts wanted to contribute to the research, but also wanted their data to remain private. In these situations, I had to figure out how to make sure that their data remained anonymised, but that their input was also formally recognized as part of the research data. This became more complex when one of my collaborators sadly passed away during the research period, and a decision had to be made to extract her data from the project. As with all things to do with online and social media spaces, ethics plays a key part in how data produced and shared by users is handled and respected, as well as how more vulnerable users identities are safeguarded and if needed, anonymised. Overall, this chapter demonstrates that there is an opening for innovate live methods and digital tools to be developed and used by social scientists to study how Coeliacs and those with comorbid illnesses visualise their disease. It also highlights varying degrees of complexity in terms of how discussion of comorbid illnesses can overlap, in terms of the biosocial identities they straddle, as well as issues of the private versus the public sharing of user experience.

Limitations of the Research

In this thesis, I have sought to extend the current field of research by demonstrating how many Coeliacs (including those with comorbid illnesses) use social media as knowledge sharing, risk aversion and self-care visualisation tools in the course of their self-management of their chronic disease. My findings are important for two main reasons in relation to the theoretical and practical implications of this work, as well as options for future research, which I discuss below.

It is acknowledged that the field of literature into the study of health and illness, and the use of social media in this area is vast, and growing. While I focussed on using the theoretical framework of Foucault's work on the Technologies of the Self and Rabinow (2005), Ene's (2009), Novas and Rose's (2007), concepts of biosociality and biosocial citizenship, it is acknowledged that the sharing of knowledge about chronic illness has been studied using different theoretical lens. This includes a further investigation of newer notions of digital habitus through Bourdieu's lens of relational interactions and habitus (Burkitt, 2002; Papacharissi, Streeter & Gillespie, 2013; Crossley, 2014). While these and a wider number of theoretical frameworks are indeed valid, I feel that the use of concepts in this current project have helped to add some interesting results to the field. It is hoped that future studies adopting different lenses of analysis will provide further insight.

Methodologically, one of the practical limitations of this study is that no interviews or long-term follow up were made of participants in each of the illustrative studies. Data was collected using the social media APIs of Twitter, Instagram, and Facebook, and illustrative study design was based on the results of analysis of this quantitative data. Although in Chapter 7, feedback was given by users of the Spoonie Living app via unsolicited email and direct messages via the various social media platforms, interviews or other follow-ups were not utilised. Coeliacs were not followed beyond the six-week study, to see if they continued to use the app. However, after the research period, a general monitoring of the sharing activity via the app's Instagram account and the app's internal private

image between May and October 2016, found that twenty-two returning users consistently posted between five - twelve images using the Spoonie Living app per month, five of which were comorbid Coeliacs. This suggests that outside of a controlled illustrative exploration, user retention of this small app has the potential to continue. It is also acknowledged that the study sample was predominantly female (85%), more so than current rates of Coeliac diagnosis (75%) (Catassi, Gatti & Fasano, 2014). Future studies should better reflect this ratio, while it is also acknowledged that such long-term feedback would have given greater insight into additional outcomes.

Policy Implications

In terms of how this research can affect policy and practice around the online support of the chronically ill online, the research in this thesis has identified how the harvesting of Big Social Health Data can be utilised to uncover biosocial practices around the self-care of illness, as well as disease specific hashtags that can travel across social media networks. While the number of individuals covered in this research is small, and only representative of a sample of Coeliacs who use social media to share their self-care practices, a larger study sample over a longer period may bring more valuable insight. As with most study of social media, this research does not claim to be representative of all Coeliacs, or indeed of all Coeliacs who use social media. Some Coeliacs may use social media but never share insights to their disease, instead preferring to discuss other life experiences, while other Coeliacs may not use social media at all, and may be better studied via more traditional qualitative surveys, interviews and questionnaires. However, by studying samples of those Coeliacs that use social media, and by following such hashtags as #NoCureNoChoice and #Spoonie, and interacting with the groups and individuals who use them, further research may give policy makers and health workers valuable insight into how the chronically ill self-manage their illness away from official social care settings. Further analysis of the types of informal remedies shared and tagged with these hashtags (as discussed in the Methodology chapter of this thesis), may also give additional valuable insight into drug interactions, and potential holistic or natural therapies to alleviate symptoms. Such potential was shown in empirical Chapter 3,

where comorbid hashtags used by individuals on the GFD, who also had a POTS (Postural Tachycardia Syndrome) diagnosis, was found to compare with new scientific literature on POTS patients independently adopting the GFD, with a percentage of them then later being diagnosed with CD (Penny *et al.*, 2016). It is arguable that while such patterns may be uncovered in medical health centres and group trials, an analysis of Big Social Health Data may also be valuable in uncovering further insight.

While it has been found that some Coeliacs use a variety of different social media platforms to share their experience with the disease, as well as managing comorbid illnesses, these stories highlight important factors about the experiences of some Coeliacs journeys before, during and after diagnosis. The self-reported experiences of some of these Coeliacs have revealed in ways that might not be immediately apparent when shared within a controlled research environment. This gaining of insight into the self-reported experiences, frustrations, and feelings of stigma, triumph and collective activities of Coeliacs, is important for understanding how some Coeliacs manage their lives with CD outside of the feedback given within a clinical or institutionalised setting. These additional insights into the daily practices of some Coeliacs may be useful for informing future policy on how to structure and co-ordinate online resources of care for many Coeliacs. These analyses may also be helpful for planning how to link up online resources and community care with the on-going care they are receiving for other comorbid diseases.

One of the most significant implications of this research for practice in the social science study of CD and other chronic illnesses, is that created by the use of smartphone m-health applications and Live Methods to carry out investigation into Coeliacs' self-care practices. While m-health and gaming apps have been used in a number of studies (Van Laere, De Ruyck & Willems, 2013; Munson *et al.*, 2014), an investigation of the literature has not uncovered an illustrative study where a games character has been created to represent patients with CD, and also used to investigate and encourage behavioural change. In Chapter 7, the visualisation, development and deployment of the Spoonie Living app was based on the social science analysis of self-reported hashtags and posts in the live flow

of Big social data shared by Coeliac patients. This was in answer to Pols' call for the use of gamification research on patient knowledge to be used in a creative way that would help other patients: "What is patient knowledge, how does it relate to other forms of knowledge, and how can it be made useful to people with chronic disease?" (2013b:p.82). This experimental visualisation of working concepts found of patterns in Big Social Health Data was not only an attempt to re-imagine these results, but also an attempt to triangulate my findings and to discover if they would be understood not just in academia, but by the very community that were sharing their embodied experiences. The successful deployment of the Spoonie Living app, and the resulting validating feedback from users shows that the gamification of chronic illness data from social media can be actively used to help new and continuing patients.

It is hoped that the methods used for studying the visualisation of comorbidity in Chapter 7 can also be used to further disseminate research to assist in public engagement in future research. An example of this would be the development of a more interactive game that sets users with more tasks centred on the self-management of CD and the GFD. This could be developed with a form of prolonged community engagement in mind, where seasonal challenges are set, and games characters come together to complete set goals, or to help other characters learn about the self-care of their chronic illness. Such interactive gamification could in turn feed into the already vibrant Twitter and Instagram communities based around Coeliac and chronic illness hashtags, where users could engage with the call-and-response framework, giving input about different aspects of the game, that could be better adapted to fit embodied experiences. The long-term data from this experimental research could then be analysed, and a cohort of users interviewed at the beginning, middle and end of a set period to assess any significant affects or changes in behaviour as a result of engaging in the project. Indeed, the use of the call-and-response method of user collaboration is suggested as an effective way of using social media to enhance future research projects, especially in more sensitive fields of chronic health and illness. It is arguable that these techniques can work to inform and challenge such research, as well as enhance user experience.

The creation and deployment of the Spoonie Living app as a research tool and a tool for user visualisation of chronic illness, has potentially significant implication for future research projects in Coeliac Disease, comorbid and other separate chronic illnesses. This illustrative exploration shows that fairly basic research tools can be created to assist with the research of image-based social media data, in a way that also interfaces with existing social media platforms that patients and users are familiar with. The evidence in Chapter 7, that at least two Spoonies in the visualisation sample group were inspired to create un-prompted blog posts that described how to utilise this tool, and how it also enabled them to visualise their illness across social networks, shows that there is scope for the use of this tool in other research projects. The basic structure of the tool essentially means that the main things to be changed are only the images used in the interface, and the key sticker overlays, which could be adapted to match any type of social science project focussed on studying how individuals use visual meta-tagging to express their daily experiences via social media. While the limitations to using the existing app as it stands have been acknowledged in the previous section, the potential for tools of this type to be used in research of social media, is positive.

Overall, this thesis has shown that while the treatment for CD is the life-time avoidance of gluten, the self-reported experience and practices of some Coeliacs via social media, shows that self-care for CD is much more complicated than simply avoiding gluten. What these illustrative examples reveal is that many Coeliacs must balance a multitude of everyday experiences in relation to gluten free food, its source, consumption, and safety, in almost every aspect of their lives. This ranges from the challenge of finding gluten free food on the move, to finding out what to do in the event of becoming accidentally glutened, to figuring out how to manage feelings of isolation and stigma. Some Coeliacs are often actively sharing and visualising these experiences, as well as using social media to form new identities post-diagnosis, as they try to adapt their lifestyles to living with the disease. The data analysed in this thesis also suggests that some Coeliacs share this journey with others similar to themselves by using Coeliac-related hashtags that help denote a biosocial identity that shapes online discussion around the disease, and thus helps alleviate the initial

biographical disruption of diagnosis into a reformulation of biographical flow. This can eventually enable them to manage their life with the additional adherence to a safe GFD.

This thesis has demonstrated analysis of Coeliacs' use of social media to share the experience and symptoms of CD and comorbid illnesses gives us a valuable insight into how such knowledge is shared and visualised on a daily basis. The use of experimental methods and the utilisation of the results of analysis into interactive digital research toolkits also has the potential to give us valuable insight into the embodied practices and processes of adapting to and visualising chronic illness. Having access to an on-going stream of online data, allows us to spot patterns in terms of self-reported adherence to the Coeliac Diet, and different methods used to cope with complex symptoms of comorbidity with CD. It is hoped that the research in this thesis will make a positive and useful contribution to the current literature and wider awareness of the self-care CD in particular, as well as the larger field chronic and comorbid illness.

Appendix I

Smartphone Apps

This thesis contains references to the publication of two mobile m-Health apps, which have been published on the Apple iTunes store, Google Play and the Amazon App stores under a Creative Commons license. These are publically available, and can be downloaded via the links below:

Coeliac Sam

<https://appsto.re/gb/vH9o2.i>

Spoonie Living App

Website:

<http://www.spoonieliving.com>

Apple Store:

<http://appsto.re/gb/A-tPbb.i>

Android Store:

<http://bit.ly/spoonieandroid2>

Amazon Store:

<https://www.amazon.co.uk/Samantha-Martin-Spoonie-Living/dp/B01LW2XYVK/>

Instagram:

<https://www.instagram.com/spoonielivingapp/>

Twitter:

<https://twitter.com/spoonieapp>

Appendix II

Ethics Review Form

Centre for Interdisciplinary Methodologies

Research Ethics Approval Application

Please complete and sign this form and return with copies to the Director of Graduate Studies.

No research activities with ethical considerations may begin before CIM's ethics approval committee has issued its written approval. Written confirmation of the committee's decision will be emailed to the student. The Director of Graduate Studies will retain a copy of this completed form.

Before completing this form, applicants must refer to the University's Statement and Guidelines on Ethical Practice ([research_code_of_practice/](#)) in conjunction with any other guidance or ethical principles relevant to their specific research.

