

Impact case study (REF3)

Institution: University of Greenwich		
Unit of Assessment: 17 - Business and Management Studies		
Title of case study: Awareness raising of the benefits of online social networks for eating disorder sufferers, prevention of damaging punitive legislation in France and Italy, and equipping charities and health practitioners to better use these networks to improve the lives of eating disorder sufferers		
Period when the underpinning research was undertaken: January 2010 – July 2017		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Francesca Pallotti Paola Tubaro	Associate Professor Research Professor	22/04/2013 – present 01/12/2009 – 31/12/2015
Period when the claimed impact occurred: August 2013 – July 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>It is estimated that there are up to 1 million, and 3 million, eating disorder sufferers in France and Italy respectively. So-called '<i>pro-anorexia</i>' and '<i>pro-bulimia</i>' websites have been popular among these sufferers since the late 1990s. Our study 'ANAMIA' analysed these social networks and found that they do not necessarily spread unhealthy eating behaviours, but can actually have potential benefits for users.</p> <p>This led to the prevention of a punitive clause in a bill introduced to French Health Law in 2015, alongside increased understanding of, and caring capacity for, people with eating disorders by health professionals and charities supporting them. Our research strengthened communication and advocacy capacity of these organisations, and to some extent, clinical practice. Moreover, our work was used by charities to prevent a similar bill being proposed to the Italian Parliament in 2014, which was also later successfully withdrawn. Finally, the discussions initiated by our research were used to feed into a number of Italian and French eating disorder charities' work, as well as health professionals, in both countries, to ultimately improve the lives of eating disorder sufferers themselves.</p>		
2. Underpinning research		
<p>Eating disorders have the highest mortality rate of any mental illness. The age at onset is often in adolescence. In the UK, approximately 1.25 million people have an eating disorder, 25% of whom are male. In Italy, eating disorders affect about two to three million people, while in France, between 600,000 and 1 million individuals are affected. As an indicator of how serious the issue is beyond Europe, at least 30 million people suffer from an eating disorder in the US, and every 62 minutes at least one person dies as a direct result of one.</p> <p>The rise of patient-led 'pro-ana' (pro-anorexia) and 'pro-mia' (pro-bulimia) websites since the late 1990s (over 400 in America throughout the 2000s, about 600 in France in 2010) led to concerns that they may reinforce eating disorders, as their (often teenager) authors seemed to praise weight loss and thinness. In 2008, French Conservative MP Ms V. Boyer unsuccessfully attempted to impose fines and prison punishment for authors of these websites. In 2011-12, social media companies such as Instagram and Pinterest banned 'pro-ana' contents. Yet, very little scientific evidence was available at the time to corroborate those actions, and the potential effects of such prohibitions were unclear.</p> <p>This background motivated the launch of ANAMIA ('Ana-mia' Sociability: an Online/Offline Social Networks Approach to Eating Disorders) in January 2010, a comparative sociological study of the online and offline personal networks of users of websites on eating disorders in France and the UK. A web survey was completed by 284 English and French-speaking European respondents in 2011-2012, 37 for in-depth interviews. We examined how these users interact with information and access resources through these websites. The goal was to shed light on the structure, functions and effects of sufferers' social networks on their behaviours and health.</p>		

ANAMIA was a collaborative project to which **Tubaro** (one of the project's Co-PIs) and **Pallotti** at the University of Greenwich participated. They contributed with their expertise in **Social Network Analysis (SNA)** – a field in which the University's Centre for Business Network Analysis has a leading international reputation. **SNA offered innovative tools and techniques to identify the social underpinnings of eating disorder sufferers' behaviours and their online expressions.**

The novelty and significance of bringing SNA to bear on issues of health-related behaviours were highlighted by one Reviewer of article **3.1** listed below: *'The present paper presents a very interesting and relevant topic with a noted contribution because of the examination of "daily-life contexts" and relationships with peers, friends, etc. It is good to see body image research moving outside of the social realm in the context of media and moving into another aspect of the social realm—personal relationships.'*

We showed that **'pro-ana' websites do not necessarily spread unhealthy eating behaviours, but can represent important sources of social support and solidarity between sufferers, with potential benefits for health.** More specifically we found that:

1) Online relationships enhance the sociability of people with eating disorders. If the disease often results in loss of the values of pleasure and food-sharing at the table, online spaces allow at least partial recovery of this 'commensality' [3.2, 3.4].