If supervisors or students have exceptional concerns about the ethics of a project, then the proposal should be submitted for approval to a University Research Ethics Committee (REC). In most cases this will be Humanities and Social Sciences Research Ethics Sub Committee, but may be relevant to other (RECs). To establish which REC a proposal should be submitted to, please check the University Ethical Review Decision Making Tool - http://www2.warwick.ac.uk/services/rss/researchgovernance_ethics/research_code_of_practice/humanparticipants_material_data/triage/

Name of Researcher: Samantha Martin

**Research project title: Coeliac Disease:
Chronic Illness and Self-Care in the Digital Age**

Supervisor: Dr Emma Uprichard and Prof. Simon Williams

**Dates when research will be conducted: 1 October 2013 – 30
September 2016**

Proposed PhD Completion date: 1 October 2016

SECTION ONE – PROJECT DETAILS

1. **Please give a brief summary of the project (in lay terms), including the scientific benefit.**

My doctoral research will be exploring how individuals' online interactions inform their health-navigation of the city. The working title of my study is: Twitter: Re-Writing The City Landscape With Commons Health Knowledge. With the case study of coeliac disease, the study aims to visualise the flow of patient interaction through Twitter to detect patterns of decision-making and risk-aversion, by creating a virtual map of health annotations in both London and New York. Co-funded by a Warwick University and Coeliac UK, WCPRS Collaborative Studentship, I will use co-word and sentiment analysis to explore how people use Twitter as a tool to manage their health.

It is proposed that studying and visualising this activity will give social researchers, health professionals and those involved in giving Coeliacs access to gluten free food, a broader overview of patterns created via Twitter communications, and help to address problem areas and add extra resources of help/access where this occurs.

2. **Please summarise the methodology to be used.**

Over a three month period, during the 1st year of study, I will scrape Twitter for health related tweets by Coeliacs in both London and New York. I will then analyse these tweets explore their content. In particular, I will be interested in tweets which show elements of: decision-making, commons knowledge, peer support or risk-aversion behaviour. Finally, I will make sense of this big data by using innovative digital visual mapping techniques to map patterns of change and continuity over time and space at multiple micro-macro levels. Note that since all data is publically available, I do not foresee any particular ethical issues with respect to collecting and analysing the data.

3. **Please describe briefly any ethical issues and / or sensitive topics that will be covered during the course of the project.**

All data will be sampled from public access data via the public Twitter and Google Spreadsheet APIs. People will be tweeting personal (and therefore potentially sensitive) information about the symptoms of their Coeliac Disease, their self-management of the gluten free diet, questions about how and where to find gluten free food, and the results of various medical tests and procedures they go through pre- and post-diagnosis. I will have access to all the usernames and photos of users, as well as 1% of actual geo-locations of some of the tweets (though 99% will come from the more general area of New York and London, and I will not have the

specific location of 99% of tweets). The 1% of tweets that have actual geo-locations could potentially invade the privacy and security of those users. The use of any photos of posted by users could also pose copyright issues. I address this in point 4 below. Again, however, please note that whilst this data is potentially sensitive, all tweets are publically available and are shared by users voluntarily.

4. How do you intend to handle these areas?

Although harvesting of publically available tweets will give me access to all the usernames of Tweeters, their location, and the locations of the venues they tweet about, to ensure anonymity and confidentiality is preserved, all usernames, user-owned photos, exact geo-locations, and venue names will be removed from any written up material. This will ensure that confidentiality and anonymity are preserved throughout the research process and beyond.

Where any photos of food or venues that have been posted by users require use in presentations at conferences etc., I will contact users for their direct permission, and will withdraw use of an image if request is denied.

Each plot on the mapped data will only cover the general area of the city that the user or food venue resides, and not the actual address.

This study will follow the British Sociological Association's and the Social Research Association's ethical guidelines and it will insure confidentiality and anonymity in all published materials.

5. What possible or risks are there for the researcher?

I will not be engaging with the users that I study, but only quantifying the content of their publically available tweets, so there are no perceived possible risks for me as a researcher.

6. Will you or any of the research team come into contact with participants be required to obtain criminal record clearance?

Yes No

7. If "yes", please confirm that such clearance will be obtained.

SECTION TWO - PARTICIPANTS

1. How will participants be recruited?

I will use data-mining techniques via the public Twitter and Google Spreadsheet APIs. This will download health-related tweets every hour over a period of three months. There will not be any direct interaction or recruiting of participants beyond this method.

2. How many participants will be recruited?

- **The data of around 1000 – 10,000 Twitter users will be collated. This is publically available data.**

3. How will informed consent be obtained from the participants? (Please provide a copy of any consent forms and participant information sheets to be used). If no consent will be obtained, please explain why.

No consent will be obtained because I will be mining the publically available Tweets from Twitter. In addition, I will be removing all usernames/user ids, so there will be no way of tracing who they are in any written up material.

4. Will deception be used during the course of the research?

Yes No

5. If yes why is it deemed necessary?

6. Will the participant group include any children or vulnerable adults?

5) Yes No

7. If yes, please explain the necessity of including these individuals.

8. If yes, please explain how and from whom fully informed consent will be obtained.

9. **Will participants be given payment and/or incentives for participating in the research?**

Yes No

10. **If yes, please specify level of compensation, and source of the funds or incentives.**

11. **If yes, please explain the necessity of such compensation**

12. **What possible benefits and/or risks to participants are there to this research?**

Benefits to participants:

It is arguable that in a Western society where wheat and gluten are the main staple, Twitter can be used to identify new knowledge, to find food venues, make decisions about the risk of cross contamination, and also the quality of gluten free food – all in the process of planning Coeliacs' daily work, travel and vacation excursions. In this sense, Twitter can prove to be a convenient vehicle to multi-task all these activities on the move. It is in these communications, actions and navigations that the city may be overlaid with a virtual layer of health data, that is intermixed with food, expert and commons knowledge, all geared towards the self-management of a chronic condition that affects every day of a Coeliac patient's life. It is proposed that studying and visualising this activity will give social researchers, health professionals and those involved in giving Coeliacs access to gluten free food, a broader overview of patterns created via Twitter communications, and help to address problem areas and add extra resources of help/access where this occurs.

Risks to participants:

As address in Section I, point 3, above: All data will be sampled from public access data via the public Twitter and Google Spreadsheet APIs. People will be tweeting personal (and therefore potentially sensitive) information about the symptoms of their Coeliac Disease, their self-management of the gluten free diet, questions about how and where to find gluten free food, and the results of various medical tests and procedures they go through pre- and post-diagnosis. I will have access to all the usernames and 1% of actual geo-locations of some of the tweets (though 99% will come from the more general area of New York and London, and I will not have the specific location of 99% of tweets). The 1% of tweets that

have actual geo-locations could potentially invade the privacy and security of those users.

13. What arrangements have been made for reporting the results of the research to and/or debriefing the participants?

It is not intended to report the results of the research to the participants, as I will be studying the patterns of behaviour via co-word analysis and sentiment analysis of the text within the tweets collected, and not engaging directly with the users. All data will be anonymised, so my end results will look at anonymous clusters of data over the general geographical regions of London and New York.

14. What qualified personnel will be available to deal with possible adverse consequences/reactions to participating in this research?

My supervisors, Dr. Emma Uprichard and Prof. Simon Williams will be available to help.

SECTION THREE - DATA

1. How will you ensure confidentiality? (Please give details of how and at what stage in the project you will anonymise data)

Once I have harvested all the Tweets, I will go through the process of cleaning the data by stripping all the user-ids and user photos of all the Tweeters. All I need to analyse the data are the content of the Tweets and the names of the venues mentioned. I already have some code that locates the tweets within a 15 mile radius of the cities of London and New York, so there is no need to keep the exact geo-locations of the Tweets – these will also be stripped from the data.

2. Who will have access to the data?

Myself and my supervisors will have access to the raw data. Once I have analysed it, I will produce statistical, general GIS and charted information based on samples of the data, but these will be anonymised via the procedure in point 1 above. Final analysis will be accessible by my co-sponsor, Coeliac UK.

3. Where will consent forms, information sheets and project data be stored?

Project data will be stored on a secure SQL server that I have running on a laptop.

4. **For how long will the above data be kept and how and when will data then be destroyed?**

The data will be kept for the duration of my PhD, first on the secure server, and then on a secure external hard drive. It will be destroyed once the results of my thesis have been published.

5. **Is it anticipated that there will be any future use of the data and have the participants been informed of this use.**

Only the analysed anonymised results in my thesis will be used, the actual data mined from Twitter will not be used in the future.

6. **Will any interviews be audio or video-taped?**

Yes No

7. **If yes, please attach a copy of the consent/authorisation form**

SECTION FOUR - PUBLICATION

How will publications of research findings recognise the contributions of all researchers engaged in the study?

The contributions of all researchers will be recognised by name in any papers published, any conferences, or any other disseminations in this study.

SECTION FIVE – FURTHER INFORMATION

Please give any additional information you believe to be relevant to this project:

My research is co-sponsored by the charity, Coeliac UK

NB: The following information should be included **at some point** within the **participant information sheet**:

Should anyone have any complaints relating to a study conducted at the University or by University's employees or students, the complainant should be advised to contact the Deputy Registrar (contact detail below)
http://www2.warwick.ac.uk/services/rss/researchgovernance/complaints_procedure/

This information has been included. (Please check tick box on RHS)

SECTION SIX – DECLARATION

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by the ethical principles underlying the Declaration of Helsinki (<http://www.wma.net/e/policy/b3.htm>) and to abide by the University's Research Code of Conduct (<http://www2.warwick.ac.uk/services/rss/>) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- If the research is approved, I undertake to adhere to the study protocol without agreed deviation.
- I undertake to inform CIM of any changes in the protocol that would have ethical implications for my research.
- I am aware of my responsibility to be up to date and to comply with requirements of the law and the appropriate guidelines relating to security and confidentiality of participants' personal data.

APPLICANT CHECKLIST:

- Yes No Fully completed application form.
Yes No Copies of any Participant Information Sheet(s) on University letterhead.
Yes No Copies of any Participant Consent Form(s) on University letterhead.
Yes No Copies of any relevant authorisations.

Signature of Student:

Name (Please Print): Samantha Martin

Date: 19/11/2013

Signature of Supervisors.....

Name (Please Print): Emma Uprichard and Simon Williams

Date: 19/11/2013

Signature of Graduate

Director.....

Name (Please Print): Celia Lury

Date: 19/11/2013

DECISION

APPROVED without revisions: Yes No

APPROVAL CONDITIONAL ON:

RESUBMISSION: Please pay special attention to section(s):

Signature of Graduate

Director.....

Name (Please Print): Celia Lury

Date: 11/11/2013

Bibliography

- Abdelaziz, F. Ben (2007) Women's Health and Equity Indicators. *International Journal of Public Health*. [Online] 52 (S1), S1–S2. Available from: doi:10.1007/s00038-006-6045-y.
- Addolorato, G. (2001) Anxiety But Not Depression Decreases in Coeliac Patients After One-Year Gluten-free Diet: A Longitudinal Study. *Scandinavian Journal of Gastroenterology*. [Online] 36 (5), 502–506. Available from: doi:10.1080/00365520119754 [Accessed: 30 May 2014].
- Ajzen, I. (1991) The theory of planned behavior. *Organizational Behavior and Human Decision Processes*. [Online] 50, 179–211. Available from: doi:10.1016/0749-5978(91)90020-T.
- de Albuquerque, J.P., Eckle, M., Herfort, B. & Zipf, A. (2016) Crowdsourcing geographic information for disaster management and improving urban resilience: an overview of recent developments and lessons learned. In: *European Handbook of Crowdsourced Geographic Information*. Ubiquity Press. p. 309.
- Ampofo, L., Collister, S., Loughlin, O. & Chadwick, A. (2014) *Text Mining and Social Media : When Quantitative Meets Qualitative , and Software Meets Humans*. (October 2013).
- Araujo, C.S., Correa, L.P.D., Silva, A.P.C. Da, Prates, R.O., et al. (2014) It is Not Just a Picture: Revealing Some User Practices in Instagram. In: *2014 9th Latin American Web Congress*. [Online]. 2014 pp. 19–23. Available from: doi:10.1109/LAWeb.2014.12.
- Back, L. (2012) Live sociology: social research and its futures. *The Sociological Review*. [Online] 60, 18–39. Available from: doi:10.1111/j.1467-954X.2012.02115.x.
- Back, L. & Puwar, N. (2012) A manifesto for live methods: provocations and capacities. *The Sociological Review*. [Online] 60, 6–17. Available from: doi:10.1111/j.1467-954X.2012.02114.x.
- Bastian, M., Heymann, S. & Jacomy, M. (2009) Gephi: an open source software for exploring and manipulating networks. In: *International AAAI Conference on Weblogs and Social Media*. 2009 p.

- Bates, C. (2011) *A Visual Sociology of Health and Illness in Everyday Life*. Goldsmiths, University of London.
- BBC.com/News (2015) *Twitter tells users to stop posting Instagram links (BBC Newsbeat)*. [Online]. 2015. BBC (British Broadcasting Corporation). Available from: <http://www.bbc.co.uk/newsbeat/article/30948810/twitter-tells-users-to-stop-posting-instagram-links> [Accessed: 29 April 2015].
- Beck, U. (1992a) *Risk Society: Towards a New Modernity*. Theory, Culture & Society Series. Mark Ritter (ed.). [Online]. Sage. Available from: doi:10.2307/2579937.
- BeyondCeliac.org (2016) *Celiac Disease and Gluten Sensitivity Glossary | BeyondCeliac.org*. [Online]. 2016. BeyondCeliac.org. Available from: <http://www.beyondceliac.org/celiac-disease/glossary/> [Accessed: 21 January 2016].
- Bladh, G. (2014) *Hard Body 2.0 - The Construction of the Fitness Subject: An Analysis of Swedish Fitness Blogs*. [Online]. 2014. idrottsforum.org (Institutionen för idrottsvetenskap, Malmö högskola Publicerat på). Available from: doi:10.1017/S0009840X00202849 [Accessed: 15 May 2015].
- Bogost, I. (2014) Why Gamification is Bullshit. In: Steffen P. Walz & Sebastian Deterding (eds.). *The Gameful World: Approaches, Issues, Applications*. 1st edition. Cambridge, Massachusetts, MIT Press. pp. 65–79.
- Borra, E. (2015) *ToolTumblr*. [Online]. 2015. DigitalMethods.net. Available from: <https://wiki.digitalmethods.net/Dmi/ToolTumblr> [Accessed: 16 September 2016].
- boyd, d. & Crawford, K. (2011) Six Provocations for Big Data. *Computer*. [Online] 123 (1), 1–17. Available from: doi:10.2139/ssrn.1926431.
- Britten, N. & Maguire, K. (2016) Lay knowledge, social movements and the use of medicines: Personal reflections. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. [Online] 20 (2), 77–93. Available from: doi:10.1177/1363459315619021.
- Broniatowski, D.A., Paul, M.J. & Dredze, M. (2013) National and local influenza surveillance through twitter: An analysis of the 2012-2013

influenza epidemic. *PLoS ONE*. [Online] 8 (12), 1–8. Available from: doi:10.1371/journal.pone.0083672.

Brown, P. & Morello-Frosch, R. (2011) Health social movements: advancing traditional medical sociology concepts. In: *Handbook of the Sociology of Health, Illness, and Healing*. [Online]. pp. 117–137. Available from: doi:10.1007/978-1-4419-7261-3.

Brown, P. & Zavestoski, S. (2004) Social movements in health: An introduction. *Sociology of Health and Illness*. [Online] 26 (6), 679–694. Available from: doi:10.1111/j.0141-9889.2004.00413.x.

BSA (2006) *Statement of ethical practice for the British Sociological Association*.

Burkitt, I. (2002) Technologies of the Self: Habitus and Capacities. *Journal for the Theory of Social Behaviour*. [Online] 32 (2), 219. Available from: doi:10.1111/1468-5914.00184.

Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of health & illness*. 4 (2), 167–182.

Bury, M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness*. [Online] 23 (3), 263–285. Available from: doi:10.1111/1467-9566.00252 [Accessed: 10 February 2017].

Bury, M. (1997) The body health and risk. In: *Health and Illness in a Changing Society*. [Online]. Routledge. pp. 171–201. Available from: https://books.google.co.uk/books?id=1RCDrFWacdIC&dq=%22The+body+health+and+risk%22+bury&source=gbs_navlinks_s [Accessed: 3 June 2014].

Bury, M. (1991) The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*. [Online] 13, 451–468. Available from: doi:10.1111/j.1467-9566.1991.tb00522.x.

Cammaerts, B. (2015) Technologies of Self-Mediation: Affordances and Constraints of Social Media for Protest Movements. In: Julie Uldam & Anne Vestergaard (eds.). *Civic Engagement and Social Media: Political Participation Beyond Protest*. [Online]. Palgrave Macmillan. pp. 87–110. Available from: doi:10.1057/9781137434166.

Cammaerts, B. (2008) Technologies of Self-Mediation: Affordances and Constraints of Social Media for Protest Movements. In: Julie Uldam &

Anne Vestergaard (eds.). *Civic Engagement and Social Media*. pp. 87–89.

Carricaburu, D. & Pierret, J. (1995) From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health & Illness*. [Online] 17, 65–88. Available from: doi:10.1111/1467-9566.ep10934486.

Carrigan, M. (2014) *Qualitative self-tracking and the Qualified Self* | Mark Carrigan on WordPress.com. [Online]. 2014. Available from: <http://markcarrigan.net/2014/07/23/qualitative-self-tracking-and-the-qualified-self/> [Accessed: 28 July 2014].

Catassi, C., Gatti, S. & Fasano, A. (2014) The new epidemiology of celiac disease. *Journal of pediatric gastroenterology and nutrition*. [Online] 59 Suppl 1 (July), S7-9. Available from: doi:10.1097/01.mpg.0000450393.23156.59.

Celiac.org (2017) *Celiac Disease Foundation Urges You to Contact Your Representatives About Preserving Critical Affordable Care Act Patient Protections - Celiac Disease Foundation*. [Online]. 2017. Celiac.org. Available from: <https://celiac.org/blog/2017/01/celiac-disease-foundation-urges-contact-representatives-preserving-critical-affordable-care-act-patient-protections/> [Accessed: 24 February 2017].

Charlebois, S., Von Massow, M. & Pinto, W. (2014) Food Recalls and Risk Perception: An Exploratory Case of the XL Foods and the Biggest Food Recall in Canadian History. *Journal of Food Products Marketing*. [Online] 21 (1), 27–43. Available from: doi:10.1080/10454446.2013.856055.

Chen, N.N. (2009) *Food, medicine, and the quest for good health : nutrition, medicine, and culture*. Columbia University Press.

Chick, K. a. (2014) Focus on Inclusive Education: The Educational and Social Challenges of Children With Celiac Disease: What Educators Should Know. *Childhood Education*. [Online] 90 (1), 71–74. Available from: doi:10.1080/00094056.2014.872520 [Accessed: 29 May 2014].

Chunara, R., Chhaya, V., Bane, S., Mekar, S.R., et al. (2012) Online reporting for malaria surveillance using micro-monetary incentives, in urban India 2010-2011. *Malaria Journal*. [Online] 11 (1), 43. Available

from: doi:10.1186/1475-2875-11-43.

- Coeliac UK (2015a) *Coeliac Disease FAQ: How common is Coeliac Disease?* [Online]. 2015. CoeliackUK.org. Available from: <https://www.coeliac.org.uk/frequently-asked-questions/how-common-is-coeliac-disease/related/> [Accessed: 1 February 2014].
- Coeliac UK (2015b) *Product recalls: Asda, Sainsbury's, Waitrose, Morrisons, Tesco and Genius - Coeliac UK.* [Online]. 2015. Product recalls: CoeliackUK.org. Available from: <https://www.coeliac.org.uk/about-us/news/genius-asda-and-sainsburys-product-recalls/> [Accessed: 10 February 2016].
- Coeliac UK (2014) *Symptoms - Coeliac UK.* [Online]. 2014. CoeliackUK.org. Available from: <https://www.coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/symptoms/> [Accessed: 30 May 2014].
- CoeliacUK.org (2015a) *Campaign to protect prescription services in England - Coeliac UK.* [Online]. 2015. CoeliackUK.org. Available from: <https://www.coeliac.org.uk/campaigns-and-research/campaigning-on-health/campaign-to-protect-prescription-services-in-england/> [Accessed: 28 January 2016].
- CoeliacUK.org (2015b) *Gluten-free product certification - Coeliac UK.* [Online]. 2015. CoeliacUK.org. Available from: <https://www.coeliac.org.uk/food-industry-professionals/the-crossed-grain-symbol/> [Accessed: 25 February 2017].
- CoeliacUK.org (2017) *Prescription policies - Coeliac UK.* [Online]. 2017. Available from: <https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/prescription-policies/> [Accessed: 23 February 2017].
- Cohn, S. (2000) Risk, Ambiguity and the Loss of Control: How People with a Chronic Illness Experience Complex Biomedical Cause Models. In: Pat Caplan (ed.). *Risk Revisited.* [Online]. pp. 204–225. Available from: doi:10.1017/CBO9781107415324.004.
- Contento, I., Balch, G.I., Bronner, Y.L., Lytle, L.A., et al. (1995) The effectiveness of nutrition education and implications for nutrition education policy, programs, and research: a review of research.

Journal of nutrition education (USA). 227.

- Copelton, D.A. & Valle, G. (2009) 'You don't need a prescription to go gluten-free': The scientific self-diagnosis of celiac disease. *Social Science and Medicine*. [Online] 69 (4), 623–631. Available from: doi:10.1016/j.socscimed.2009.05.012.
- Coral Manton (2016) *Multimedia PhD Research and Non-text Theses Case Studies: Sam Martin*. [Online]. 2016. British Library Case Studies. Available from: <https://www.bl.uk/case-studies/sam-martin> [Accessed: 16 September 2017].
- Crossley, N. (2014) Embodied Actors, Sociability and the Limits of Reflexivity. *Body & Society*. [Online] 20 (2), 106–112. Available from: doi:10.1177/1357034X14524454.
- Crossley, N. (2004) The Circuit Trainer's Habitus: Reflexive Body Techniques and the Sociality of the Workout. *Body & Society*. [Online] 10 (1), 37–69. Available from: doi:10.1177/1357034X04041760.
- Davis, J. (2012) Social Media and Experiential Ambivalence. *Future Internet*. [Online] 4 (4), 955–970. Available from: doi:10.3390/fi4040955 [Accessed: 23 May 2014].
- Davis, J. (2013) *The Qualified Self* » *Cyborgology*. [Online]. 2013. Available from: <http://thesocietypages.org/cyborgology/2013/03/13/the-qualified-self/> [Accessed: 28 July 2014].
- DFPI (2014) *Dietitians For Professional Integrity's Distinguished Dietitian monthly recognition program*. [Online]. 2014. Dietitians for Professional Integrity. Available from: <https://www.facebook.com/DietitiansForProfessionalIntegrity/posts/782257698510774> [Accessed: 23 February 2016].
- DiscoverText.com (2015) *DiscoverText*. [Online]. 2015. Solutions. Available from: <https://discovertext.com/solutions/> [Accessed: 3 January 2014].
- Dixit, R., Lebwohl, B., Ludvigsson, J.F., Lewis, S.K., et al. (2014) Celiac disease is diagnosed less frequently in young adult males. *Digestive Diseases and Sciences*. [Online] 59 (7), 1509–1512. Available from: doi:10.1007/s10620-014-3025-6.
- Don (2013) *Interior Monologue Captioning*. [Online]. 2013. Know Your Meme. Available from: <http://knowyourmeme.com/memes/interior->

monologue-captioning [Accessed: 27 October 2015].