2) 'Ana-mia' websites are a source of support for users. They offer information, empathy, practical help and companionship. Their separation from other contexts of interaction allows users to access support in a welcoming and non-judgmental environment [3.5].

3) The 'pro-ana' label popularized by press debates is misplaced. Most web communities reject the accusation of advocating anorexia nervosa or any problematic eating behaviour. Besides, emphasis on anorexia only is misleading as it disregards a wider range of eating disorders [3.1].

4) Censorship of 'ana' and 'mia' web sites is ineffective (the number of sites has remained about stable over time, despite repeated restriction threats) **and harmful** (leading communities to hide, thereby impeding outreach by health professionals) [3.6].

5) 'Ana-mia' website users do not refuse healthcare. Over half of those with a disorder are treated, usually by several professionals (GP, psychiatrist, nutritionist...), for long periods (3-4 years). However, they often consider the available provision of care insufficient [3.2].

6) 'Ana-mia' websites tend to evolve towards moderate orientations. Any radicalization, whether 'pro-ana' or 'pro-recovery', can lead to fragmentation of the community into opposing groups, but is unlikely to impose itself unto all members [3.3].

3. References to the research

- F. Pallotti, P. Tubaro, A.A. Casilli & T.W. Valente** (article, 2018). 'You see yourself like in a mirror': the effects of internet-mediated personal networks on body image and eating disorders. *Health Communication*, 33(9): 1166-1176.
<https://doi.org/10.1080/10410236.2017.1339371>
The review of article 3.1 (mentioned in Section 2) indicting novelty and significance of the research can be provided by the university on request in pdf form
- A.A. Casilli & P. Tubaro** (book, 2016). *Le phénomène 'pro-ana': Troubles alimentaires et réseaux sociaux*. Paris: Presses Universitaires des Mines. ISBN-10:2356713859 (Although the book was published in 2016, the underpinning research was conducted by Tubaro whilst at UoG). [Available on request from the university]
- A.A. Casilli, J. Rouchier & P. Tubaro** (article, 2014) How to build consensus in a health-oriented online community: modelling a 'pro-ana' forum, *Revue Française de Sociologie*, 55(4): 731-764. ISBN-13 : 978-2356713858. <https://doi.org/10.3917/rfs.554.0731>
- P. Tubaro, A.A. Casilli & L. Mounier** (article, 2014). Eliciting personal network data in web surveys through participant-generated sociograms, *Field Methods*, 26 (2): 107-125. <https://doi.org/10.1177/1525822X13491861>
- P. Tubaro & L. Mounier** (article, 2014). Sociability and support in online eating disorder communities: Evidence from personal networks, *Network Science*, 2(1): 1-25. <https://doi.org/10.1017/nws.2014.6>

6. A.A. Casilli, F. Pailler & P. Tubaro (article, 2013) Online networks of eating-disorder websites: why censoring pro-ana might be a bad idea, *Perspectives in Public Health*, 133(2): 94-95. <https://doi.org/10.1177/1757913913475756>

4. Details of the impact

Impacts from the research in France

The ANAMIA project prevented the introduction of harmful legislation in France. The main impact of our research has been prevention of the enactment of a legal measure that could have had negative consequences on eating disorder sufferers and their families. We achieved this by influencing public debate through our broad dissemination strategy and collaboration with stakeholders – health professionals and charities.

The preliminary results of our research were first disseminated in a public symposium (2012) and in a report (2013). Our findings [3.1 – 3.6] reached four French MPs who raised formal questions to the Minister of Health in 2013. In their words, our results ‘highlight the fact that these blogs can be, for some patients, bearers of a message of solidarity between anorexic and bulimic persons and thus constitute a kind of intermediary between patients and the medical profession’. [5.4]