- Douglas, M. (1986) *Natural Risk*. In: *Risk Acceptability According to the Social Sciences*. New York, Russell Sage Foundation. pp. 53–64.
- Dovey, T.M., Staples, P.A., Gibson, E.L. & Halford, J.C.G. (2008) Food neophobia and 'picky/fussy' eating in children: A review. *Appetite*. [Online] 50 (2–3), 181–193. Available from: doi:10.1016/j.appet.2007.09.009 [Accessed: 4 March 2017].
- Draper, A., Dowler, E., Sloan, L., Williams, M., et al. (2016) *Understanding public concerns about food risks and food safety: Role and usefulness of Twitter*.
- Drew, S.E., Duncan, R.E. & Sawyer, S.M. (2010) Visual Storytelling: A Beneficial But Challenging Method for Health Research With Young People. *Qualitative Health Research*. [Online] 20 (12), 1677–1688. Available from: doi:10.1177/1049732310377455.
- Dreyfuss, I. (2015) *How Members of the Public Have Used Facebook and Twitter in Response to a Disaster: A Comparative Case Study*.
- Driscoll, K. & Walker, S. (2014) Big Data, Big Questions| Working Within a Black Box: Transparency in the Collection and Production of Big Twitter Data. *International Journal of Communication*. [Online] 8 (2014), 1745–1764. Available from: <http://ijoc.org/index.php/ijoc/article/view/2171>.
- DunnGalvin, A., Chan, C.H., Crevel, R., Grimshaw, K., et al. (2015) Precautionary allergen labelling: Perspectives from key stakeholder groups. *Allergy: European Journal of Allergy and Clinical Immunology*. [Online] 70 (9), 1039–1051. Available from: doi:10.1111/all.12614.
- Ene, S. (2009) *Biosocial Citizenship : Community Participation in Public Health*. [Online]. 2009. Public Health Management & Policy. Available from: http://www.cwru.edu/med/epidbio/mphp439/Biosocial_Comm.pdf.
- England, C.Y. & Nicholls, A.M. (2004) Advice available on the Internet for people with coeliac disease: An evaluation of the quality of websites. *Journal of Human Nutrition and Dietetics*. [Online] 17 (6), 547–559. Available from: doi:10.1111/j.1365-277X.2004.00561.x.
- Epstein, S. (1996) *Impure science: AIDS, activism, and the politics of*

knowledge. Univ of California Press.

- Facebook.com (2016) *Facebook: Privacy*. [Online]. 2016. Available from: <https://developers.facebook.com/docs/privacy> [Accessed: 21 September 2016].
- Fasano, A. (2006) Systemic autoimmune disorders in celiac disease. *Current opinion in gastroenterology*. [Online] 22 (6), 674–679. Available from: doi:10.1097/01.mog.0000245543.72537.9e.
- Fasano, A., Sapone, A., Zevallos, V. & Schuppan, D. (2015a) Non-celiac Gluten Sensitivity. *Gastroenterology*. [Online] (March), 1–10. Available from: doi:10.1053/j.gastro.2014.12.049.
- Faucher, M.A. & Garner, S.L. (2015) A method comparison of photovoice and content analysis: Research examining challenges and supports of family caregivers. *Applied Nursing Research*. [Online] 28 (4), 262–267. Available from: doi:10.1016/j.apnr.2015.02.005.
- Food & Drug Administration (2016) *FDA: Food Labeling; Gluten-Free Labeling of Fermented or Hydrolyzed Foods - Proposed Rule Document*. [Online]. 2016. Available from: <http://www.regulations.gov/#!documentDetail;D=FDA-2014-N-1021-0001> [Accessed: 11 February 2016].
- Food & Drug Administration (2013) *FDA defines 'gluten-free' for food labeling*. [Online]. 2013. FDA News Release. Available from: <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm363474.htm> [Accessed: 30 March 2016].
- Food & Drug Administration (2015) *Safety Alerts & Advisories - FDA Investigates Complaints Associated with Cheerios Labeled Gluten Free: General Mills Voluntarily Recalls Affected Lots*. [Online]. 2015. Available from: <http://www.fda.gov/Food/RecallsOutbreaksEmergencies/SafetyAlertsAdvisories/ucm465984.htm> [Accessed: 23 February 2016].
- Food Standards Agency (2014) *EU Food Information for Consumers Regulation*. [Online]. 2014. Available from: <http://www.food.gov.uk/science/allergy-intolerance> [Accessed: 19 January 2015].
- Food Standards Agency (2015) *Genius Foods, and retailers Asda,*

Morrisons, Sainsbury's, Tesco and Waitrose are recalling some gluten free products due to the undeclared presence of gluten | Food Standards Agency. [Online]. 2015. Food.gov.uk. Available from: <http://www.food.gov.uk/news-updates/news/2015/14063/some-gluten-free-products-recalled> [Accessed: 10 February 2016].

Ford, S., Howard, R. & Oyebode, J. (2012a) Psychosocial aspects of coeliac disease: A cross-sectional survey of a UK population. *British Journal of Health Psychology*. [Online] 17 (4), 743–757. Available from: doi:10.1111/j.2044-8287.2012.02069.x.

Foucault, M. (1984) Practices and Sciences of the Self. In: *The Foucault Reader*. [Online]. pp. 331–373. Available from: [http://fairbanksonline.net/Fairbanks_Online/Reading_Assignments_files/Sherman_Ch_8 - The Enlightenment.pdf](http://fairbanksonline.net/Fairbanks_Online/Reading_Assignments_files/Sherman_Ch_8_-_The_Enlightenment.pdf).

Foucault, M. (1988) *Technologies of the Self: A Seminar with Michel Foucault*. [Online]. University of Massachusetts Press. Available from: <https://books.google.com/books?id=hNJOAAAAMAAJ&pgis=1> [Accessed: 1 July 2015].

Foucault, M., Rabinow, P. & Hurley, R. (1997) *The essential works of Michel Foucault, 1954-1984*.

Foucault, M. & Sheridan, A.M. (1973) *The Birth of the Clinic* (1963). *Abingdon: Routledge*. [Online] 1–146. Available from: <http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:The+Birth+of+the+Clinic#9>.

Fox, S. & Duggan, M. (2013) *Sources of Health Information*. [Online]. 2013. Pew Research Center: Internet, Science & Tech: Sources of Health Information. Available from: <http://www.pewinternet.org/2013/11/26/part-two-sources-of-health-information/> [Accessed: 6 October 2016].

Frank, A.W. (1995) *The Wounded Storyteller: Body, Illness, and Ethics, Second Edition (Google eBook)*. [Online]. University of Chicago Press. Available from: <http://books.google.com/books?id=qacxAQAAQBAJ&pgis=1> [Accessed: 30 May 2014].

Fritz, R.D., Chen, Y. & Contreras, V. (2017) Gluten-containing grains skew

gluten assessment in oats due to sample grind non-homogeneity. *Food Chemistry*. [Online] 216, 170–175. Available from: doi:10.1016/j.foodchem.2016.08.031.

García-Leiva, J.M., Carrasco, J.L.O., Slim, M. & Calandre, E.P. (2015) Celiac symptoms in patients with fibromyalgia: a cross-sectional study. *Rheumatology International*. [Online] 35 (3), 561–567. Available from: doi:10.1007/s00296-014-3110-3.

Garner, S.L. (2014) Photovoice as a teaching and learning strategy for undergraduate nursing students. *Nurse Education Today*. [Online] 34 (10), 1272–1274. Available from: doi:10.1016/j.nedt.2014.03.019.

Gaspar, R., Gorjão, S., Seibt, B., Lima, L., et al. (2014) Tweeting during food crises: A psychosocial analysis of threat coping expressions in Spain, during the 2011 European EHEC outbreak. *International Journal of Human Computer Studies*. [Online] 72 (2), 239–254. Available from: doi:10.1016/j.ijhcs.2013.10.001.

Gazzola, A. (2014) *Total recall?* [Online]. 2014. Food Allergy and Intolerance Ink. Available from: <http://foodallergyandintolerance.blogspot.co.uk/2014/12/total-recall.html> [Accessed: 26 April 2016].

Genius Foods (2015) *Genius Gluten Free Recall: Customer Notice*. [Online]. 2015. GeniusGlutenFree.com. Available from: http://www.geniusglutenfree.com/en_GB/blog/Dear+Genius+Customer [Accessed: 10 February 2016].

Gibbon, S. & Novas, C. (2007) Introduction Biosocialities genetics and the social sciences. In: *Genetics, Biosociality and the Social Sciences: Making Biologies and Identities*. [Online]. Routledge. pp. 1–19. Available from: http://books.google.com/books?hl=en&lr=&id=0frUfN_gH-AC&pgis=1 [Accessed: 1 October 2014].

Gibbons, C.H. & Freeman, R. (2005) Autonomic neuropathy and coeliac disease. *Journal of neurology, neurosurgery, and psychiatry*. [Online] 76 (4), 579–581. Available from: doi:10.1136/jnnp.2004.047480.

Gibbs, M., Bellamy, C., Arnold, M., Nansen, B., et al. (2013) Digital registers and estate planning. *Retirement and Estate Planning*

Bulletin. 16 (3), 63–68.

- Gibbs, M., Meese, J., Arnold, M. & Nansen, B. (2015) # Funeral and instagram : death , social media , and platform vernacular. *Information, Communication & Society*. [Online] 18 (3), 255–268. Available from: doi:10.1080/1369118X.2014.987152.
- Giddens, A. (1991) *Modernity and Self-Identity. Self and Society in the Modern Age*. Polity Press.
- Gilbert, L. & Walker, L. (2010) 'My biggest fear was that people would reject me once they knew my status...': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health & social care in the community*. [Online] 18 (2), 139–146. Available from: doi:10.1111/j.1365-2524.2009.00881.x [Accessed: 25 May 2014].
- GlutenDude.com (2016) *Gluten-Free Cheerios? NOT Recommended by the CCA*. [Online]. 2016. GlutenDude.com. Available from: <http://glutendude.com/not-gluten-free/gluten-free-cheerios-not-recommended-by-the-cca/> [Accessed: 27 August 2016].
- GlutenDude.com (2015) *The Cheerios Recall (aka...The Gluten-Free Sh*t Storm)*. [Online]. 2015. Gluten Dude: The Naked Truth About Living Gluten Free. Available from: <http://glutendude.com/not-gluten-free/the-gluten-free-cheerios-recall/> [Accessed: 20 February 2017].
- Gnip (2016) *Gnip*. [Online]. 2016. Gnip.com. Available from: <https://gnip.com/about/> [Accessed: 16 September 2016].
- Golder, S.A. & Macy, M.W. (2014) Digital Footprints: Opportunities and Challenges for Online Social Research. *Annual Review of Sociology*. [Online] 40 (1), 129–152. Available from: doi:10.1146/annurev-soc-071913-043145.
- González-Bailón, S., Wang, N., Rivero, A., Borge-Holthoefer, J., et al. (2012) Assessing the bias in samples of large online networks. *Social Networks*. [Online] 38 (1), 16–27. Available from: doi:10.1016/j.socnet.2014.01.004.
- Gonzalez-Polledo, E. (2016) Chronic Media Worlds: Social Media and the Problem of Pain Communication on Tumblr. *Social Media + Society*. [Online] 2 (1), 1–11. Available from: doi:10.1177/2056305116628887.
- Gonzalez-Polledo, E. & Tarr, J. (2014) The thing about pain: The remaking

- of illness narratives in chronic pain expressions on social media. *New Media & Society*. [Online] 1461444814560126-. Available from: doi:10.1177/1461444814560126.
- Gordon, E. & de Souza e Silva, A. (2011) Urban Spaces. In: *Net Locality*. [Online]. John Wiley & Sons, Ltd. pp. 85–104. Available from: doi:10.1002/9781444340679.ch4.
- Gov.UK (2017) *Advisory Committee on Borderline Substances - GOV.UK*. [Online]. 2017. Advisory Committee on Borderline Substances. Available from: <https://www.gov.uk/government/groups/advisory-committee-on-borderline-substances> [Accessed: 13 January 2017].
- Grace Shockey (2016) *Instagram for the Chronically Ill: #SpoonieLivingApp*. [Online]. 2016. Thee Crohnie Grace. Available from: <https://theecrohniegrace.wordpress.com/2016/08/23/instagram-for-the-chronically-ill-spoonielivingapp/> [Accessed: 23 August 2016].
- Grady, J. (1996) The Scope of Visual Sociology. *Visual Sociology*. [Online] 11 (2), 10–24. Available from: doi:10.1080/14725869608583762.
- Greaves, F., Lavery, A. a, Cano, D.R., Moilanen, K., et al. (2014) Tweets about hospital quality: a mixed methods study. *BMJ quality & safety*. [Online] 23 (10), 838–846. Available from: doi:10.1136/bmjqs-2014-002875 [Accessed: 6 January 2015].
- Green, J., Draper, A. & Dowler, E. (2003) Short cuts to safety: Risk and 'rules of thumb' in accounts of food choice. *Health, Risk & Society*. [Online] 5 (1), 33–52. Available from: doi:10.1080/1369857031000065998 [Accessed: 2 April 2016].
- Van Grove, J. (2011) *Gamification: How Competition Is Reinventing Business, Marketing & Everyday Life*. [Online]. 2011. Mashable.com. Available from: <http://mashable.com/2011/07/28/gamification/#xwe7T7tjoukt> [Accessed: 25 September 2015].
- Gruzd, A. (2016) *Netlytic: Software for Automated Text and Social Network Analysis*. [Online]. Available from: <http://netlytic.org>.
- Hamari, J., Koivisto, J. & Sarsa, H. (2014) Does gamification work? - A literature review of empirical studies on gamification. *Proceedings of the Annual Hawaii International Conference on System Sciences*.

[Online] 3025–3034. Available from: doi:10.1109/HICSS.2014.377.

Hamshaw, R.J.T., Barnett, J. & Lucas, J.S. (2017) Framing the debate and taking positions on food allergen legislation: The 100 chefs incident on social media. *Health, Risk and Society*. [Online] 19 (3–4), 145–167. Available from: doi:10.1080/13698575.2017.1333088.

Hattersley, S., Ward, R., Baka, A. & Crevel, R.W.R. (2014) Advances in the risk management of unintended presence of allergenic foods in manufactured food products—an overview. *Food and chemical toxicology: an international journal published for the British Industrial Biological Research Association*. [Online] 67, 255–261. Available from: doi:10.1016/j.fct.2014.01.036.

van Hees, N.J.M., Van der Does, W. & Giltay, E.J. (2013) Coeliac disease, diet adherence and depressive symptoms. *Journal of psychosomatic research*. [Online] 74 (2), 155–160. Available from: doi:10.1016/j.jpsychores.2012.11.007 [Accessed: 25 May 2014].

Henricksen, K. & Viller, S. (2012) *Design of Software to Support Families with Food- Allergic and Food-Intolerant Children*. 2012 (November), 1–10.

Hermann, R., Turpeinen, H., Laine, a P., Veijola, R., et al. (2003) HLA DR-DQ-encoded genetic determinants of childhood-onset type 1 diabetes in Finland: an analysis of 622 nuclear families. *Tissue antigens*. [Online] 62, 162–169. Available from: doi:10.1034/j.1399-0039.2003.00071.x.

Hilbert, R.A. (1984) The Acultural Dimensions of Chronic Pain: Flawed Reality Construction and the Problem of Meaning. *Social Problems*. [Online]. 31 pp.365–378. Available from: doi:10.1525/sp.1984.31.4.03a00010.

Hingle, M., Yoon, D., Fowler, J., Kobourov, S., et al. (2013) Collection and visualization of dietary behavior and reasons for eating using Twitter. *Journal of medical Internet research*. [Online] 15 (6), 1–14. Available from: doi:10.2196/jmir.2613 [Accessed: 25 June 2014].

Hobday, V., Law, G.U. & Howard, R. (2015) A Tale of Two Diagnoses: An Interpretative Phenomenological Analysis of Healthcare Professionals Working with Children with Type 1 Diabetes and Coeliac Disease.

- International Journal of Celiac Disease*. [Online] 3 (4), 139–147.
Available from: doi:10.12691/ijcd-3-4-10.
- Hochman, N. & Manovich, L. (2013) *Zooming into an Instagram City: Reading the local through social media*. [Online]. 17 June 2013. First Monday. Available from: doi:10.5210/fm.v18i7.4711 [Accessed: 9 July 2014].
- Holmes, G.K.T. & Moor, F. (2012) Coeliac disease in Asians in a single centre in southern Derbyshire. *Frontline Gastroenterology* . [Online] 1–5. Available from: doi:10.1136/flgastro-2012-100200.
- Howard, R. & Law, G.U.- (2011) *Psychological well-being of children and young people with coeliac disease*. 186–207.
- Howard, R., Law, G.U. & Petty, J. (2011) Long-Term Conditions: Challenges in Health & Social Care (Google eBook). In: Cathy Lloyd & Tom Heller (eds.). *Long-Term Conditions: Challenges in Health & Social Care*. SAGE. pp. 108–123.
- IFTTT.com (2015) *IFTTT: If This Then That*. [Online]. 2015. About IFTTT. Available from: <https://ifttt.com/wtf> [Accessed: 1 February 2014].
- Ignatow, G. & Radev, D. (2016) *Text mining : a guidebook for the social sciences*. SAGE Publications.
- Instagram.com (2016) *#spoonie • Instagram photos and videos*. [Online]. 2016. Instagram.com. Available from: <https://www.instagram.com/explore/tags/spoonie/> [Accessed: 30 September 2016].
- Instagram.com (2015a) *Instagram API*. [Online]. 2015. Available from: <https://instagram.com/developer/realtime/> [Accessed: 1 November 2014].
- Instagram.com (2015b) *Removing pre-filled captions from mobile sharing*. [Online]. 2015. Instagram Developers. Available from: <http://developers.instagram.com/post/125972775561/removing-pre-filled-captions-from-mobile-sharing> [Accessed: 27 October 2015].
- James, E.L. (2011) *Fifty shades of Grey*. Vintage Books.
- Jones, R. (2013) Health, Risk and the Entextualized Body. In: *Health and Risk Communication: An Applied Linguistic Perspective*. [Online].

Routledge. pp. 106–129. Available from:
http://books.google.com/books?id=YI9_tODvRCoC&pgis=1
[Accessed: 17 June 2014].

Karalexis, K. (2015) *Should I be Filing for a Gluten-Free Food Tax Deduction? - MsModify*. [Online]. 2015. MsModify.com. Available from:
<http://msmodify.com/should-i-be-filing-for-a-gluten-free-food-tax-deduction/> [Accessed: 30 January 2017].

Kathleen Hoffman (2014) *What's Up With All The Spoons? Spoonies*. [Online]. 2014. Medivizor. Available from:
<https://medivizor.com/blog/2014/09/29/whats-spoons-spoonies/>
[Accessed: 12 December 2015].

Kaufer, E. (2015) *Instagram: The Next Big (Academic) Thing?* [Online]. 2015. Oxford Internet Institute: Rough Consensus. Available from:
<http://blogs.oii.ox.ac.uk/roughconsensus/2015/02/instagram-the-next-big-academic-thing/> [Accessed: 18 October 2015].

Kelleher, D. (1988) Coming to terms with diabetes: coping strategies and non-compliance. *Living with chronic illness: The experience of patients and their families*. [Online] 137–155. Available from:
<http://scholar.google.com/scholar?cluster=8424382870588067637&hl=en&oi=scholar#0> [Accessed: 17 June 2014].

Kennedy, J. (2012) *Hanging with the 'The Chronicles' online: Autopathography and Narrative Associations in an online support group for Chronic Lymphocytic Leukemia*.

Khaled, R. (2014) Gamification and Culture. In: Steffen P. Walz & Sebastian Deterding (eds.). *The Gameful World: Approaches, Issues, Applications*. Cambridge, Massachusetts, MIT Press. pp. 301–321.

Klang, M. (2013) *Coping with Death and Grief Through Technology*. (1981).

Kleinman, A. (1988) *The illness narratives: suffering, healing, and the human condition*. Basic Books.

Kleinman, A. & Barad, K. (2012) Intra-actions. *Special dOCUMENTA (13) - Mousse Magazine*. pp.76–81.

Kothe, E.J., Sainsbury, K., Smith, L. & Mullan, B.A. (2015) Explaining the intention-behaviour gap in gluten free diet adherence: The moderating roles of habit and perceived behavioural control. *Psychology & Health*

(ahead-of-print). 1–26.

- Kramer, L., Schwartz, P., Cheadle, A. & Rauzon, S. (2013) Using photovoice as a participatory evaluation tool in Kaiser Permanente's Community Health Initiative. *Health Promotion Practice*. 14, 686–694.
- Kurppa, K., Paavola, A., Collin, P., Sievänen, H., et al. (2014) Benefits of a Gluten-free diet for Asymptomatic Patients with Serologic Markers of Celiac Disease. *Gastroenterology*. [Online] 147, 610–617. Available from: doi:<http://dx.doi.org/10.1053/j.gastro.2014.05.003> [Accessed: 2 June 2014].
- Kuttschreuter, M., Rutsaert, P., Hilverda, F., Regan, Á., et al. (2014) Seeking information about food-related risks: The contribution of social media. *Food Quality and Preference*. [Online] 37, 10–18. Available from: doi:[10.1016/j.foodqual.2014.04.006](https://doi.org/10.1016/j.foodqual.2014.04.006) [Accessed: 15 June 2014].
- Van Laere, S., De Ruyck, T. & Willems, A. (2013) *Game on qualitative researchers: Using gamification to increase participant engagement, data quality and client impact in Market Research Online Communities*. [Online]. 2013. Available from: <http://www.slideshare.net/InSitesConsulting/game-on-qualitative-researchers>.
- Ledford, C.J.W. & Anderson, L.N. (2013) Online social networking in discussions of risk: applying the CAUSE model in a content analysis of Facebook. *Health, Risk & Society*. [Online] 15 (3), 251–264. Available from: doi:[10.1080/13698575.2013.776016](https://doi.org/10.1080/13698575.2013.776016) [Accessed: 21 July 2014].
- Lee, J.L., DeCamp, M., Dredze, M., Chisolm, M.S., et al. (2014) What Are Health-Related Users Tweeting? A Qualitative Content Analysis of Health-Related Users and Their Messages on Twitter. *Journal of Medical Internet Research*. [Online] 16 (10), 1–7. Available from: doi:[10.2196/jmir.3765](https://doi.org/10.2196/jmir.3765) [Accessed: 22 October 2014].
- Lezaun, J., Marres, N. & Tironi, M. (2016) 07. Experiments in Participation. In: C Miller, L Smith-Doerr, & Felt R. Fouche (eds.). *Handbook of Science and Technology Studies*. Cambridge, Massachusetts, MIT Press. pp. 1–42.
- Lieberman, D.A. (1997) Interactive video games for health promotion: Effects on knowledge, self-efficacy, social support, and health. *Health*

promotion and interactive technology: Theoretical applications and future directions. 103–120.

- Liegl, M. (2014) Nomadcity and the Care of Place-on the Aesthetic and Affective Organization of Space in Freelance Creative Work. *Computer Supported Cooperative Work: CSCW: An International Journal*. [Online] 1–21. Available from: doi:10.1007/s10606-014-9198-x.
- Lionetti, E., Gatti, S., Pulvirenti, A. & Catassi, C. (2015) Celiac disease from a global perspective. *Best Practice & Research Clinical Gastroenterology*. [Online] 29 (3), 365–379. Available from: doi:10.1016/j.bpg.2015.05.004.
- Lupton, D. (2014) *Beyond the quantified self: the reflexive monitoring self* | *This Sociological Life on WordPress.com*. [Online]. 2014. Available from: <http://simplysociology.wordpress.com/2014/07/28/beyond-the-quantified-self-the-reflexive-monitoring-self/> [Accessed: 28 July 2014].
- Lupton, D. (2002) Food, Risk and Subjectivity. In: Simon J Williams, Jonathan Gabe, & Michael Calnan (eds.). *Health, Medicine and Society: Key Theories, Future Agendas*. [Online]. Routledge. pp. 205–218. Available from: http://books.google.com/books?hl=en&lr=&id=tm-7Wfl_yP4C&pgis=1.
- Lupton, D. (2012) *Medicine as Culture: Illness, Disease and the Body (Google eBook)*. [Online]. SAGE. Available from: <http://books.google.com/books?id=7wkR0ImKogIC&pgis=1> [Accessed: 17 June 2014].
- Lupton, D. (2013a) Quantifying the body: monitoring and measuring health in the age of mHealth technologies. *Critical Public Health*. [Online] 23 (4), 393–403. Available from: doi:10.1080/09581596.2013.794931.
- Lupton, D. (2013c) *Risk*.
- MacKerron, G. & Mourato, S. (2013) Happiness is greater in natural environments. *Global Environmental Change*. [Online] 23 (5), 992–1000. Available from: doi:10.1016/j.gloenvcha.2013.03.010.
- MacLean, D.L. & Heer, J. (2013) Identifying medical terms in patient-authored text: a crowdsourcing-based approach. *Journal of the American Medical Informatics Association : JAMIA*. [Online] 20 (6),

1120–1127. Available from: doi:10.1136/amiajnl-2012-001110.