However in April 2015, the government proposed punitive measures against ‘pro-ana’ website users as part of a broader health reform [5.1]. *Assemblée Nationale*, the lower Chamber, approved at first reading a clause establishing fines (EUR10,000) and one year of prison. In the effort to convince the Senate (which was next to read the bill) to remove the clause, we leveraged our contacts with the press and published a two-page op-ed in newspaper *Libération* (it ranked 7th in France by circulation in 2020) – which also chose to devote its first page to the issue. In the following weeks, we gave over 20 interviews to several other dailies, magazines and radio-TV channels (such as *Europe 1*, *Métro*, *France 24*, *Courrier International*, *Radio France Inter*, etc.). We liaised with eating disorder specialists and charities. We co-authored an op-ed in the online magazine *Slate.fr* with N. Sahuc, a dietician specialising in eating disorders, and we published online a joint appeal to the Senate (April 2015) with the French federation of eating disorder charities (FNA-TCA) grouping 25 charities in 2015. We obtained a meeting with a Senator, Ms P. Schillinger (May 2015) and with the Commission of Social Affairs of the Senate (June 2015), where we again presented our findings [3.1 - 3.6]. As a result of all these efforts, the controversial clause was removed and Parliament’s documents cited our hearings at the Senate as a turning point in their understanding of ‘pro-ana’ websites. **In November 2015, the last reading of the bill in Parliament confirmed the suppression of punitive measures: in the law that eventually passed, there are no fines, and no prison, for users of ‘pro-ana’ websites [5.3].** The minutes of the meeting mention the following reasons, and acknowledge our research project as the source of these insights [5.2]:

- *These websites do not cause the disorder, which depends on multiple factors [3.3];*
- *The authors of these websites are primarily young people (mostly women), who are already ill [3.5];*
- *These websites are a source of information and support for these people, and a place where families, carers, health professionals and associations may reach them easily [3.1, 3.2];*
- *Sanctions may not be effective in limiting the spread of eating disorders [3.4];*
- *Without this part of the web, sufferers may be deprived of a space where they can voice their problems – with potential negative health consequences [3.6].*

The ANAMIA project has also strengthened the caring capacity of health practitioners and charities in France. Our results have helped these organisations better understand online networking, adjust their approaches, and position themselves in the legislative debates surrounding the 2015 health bill. ‘Pro-ana’ websites challenged established practices and therapeutic approaches, especially programmes that required patients’ isolation. More generally, practitioners lacked the tools to unpack the drivers and modes of sufferers’ online networking – they saw them as a threat rather than a resource they could leverage for their benefits. As our results inverted this perspective, we reached out to them through the above-mentioned

symposium and online report (2013). Their urgent need for better understanding led to invitations to present our work at a number of highly-attended events for health practitioners and charities (Paris 2014, 2015; Nîmes 2016; Montpellier 2018).

Our research had a clear effect on the way health professionals and charities view 'pro-ana' websites. N. Sahuc, for example, dietician, said the study covers ground '*previously unexplored by medical professionals*' and that our results '*teach us the errors of our prevention decisions*' [5.8d]. B. Remy, medical doctor, found useful to understand the '*role of social networks for isolated patients*' and noted '*care contacts*' in them [5.8b]. Representing a group of Parisian charities (CISS IDF), J.L. Plavis acknowledged the merits of our study in highlighting the existence of online support groups in addition to seemingly 'pro-illness' messages [5.8a]. D. Castellotti, President of FNA-TCA, the federation of eating disorders associations, confirmed that our research '*lifted the veil on the influence, not only negative but also positive, of online social networks on eating behaviour*' [5.8c].

The research has enabled French clinical practitioners to take a more nuanced approach with their patients, balancing the benefits of online social networks they use against any negatives. D. Castellotti of FNA-TCA said that insights from our study '*now enable [health practitioners] to respond to the various problems posed by online social networks with full knowledge of the facts and to take action adapted to the situation*' [5.8c]. N. Godart, the President of FFAB, the French association of eating disorder professionals, says that our results '*continue to inspire us today and have led us to propose to the Ministry of Solidarity and Health the organization of a "National Anorexia and Bulimia Awareness Day"*' [5.8e].

Preventing harmful legislation in France aided patients' journey toward recovery. Although our ethical commitment to destroy contact information of study participants prevented us from collecting direct evidence of benefits to sufferers (for instance, in the form of supporting statements), they are the ultimate beneficiaries of our research. J.L. Plavis of CISS IDF gladly noticed that today there are online groups that enable mutual support between patients and have a very positive role in promoting recovery, although some of their users have gone through pro-anorexia sites in the past. Had they been fined or imprisoned earlier on, they could not have made this journey which now brings them not only to recovery, but also to helping others [5.8a].