- Madsen, C.B., Hattersley, S., Allen, K.J., Beyer, K., et al. (2012a) Can we define a tolerable level of risk in food allergy? Report from a EuroPrevall/UK Food Standards Agency workshop. *Clinical and Experimental Allergy*. [Online] 42 (1), 30–37. Available from: doi:10.1111/j.1365-2222.2011.03868.x.
- Mahrt, M. & Scharrow, M. (2013) The Value of Big Data in Digital Media Research. *Journal of Broadcasting & Electronic Media*. [Online] 57 (January 2015), 20–33. Available from: doi:10.1080/08838151.2012.761700.
- Malik, O. (2014) *On visual web, a photo is worth more than a 1000 words*. [Online]. 2014. Available from: <http://om.co/2014/12/10/weaving-a-very-visual-web/> [Accessed: 5 February 2015].
- Manovich, L. (2011) Trending: The Promises and the Challenges of Big Social Data. *Debates in the Digital Humanities*. [Online] 1–10. Available from: doi:http://www.manovich.net/DOCS/Manovich_trending_paper.pdf.
- Markula, P. (2004) 'Tuning into one's self:' Foucault's technologies of the self and mindful fitness. *Sociology of Sport Journal*. [Online] 21 (3), 302–321. Available from: <http://hk.humankinetics.com/eJournalMedia/pdfs/4071.pdf>.
- Marres, N. (2012a) *The redistribution of methods : on intervention in digital social research , broadly conceived*. [Online] 165, 139–165. Available from: doi:10.1111/j.1467-954X.2012.02121.x.
- Marres, N., Gerlitz, C. & Studies, M. (2016) Interface Methods : Renegotiating relations between digital research , STS and Sociology. *Sociological Review*. [Online] 64 (3), 1–33. Available from: doi:10.1111/1467-954X.12314.
- Marres, N. & Weltevrede, E. (2012) *Scraping the Social? Issues in real-time social research*. [Online] Available from: doi:10.1080/17530350.2013.772070.
- Martin, S. (2014a) *Coeliac Sam*. [Online]. 2014. Amazon Appstore for Android. Available from: <http://www.amazon.co.uk/Samantha-Martin-Coeliac->

- Sam/dp/B00MW7TDC0/ref=sr_1_1?ie=UTF8&qid=1445634203&sr=8-1&keywords=coeliac+sam [Accessed: 23 October 2015].
- Martin, S. (2014b) *Coeliac Sam on the App Store*. [Online]. 2014. Apple Store. Available from: <https://itunes.apple.com/gb/app/coeliac-sam/id909891669?mt=8> [Accessed: 23 September 2015].
- Martin, S. (2014d) *Gluten Fighters on the App Store*. [Online]. 2014. Apple Store. Available from: <https://itunes.apple.com/gb/app/gluten-fighters/id960072604?mt=8> [Accessed: 23 October 2015].
- Martin, S. (2015) *Spoonie Living App on the App Store*. [Online]. 2015. iTunes.apple.com. Available from: <https://itunes.apple.com/gb/app/spoonie-living-app/id1101348762?mt=8> [Accessed: 3 September 2017].
- Mazzarella, G., Stefanile, R., Camarca, A., Giliberti, P., et al. (2008) Gliadin Activates HLA Class I-Restricted CD8+ T Cells in Celiac Disease Intestinal Mucosa and Induces the Enterocyte Apoptosis. *Gastroenterology*. [Online] 134 (4), 1017–1027. Available from: doi:10.1053/J.
- Megha, P. & Sang, A.C.Y. (2015) Capturing the visual language of social media. In: *IEEE International Conference on Multimedia and Expo (ICME), 2015*. [Online]. 2015 pp. 1–6. Available from: doi:10.1109/ICME.2015.7177469.
- Megiorni, F., Mora, B., Bonamico, M., Barbato, M., et al. (2008) HLA-DQ and Susceptibility to Celiac Disease: Evidence for Gender Differences and Parent-of-Origin Effects. *Am J Gastroenterol*. [Online] 103 (4), 997–1003. Available from: <http://dx.doi.org/10.1111/j.1572-0241.2007.01716.x>.
- Mehrabi, D., Hassan, M.A. & Sham Shahkat Ali, M. (2009) News Media Credibility of the Internet and Television. *European Journal of Social Sciences*. 11 (1), 136–148.
- Menon, K.U. (2006) SARS revisited: Managing ‘outbreaks’ with ‘communications’. *Annals of the Academy of Medicine Singapore*. [Online] 35 (5), 361–367. Available from: doi:10.1371/journal.pone.0014118.
- Mercer, A. & gi97ol (2015) *Image Macros*. [Online]. 2015. Know Your

Meme. Available from: <http://knowyourmeme.com/memes/image-macros> [Accessed: 27 October 2015].

- Merolli, M., Gray, K. & Martin-Sanchez, F. (2013) Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. *Journal of Biomedical Informatics*. [Online] 46 (6), 957–969. Available from: doi:10.1016/j.jbi.2013.04.010 [Accessed: 23 May 2014].
- Michael, M. & Lupton, D. (2015) Toward a manifesto for the 'public understanding of big data'. *Public Understanding of Science*. [Online] Available from: doi:10.1177/0963662515609005.
- Miserandino, C. (2003) *The Spoon Theory*. [Online]. 2003. [butyoudontlooksick.com](http://www.butyoudontlooksick.com). Available from: <http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/> [Accessed: 1 September 2015].
- Mitton, G. (2013) Food as Medicine For Body and Soul. In: A. Mizrahi, Stephen Fulder, & Nimrod Sheinman (eds.). *Potentiating health and the crisis of the immune system : integrative approaches to the prevention and treatment of modern diseases*. pp. 79–81.
- Mizen, P. & Wolkowitz, C. (2012) Visualising changing landscapes of work and labour. *Sociological Research Online*. 17 (2).
- Mizuko, I. & Okabe, D. (2005) Intimate Visual Co-Presence. In: *Ubiquitous Computing Conference*. 2005 pp. 1–4.
- Moore, S.E.H. & Burgess, A. (2011) Risk rituals? *Journal of Risk Research*. [Online] 14 (1), 111–124. Available from: doi:10.1080/13669877.2010.505347.
- Mosenzon, D. (2014) *Memes, Humor, and Community: The Case of Mental Health Memes*. [Online]. Available from: https://www.academia.edu/15569046/Memes_Humor_and_Community_The_Case_of_Mental_Health_Memes.
- Munro, C., Semic-Jusufagic, A., Pyrz, K., Couch, P., et al. (2015) An eHealth Approach to Reporting Allergic Reactions to Food and Closing the Knowledge Gap. *Studies in Health Technology and Informatics*. [Online] 216 (AUGUST), 320–324. Available from: doi:10.3233/978-1-61499-564-7-320.

- Munson, S.A., Poole, E., Perry, D.B. & Peyton, T. (2014) Gamification and Health. In: Steffen P. Walz & Sebastian Deterding (eds.). *The Gameful World: Approaches, Issues, Applications*. [Online]. Cambridge, Massachusetts, MIT Press. pp. 597–623. Available from: doi:10.1016/0005-7967(82)90163-2.
- Murphy, J. (2015) *General Mills announces recall of certain code dates of Cheerios and Honey Nut Cheerios*. [Online]. 2015. Available from: <http://www.blog.generalmills.com/2015/10/general-mills-announces-recall-of-certain-boxes-of-cheerios-and-honey-nut-cheerios/> [Accessed: 12 February 2016].
- Murthy, D. (2012) Towards a Sociological Understanding of Social Media: Theorizing Twitter. *Sociology*. [Online] 46 (6), 1059–1073. Available from: doi:10.1177/0038038511422553 [Accessed: 23 May 2014].
- Murthy, D. (2011) Twitter: Microphone for the masses? *Media, Culture & Society*. [Online] 33 (5), 779–789. Available from: doi:10.1177/0163443711404744 [Accessed: 23 May 2014].
- Murthy, D., Gross, A. & Longwell, S. (2011) *Twitter and e-Health*. 110–113.
- Murthy, D., Gross, A. & Oliveira, D. (2011) Understanding Cancer-based Networks in Twitter using Social Network Analysis. In: *ICSC '11 Proceedings of the 2011 IEEE Fifth International Conference on Semantic Computing*. [Online]. 2011 p. Available from: doi:<http://doi.ieeecomputersociety.org/10.1109/ICSC.2011.51>.
- Nazareth, S., Lebowitz, B., Voyksner, J.S. & Green, P.H. (2015) Widespread Contamination of Probiotics With Gluten, Detected by Liquid Chromatography-Mass Spectrometry. *Gastroenterology*. 148 (4), S-28.
- Neches, J.W., Chung, E.Q., Hawes-Dawson, J., Ryan, G.W., et al. (2007) The Teen Photovoice Project: A pilot study to promote health through advocacy. *Progress in Community Health Partnerships: Research, Education, and Action*. 221–229.
- Neimark, J. (2015) *The gluten-free craze is making celiacs like me sick*. [Online]. 2015. Quartz.com. Available from: <http://qz.com/569410/the-gluten-free-craze-is-making-celiacs-like-me-sick/> [Accessed: 10 February 2016].

- Nettleton, S. & Burrows, R. (2003) E-Scaped Medicine? Information, Reflexivity and Health. *Critical Social Policy*. [Online] 23 (2), 165–185. Available from: doi:10.1177/0261018303023002003 [Accessed: 23 May 2014].
- NHS Choices (2015) *Health A-Z - Conditions and treatments*. [Online]. 2015. Available from: <https://www.nhs.uk/Conditions/Pages/hub.aspx> [Accessed: 29 December 2015].
- Noar, S.M. (2006) A 10-year retrospective of research in health mass media campaigns: where do we go from here? *Journal of health communication*. [Online] 11 (1), 21–42. Available from: doi:10.1080/10810730500461059 [Accessed: 5 February 2016].
- NVivo (2014) *NVivo NCapture*. [Online]. 2014. Available from: http://www.qsrinternational.com/products_nvivo_add-ons.aspx [Accessed: 12 May 2014].
- O’Connell, R. (2013) The use of visual methods with children in a mixed methods study of family food practices. *International Journal of Social Research Methodology*. [Online] 16 (1), 31–46. Available from: doi:10.1080/13645579.2011.647517.
- O’Donnell, C. (2014) Getting played: Gamification, bullshit, and the rise of algorithmic surveillance. *Surveillance and Society*. 12 (3), 349–359.
- Van Olmen, J., Ku, G.M., Bermejo, R., Kegels, G., et al. (2011) The growing caseload of chronic life-long conditions calls for a move towards full self-management in low-income countries. *Globalization and Health*. [Online] 7 (1), 38. Available from: doi:10.1186/1744-8603-7-38.
- Oudshoorn, N. (2015) Sustaining cyborgs: Sensing and tuning agencies of pacemakers and implantable cardioverter defibrillators. *Social Studies of Science*. [Online] 45 (1), 56–76. Available from: doi:10.1177/0306312714557377.
- Palen, L., Vieweg, S., Liu, S.B. & Hughes, A.L. (2009) Crisis in a Networked World: Features of Computer-Mediated Communication in the April 16, 2007, Virginia Tech Event. *Social Science Computer Review*. [Online] 27 (4), 467–480. Available from: doi:10.1177/0894439309332302.

- Papacharissi, Z., Streeeter, T. & Gillespie, T. (2013) Culture Digitally: Habitus of the New. *Journal of Broadcasting & Electronic Media*. [Online] 57 (4), 596–607. Available from: doi:10.1080/08838151.2013.846344 [Accessed: 24 November 2014].
- Peck, A. (2014) A Laugh Riot: Photoshopping as Vernacular Discursive Practice. *International Journal of Communication*. [Online] 8, 1638–1662. Available from: https://www.academia.edu/16708529/A_Laugh_Riot_Photoshopping_as_Vernacular_Discursive_Practice [Accessed: 27 October 2015].
- Penny, H.A., Aziz, I., Ferrar, M., Atkinson, J., et al. (2016) Is there a relationship between gluten sensitivity and postural tachycardia syndrome? *European Journal of Gastroenterology & Hepatology*. [Online] 1. Available from: doi:10.1097/MEG.0000000000000740.
- Perruzza, N. & Kinsella, E.A. (2010) Creative arts occupations in therapeutic practice: A review of the literature. *British Journal of Occupational Therapy*. [Online] 73 (6), 261–268. Available from: doi:10.4276/030802210X12759925468943.
- Perry, J. (2015a) *Dear General Mills, about your 'gluten-free' Cheerios...* [Online]. 2015. In Johnna's Kitchen. Available from: <http://injohnnaskitchen.com/2015/09/dear-general-mills-about-your-gluten-free-cheerios/> [Accessed: 23 February 2016].
- Perry, J. (2015b) *Five Things You Need To Know About 'Gluten-Free' Cheerios*. [Online]. 2015. In JohannasKitchen.com. Available from: <http://injohnnaskitchen.com/2015/09/five-things-you-need-to-know-about-gluten-free-cheerios/> [Accessed: 25 January 2017].
- Phillips, B.J. (2016) *Beyond Badges: Changing the Gamification Narrative*. [Online]. The University of Arizona. Available from: <http://hdl.handle.net/10150/556586>.
- Pickard, K.T. & Swan, M. (2013) *Big Desire to Share Big Health Data : A Shift in Consumer Attitudes toward Personal Health Information*.
- Pieroni, A. & Price, L.L. (2006) *Eating and healing : traditional food as medicine*. Food Products Press.
- Pietzak, M. (2012) Celiac disease, wheat allergy, and gluten sensitivity: when gluten free is not a fad. *JPEN. Journal of parenteral and enteral*

- nutrition*. [Online] 36 (1 Suppl), 68S–75S. Available from:
doi:10.1177/0148607111426276 [Accessed: 12 December 2014].
- Pinar, M.J. (2014) Comic Books. In: Sigrid Norris & Carmen Daniela Maier (eds.). *Interactions, Images and Texts: A Reader in Multimodality*. [Online]. De Gruyter. p. 369. Available from:
<https://books.google.com/books?hl=en&lr=&id=jq7mBQAAQBAJ&pgis=1> [Accessed: 27 October 2015].
- Pingree, S., Hawkins, R., Baker, T., Dubenske, L., et al. (2010) *The Value of Theory for Enhancing and Understanding e-Health Interventions*. [Online] 38 (1), 103–109. Available from:
doi:10.1016/j.amepre.2009.09.035.
- Pink, S., Horst, H., Postill, J., Hjorth, L., et al. (2015) Ethnography in a Digital World. In: *Digital Ethnography: Principles and Practice*. pp. 0–18.
- Pols, J. (2013a) Knowing Patients: Turning Patient Knowledge into Science. *Science, Technology & Human Values*. [Online] 39 (1), 73–97. Available from: doi:10.1177/0162243913504306.
- Pols, J. (2013b) The patient 2. Many: About diseases that remain and the different forms of knowledge to live with them. *Science & Technology Studies*. 26 (2), 80–97.
- Pound, P., Gompertz, P. & Ebrahim, S. (1998) Illness in the context of older age :the case of stroke. *Sociology of Health & Illness*. [Online] 20, 489–506. Available from: doi:10.1111/1467-9566.00112.
- Prabhakar, A.S., Guerra-Reyes, L., Kleinschmidt, V.M., Jelen, B., et al. (2017) Investigating the Suitability of the Asynchronous, Remote, Community-based Method for Pregnant and New Mothers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*. [Online] 4924–4934. Available from:
doi:10.1145/3025453.3025546.
- Pulsar (2016) *Pulsar*. [Online]. 2016. PulsarPlatform.com. Available from:
<http://www.pulsarplatform.com/> [Accessed: 16 September 2016].
- Puwar, N. & Sharma, S. (2012) Curating sociology. *The Sociological Review*. [Online] 60, 40–63. Available from: doi:10.1111/j.1467-954X.2012.02116.x.
- Pyrz, K.M. & Galvin, A.D. (2015) How can we get better at managing food

- allergies? A trans-disciplinary approach. In: *PSI PBS Psychology Health Medicine*. 2015 Belfast. p. 2015.
- Rabeharisoa, V., Moreira, T. & Akrich, M. (2014) Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties*. [Online] 9 (2), 111–128. Available from: doi:10.1057/biosoc.2014.2.
- Rabinow, P. (2005) Artificiality and Enlightenment: From Sociobiology to Biosociality. In: *Anthropologies of Modernity: Foucault, Governmentality, and Life Politics*. [Online]. Oxford, UK, Blackwell Publishing Ltd, Oxford. pp. 179–193. Available from: doi:10.1002/9780470775875.ch7.
- Rabinow, P. (1996) *Making PCR: A Story of Biotechnology*. [Online]. University of Chicago Press. Available from: http://books.google.com/books?hl=en&lr=&id=tl-VuLDM_TUC&pgis=1 [Accessed: 13 September 2014].
- Radley, A. (2009) *Works of illness : narrative, picturing and the social response to serious disease*. InkerMen.
- Raj, S.R. (2013) Postural Tachycardia Syndrome (POTS). *Circulation*. [Online] 127 (23), 2336–2342. Available from: doi:10.1161/CIRCULATIONAHA.112.144501.
- Rajpoot, P. & Makharia, G.K. (2013) Problems and challenges to adaptation of gluten free diet by Indian patients with celiac disease. *Nutrients*. [Online] 5 (12), 4869–4879. Available from: doi:10.3390/nu5124869 [Accessed: 29 May 2014].
- Rieder, B. (2013) *Studying Facebook via Data Extraction : The Netvizz Application*.
- Rigby, C.S. (2014) Gamification and Motivation - Our Motivation for Gamification: Why Gamification and Why Now? In: Steffen P. Walz and Sebastian Deterding (ed.). *The Gameful World: Approaches, Issues, Applications*. Cambridge, Massachusetts, MIT Press. pp. 113–137.
- Rose, C. & Howard, R. (2014a) Living with coeliac disease: a grounded theory study. *Journal of human nutrition and dietetics : the official journal of the British Dietetic Association*. [Online] 27 (1), 30–40.

Available from: doi:10.1111/jhn.12062 [Accessed: 23 May 2014].

- Rose, N. (1999) *Powers of Freedom: Reframing Political Thought*. Cambridge University Press.
- Rose, N. & Novas, C. (2007) Biological Citizenship. In: *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Blackwell Publishing Ltd. pp. 439–463.
- Rubin, L.C. (2007) *Using superheroes in counseling and play therapy*. Springer.
- Rubio-Tapia, A., Ludvigsson, J.F., Brantner, T.L., Murray, J.A., et al. (2012) The prevalence of celiac disease in the United States. *The American journal of gastroenterology*. [Online] 107 (10), 1538–44, 1545. Available from: doi:10.1038/ajg.2012.219 [Accessed: 2 June 2014].
- Ruppert, E., Law, J. & Savage, M. (2013) Reassembling Social Science Methods: The Challenge of Digital Devices. *Theory, Culture & Society*. [Online] 30 (4), 22–46. Available from: doi:10.1177/0263276413484941 [Accessed: 23 May 2014].
- Rutsaert, P., Barnett, J., Gaspar, R., Marcu, A., et al. (2015) Beyond information seeking: Consumers' online deliberation about the risks and benefits of red meat. *Food Quality and Preference*. [Online] 39, 191–201. Available from: doi:10.1016/j.foodqual.2014.07.011.
- Rutsaert, P., Regan, Á., Pieniak, Z., McConnon, Á., et al. (2013) The use of social media in food risk and benefit communication. *Trends in Food Science and Technology*. [Online] 30, 84–91. Available from: doi:10.1016/j.tifs.2012.10.006.
- Sainsbury, A., Sanders, D.S. & Ford, A.C. (2013) Prevalence of irritable bowel syndrome-type symptoms in patients with celiac disease: A meta-analysis. *Clinical Gastroenterology and Hepatology*. [Online] 11 (4), 359–365. Available from: doi:10.1016/j.cgh.2012.11.033.
- Sainsbury, K. & Mullan, B. (2011) Measuring beliefs about gluten free diet adherence in adult coeliac disease using the theory of planned behaviour. *Appetite*. [Online] 56 (2), 476–483. Available from: doi:10.1016/j.appet.2011.01.026 [Accessed: 23 May 2014].
- Sainsbury, K., Mullan, B. & Sharpe, L. (2013a) Gluten free diet adherence in coeliac disease. The role of psychological symptoms in bridging the

- intention-behaviour gap. *Appetite*. [Online] 61 (1), 52–58. Available from: doi:10.1016/j.appet.2012.11.001 [Accessed: 23 May 2014].
- Sainsbury, K., Mullan, B. & Sharpe, L. (2013b) Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms. *Journal of psychosomatic research*. [Online] 75 (2), 135–141. Available from: doi:10.1016/j.jpsychores.2013.05.011 [Accessed: 25 May 2014].
- Samantha Stein (2014) *An interview with Sam Martin, the creator of 'Coeliac Sam' – The Happy Coeliac*. [Online]. 2014. The Happy Coeliac. Available from: <http://thehappycoeliac.com/2014/09/an-interview-with-sam-martin-the-creator-of-coeliac-sam/> [Accessed: 23 September 2014].
- Sarah Nettleton, Woods, B., Burrows, R., Kerr, A., et al. (2010) Experiencing Food Allergy and Food Intolerance : An Analysis of Lay Accounts. *Sociology*. [Online] 44 (2), 289–305. Available from: doi:10.1177/0038038509357208.
- Sarrett, J.C. (2016) Biocertification and Neurodiversity: the Role and Implications of Self-Diagnosis in Autistic Communities. *Neuroethics*. [Online] 9 (1), 23–36. Available from: doi:10.1007/s12152-016-9247-x.
- Savage, M. & Burrows, R. (2009) Some Further Reflections on the Coming Crisis of Empirical Sociology. *Sociology*. [Online] 43 (4), 762–772. Available from: doi:10.1177/0038038509105420.
- Schroeder, R.D. & Mowen, T.J. (2014) 'You Can't Eat WHAT?' Managing the Stigma of Celiac Disease. *Deviant Behavior*. [Online] 35 (6), 456–474. Available from: doi:10.1080/01639625.2014.855105 [Accessed: 29 May 2014].
- Serfaty, V. (2004) Online Diaries: Towards a Structural Approach. *Journal of American Studies*. 38 (3), 457–471.
- Shan, L.C., Panagiotopoulos, P., Regan, Á., De Brún, A., et al. (2015) Interactive Communication With the Public : Qualitative Exploration of the Use of Social Media by Food and Health Organizations. *Journal of nutrition education and behavior*. [Online] 47 (1), 104–108. Available from: doi:10.1016/j.jneb.2014.09.004 [Accessed: 25 December 2014].
- Shankar, A., Cherrier, H. & Canniford, R. (2006) Consumer empowerment:

- a Foucauldian interpretation. *European Journal of Marketing*. [Online] 40 (9/10), 1013–1030. Available from:
doi:10.1108/03090560610680989 [Accessed: 23 May 2014].
- Sharma, G.M., Pereira, M. & Williams, K.M. (2015) Gluten detection in foods available in the United States - a market survey. *Food chemistry*. [Online] 169, 120–126. Available from:
doi:10.1016/j.foodchem.2014.07.134 [Accessed: 11 January 2015].
- Shortt, H. (2012) Identityscapes of a hair salon: Work identities and the value of visual methods. *Sociological Research Online*.17 (2).
- Skjerning, H., Mahony, R.O., Husby, S. & Dunngalvin, A. (2014) Health-related quality of life in children and adolescents with celiac disease: patient-driven data from focus group interviews. *Quality of Life Research*. [Online] 23 (6), 1883–1894. Available from:
doi:10.1007/s11136-014-0623-x [Accessed: 29 May 2014].
- St Louis, C. & Zorlu, G. (2012) Can Twitter predict disease outbreaks? *Bmj*. [Online] 344 (e2353), 1–3. Available from: doi:10.1136/bmj.e2353.
- Stjerna, M.-L. (2015) Food, risk and place: agency and negotiations of young people with food allergy. *Sociology of Health & Illness*. [Online] 37 (2), 284–297. Available from: doi:10.1111/1467-9566.12215.
- Stoové, M. a & Pedrana, A.E. (2014) Making the most of a brave new world: Opportunities and considerations for using Twitter as a public health monitoring tool. *Preventive medicine*. [Online] 63, 109–111. Available from: doi:10.1016/j.ypmed.2014.03.008 [Accessed: 23 May 2014].
- Strangleman, T. (2008) Representations of Labour: Visual Sociology and Work. *Sociology Compass*. [Online] 2, 1491–1505. Available from:
doi:10.1111/j.1751-9020.2008.00149.x.
- Sugiura, L. (2014) Live methods. *Information, Communication & Society*. [Online] 17 (5), 643–644. Available from:
doi:10.1080/1369118X.2013.865066.
- Swan, M. (2012) Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen. *Journal of Personalized Medicine*. [Online] 2 (4), 93–118. Available from: doi:10.3390/jpm2030093 [Accessed: 23 May 2014].

- Swan, M. (2013) The Quantified Self: Fundamental Disruption in Big Data Science and Biological Discovery. *Big Data*. [Online] 1 (2), 85–99. Available from: doi:10.1089/big.2012.0002 [Accessed: 21 July 2014].
- Symplur.com (2016) #spoonie - Healthcare Social Media Transcript. [Online]. 2016. Symplur Healthcare Hashtags. Available from: <http://embed.symplur.com/twitter/transcript?hashtag=spoonie&fdate=12%2F12%2F2006&shour=00&smin=00&tdate=10%2F01%2F2016&thour=00&tmin=00> [Accessed: 30 September 2016].
- Talbot, C.B. (2015) *Urban Dictionary: Coeliac*. [Online]. 2015. Urbandictionary.com. Available from: <http://www.urbandictionary.com/define.php?term=Coeliac> [Accessed: 10 February 2016].
- Tharner, A., Jansen, P.W., Jong, J.C.K., Moll, H.A., et al. (2014) Toward an operative diagnosis of fussy/picky eating: a latent profile approach in a population-based cohort. *International Journal of Behavioral Nutrition and Physical Activity*. [Online] 11 (14), 1–11. Available from: doi:10.1007/s11920-012-0293-8 [Accessed: 4 March 2017].
- Thelwall, M., Goriunova, O., Vis, F., Faulkner, S., et al. (2015) Chatting through Pictures? A Classification of Images Tweeted in one week in the UK and USA. *Journal of the Association for Information Science and Technology*. 66 (7).
- Thompson, T., Lee, A.R. & Grace, T. (2010) Gluten Contamination of Grains, Seeds, and Flours in the United States: A Pilot Study. *Journal of the American Dietetic Association*. [Online] 110 (6), 937–940. Available from: doi:10.1016/j.jada.2010.03.014.
- Thompson, T. & Simpson, S. (2014) A comparison of gluten levels in labeled gluten-free and certified gluten-free foods sold in the United States. *European journal of clinical nutrition*. [Online] (August), 1–4. Available from: doi:10.1038/ejcn.2014.211 [Accessed: 11 January 2015].
- Thrul, J., Belohlavek, A., Hambrick, D., Kaur, M., et al. (2017) Conducting online focus groups on Facebook to inform health behavior change interventions: Two case studies and lessons learned. *Internet Interventions*. [Online] 9 (June), 106–111. Available from: doi:10.1016/j.invent.2017.07.005.

- Tonutti, E. & Bizzaro, N. (2014) Autoimmunity Reviews Diagnosis and classification of celiac disease and gluten sensitivity. *Autoimmunity Reviews*. [Online] 13 (4–5), 472–476. Available from: doi:10.1016/j.autrev.2014.01.043.
- Townsend, L. & Wallace, P.C. (2016) *Social Media Research : A Guide to Ethics*.
- Tricia Thompson (2016a) *About | Gluten Free Watchdog*. [Online]. 2016. Glutenfreewatchdog.org. Available from: <https://www.glutenfreewatchdog.org/about> [Accessed: 14 March 2016].
- Tricia Thompson (2016b) *Frequently Asked Questions | Gluten Free Watchdog*. [Online]. 2016. Glutenfreewatchdog.org. Available from: <https://www.glutenfreewatchdog.org/faq> [Accessed: 14 March 2016].
- Tricia Thompson (2016c) *Must Read Study Courtesy of Quaker on Testing Oats for Gluten - Gluten Free Watchdog*. [Online]. 2016. Gluten Free Watchdog. Available from: <https://www.glutenfreewatchdog.org/news/must-read-study-courtesy-quaker-testing-oats-gluten/> [Accessed: 24 August 2016].
- Tulloch, J. & Lupton, D. (2003) *Risk and Everyday Life*. [Online]. SAGE Publications. Available from: https://books.google.co.uk/books/about/Risk_and_Everyday_Life.html?id=KpoAXMuLyLAC&pgis=1 [Accessed: 16 February 2016].
- Tumblr.com (2014) *Tumblr: Application Developer and API License Agreement*. [Online]. 2014. Available from: https://www.tumblr.com/docs/en/api_agreement [Accessed: 21 September 2016].
- Tursi, A., Giorgetti, G.M., Tursi, A., Iani, C., et al. (2004) *Assessment of autonomic function in untreated adult coeliac disease . Assessment of autonomic function in untreated adult coeliac disease*. 10 (OCTOBER), 2715–2718.
- Twitter.com (2016) *Developer Policy - Terms of Use*. [Online]. 2016. Available from: <https://dev.twitter.com/overview/terms/policy> [Accessed: 21 September 2016].
- Twitter.com (2015) *Twitter Streaming APIs*. [Online]. 2015. The Streaming

APIs: Overview. Available from:

<https://dev.twitter.com/streaming/overview> [Accessed: 1 February 2013].

- Uenishi, R.H., Gandolfi, L., Almeida, L.M., Fritsch, P.M., et al. (2014) Screening for celiac disease in 1st degree relatives: a 10-year follow-up study. *BMC gastroenterology*. [Online] 14, 36. Available from: doi:10.1186/1471-230X-14-36 [Accessed: 2 June 2014].
- Vermeren, I. (2016) *Brandwatch Blog*. [Online]. 2016. Brandwatch. Available from: <https://www.brandwatch.com/2015/01/men-vs-women-active-social-media/> [Accessed: 25 May 2016].
- Vis, F. (2013) A critical reflection on Big Data: Considering APIs, researchers and tools as data makers. *First Monday*. 18 (10), 1–16.
- Vis, F. (2014) *How images took over the internet*. [Online]. 2014. The World Economic Forum. Available from: <http://forumblog.org/2014/06/image-worth-in-online-world/> [Accessed: 10 July 2014].
- Walker Rettberg, J. (2014) *Seeing Ourselves through Technology: How We Use Selfies, Blogs and Wearable Devices to See and Shape Ourselves*. [Online]. Palgrave Macmillan. Available from: doi:10.1057/9781137476661 [Accessed: 3 October 2014].
- Wang, C.C. & Burris, M.A. (1997) Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*. 24, 369–387.
- Weiner, K. & Will, C. (2015) Playing around with blood pressure monitors. In: *Gamification symposium, BSA Medical Sociology Conference*. 2015 York. pp. 1–19.
- West, J., Fleming, K.M., Tata, L.J., Card, T.R., et al. (2014) Incidence and Prevalence of Celiac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study. *The American journal of gastroenterology*. [Online] 109 (5), 757–768. Available from: doi:10.1038/ajg.2014.55 [Accessed: 23 May 2014].
- White, L.E., Bannerman, E. & Gillett, P.M. (2016) Coeliac disease and the gluten-free diet: a review of the burdens; factors associated with adherence and impact on health-related quality of life, with specific focus on adolescence. *Journal of Human Nutrition and Dietetics*.

- [Online] 29 (5), 593–606. Available from: doi:10.1111/jhn.12375.
- Whitson, J.R. (2013) Gaming the quantified self. *Surveillance and Society*. [Online] 11 (1–2), 163–176. Available from: doi:10.1089/big.2012.0002.
- Wilkie, A., Michael, M. & Plummer-Fernandez, M. (2015) Speculative method and Twitter: Bots, energy and three conceptual characters. *Sociological Review*. [Online] 63 (1), 79–101. Available from: doi:10.1111/1467-954X.12168.
- Williams, M.L., Burnap, P. & Sloan, L. (2017) Towards an Ethical Framework for Publishing Twitter Data in Social Research: Taking into Account Users' Views, Online Context and Algorithmic Estimation. *Sociology*. [Online] 3803851770814. Available from: doi:10.1177/0038038517708140.
- Williams, S. (2000a) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*. [Online] 22 (1), 40–67. Available from: doi:10.1111/1467-9566.00191.
- Williams, S., Sheffield, D. & Knibb, R.C. (2013) A snapshot of the lives of women with Polycystic Ovary Syndrome (PCOS): A photovoice investigation. *Journal of Health Psychology*. [Online] Available from: doi:10.1177/1359105314547941.
- Williams, S.J. (2011) *The politics of sleep : rights, risks and regulation*. Basingstoke :, Palgrave Macmillan.
- Woollaston, V. (2015) *Instagram is now bigger than Twitter with 400m users sharing 80m images a day*. [Online]. 2015. Daily Mail Online. Available from: <http://www.dailymail.co.uk/sciencetech/article-3245976/Instagram-bigger-Twitter-Photo-sharing-app-400-millions-users-share-80-million-images-day.html> [Accessed: 26 October 2015].
- Wraggett, A. (2016) *Canadian Celiac Association Notice about GF Cheerios*. [Online]. 2016. Available from: http://www.celiac.ca/b/wp-content/uploads/2016/08/CCA_Statement_on_Cheerios.pdf [Accessed: 29 September 2016].
- Yi-Frazier, J.P., Cochrane, K., Mitrovich, C., Pascual, M., et al. (2015) Using Instagram as a Modified Application of Photovoice for

- Storytelling and Sharing in Adolescents With Type 1 Diabetes. *Qualitative health research*. [Online] 25 (10), 1372–1382. Available from: doi:10.1177/1049732315583282.
- Yoo, Y.J., Saliba, A.J. & Prenzler, P.D. (2010) Should red wine be considered a functional food? *Comprehensive Reviews in Food Science and Food Safety*. [Online] 9 (5), 530–551. Available from: doi:10.1111/j.1541-4337.2010.00125.x.
- Zajanckauskaite, E. (2017) Apps: solutions to sociological and health problems. *The Lancet Gastroenterology & Hepatology*. [Online] 2 (8), 554. Available from: doi:10.1016/S2468-1253(17)30191-7 [Accessed: 14 July 2017].
- Zappavigna, M. (2011) Ambient affiliation: A linguistic perspective on Twitter. *New Media & Society*. [Online] 13 (5), 788–806. Available from: doi:10.1177/1461444810385097 [Accessed: 23 July 2014].
- Zappavigna, M. (2014) Enacting identity in microblogging through ambient affiliation. *Discourse & Communication*. [Online] 8 (2), 209–228. Available from: doi:10.1177/1750481313510816.
- Zappavigna, M. (2016) Social media photography: Construing subjectivity in Instagram images. *Visual Communication*. [Online] 0 (0), 1–22. Available from: doi:10.1177/1470357216643220.
- Zappavigna, M. (2010) *Social tagging* •.
- Ziebland, S. (2004) The importance of being expert: The quest for cancer information on the Internet. *Social Science and Medicine*. [Online] 59 (9), 1783–1793. Available from: doi:10.1016/j.socscimed.2004.02.019.
- Ziebland, S. & Wyke, S. (2012) Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *The Milbank quarterly*. [Online] 90 (2), 219–249. Available from: doi:10.1111/j.1468-0009.2012.00662.x.