Impacts from the research in Italy

The ANAMIA project also prevented the introduction of harmful legislation in Italy. In June 2014, a bill inspired by Boyer's one was submitted to the Italian Parliament by a group of MPs headed by Ms M. Marzano [5.6]. La Fenice, an Italian eating disorder charity that initiated a petition against this bill, knew about ANAMIA, and cited us in their discussions [5.7]. After we published a Medium post in Summer 2014 to warn against the potential drawbacks of Ms Marzano's bill, the national association of Italian charities contacted us (<https://www.coordinamentonazionaleedca.it/>), and we received several invitations to speak about ANAMIA (Pisa 2014; Parma 2014; Venice 2015; Lecce 2015). They appreciated our results as an evidence base that corroborated their views (which relied mostly on reflective practice), in international comparative perspective. Ms Marzano withdrew her bill on 17 September 2015.

The discussions initiated by our research were further used to feed into Italian charities' work. Sufferers' families appreciated our presentations: Informal feedback confirmed that understanding precisely what their children were doing online somehow reassured them, as they realized that there could be recovery opportunities where they previously saw only risks. Additionally, we created linkages between Italian and French eating disorders charities, for example by obtaining an invitation for an Italian representative to a FNA-TCA event in Paris (June 2015). We also informally advised one parents' association (MIDORI) on how to best use the web to provide support to members.

5. Sources to corroborate the impact

1. Health bill proposed by the French government, 27 May 15, including clause establishing punishments for people who promote excessive thinness online <http://www.assemblee-nationale.fr/14/amendements/2673/AN/1052.asp> (Pro-anamia sites especially targeted)
2. Official minutes of 2015 health bill's final reading session at French Parliament, 24 Nov 15, in which decision is made to remove that clause from final version of the law. ANAMIA is cited by Mr M. Gérard Sebaoun (MP, referee on this bill) as a reason for this change: 'For several years, there have been blogs and discussion forums, where people talk about their eating disorders. The ANAMIA study, carried out by renowned researchers between 2010 and 2014, pointed to the risk of nullifying these spaces: it would be difficult to hear the voices of these young women - 90% of people with anorexia being women'.
URL: <http://www.assemblee-nationale.fr/14/cr/2015-2016/20160064.asp#P662456>
3. The Health Act as eventually passed by French legislature – no longer including the clause punishing 'pro-ana' website users (17 Dec 15): <http://www.assemblee-nationale.fr/14/ta/ta0650.asp>
4. Formal questions asked by French MPs to the *Ministère des Affaires sociales et santé* (Ministry of Social Affairs and Health) after the ANAMIA 2012 project conference which made available the first key findings. They cite the research to invite the government to re-think the country's approach to eating disorders:
 - Question n° 15670 of Ms Sandrine Doucet (Socialist Party), 15 Jan 13, <http://questions.assemblee-nationale.fr/q14/14-15670QE.htm>
 - Question n° 16845 of Ms Martine Faure (Socialist Party), 29 Jan 13, <http://questions.assemblee-nationale.fr/q14/14-16845QE.htm>
 - Question n° 19774 of Mr René Rouquet (Socialist Party), 2 Feb 13, <http://questions.assemblee-nationale.fr/q14/14-19774QE.htm>
 - Question n° 21457 of Mr Marc Le Fur (Conservative Party), 2 Jul 13, <http://questions.assemblee-nationale.fr/q14/14-21457QE.htm>
5. Petition co-signed by ANAMIA researchers and FNA-TCA (French federation of associations of eating disorder patients and their families), asking the French Senate to suppress the clause establishing fines and jail terms for 'pro-ana' website users, 29 Apr 15: <https://web.archive.org/web/20151112134407/http://www.anamia.fr/appeal-anamia-fnatca-amendement-anti-anorexiques/>
6. Bill C. 2472, proposed to Italian Parliament by Hon. M. Marzano and other MPs to establish monetary fines and prison terms for "pro-ana" website users on 19 Jun 14, withdrawn on 17 Sep 15: https://parlamento17.openpolis.it/singolo_atto/30627
7. Mention of ANAMIA research by Italian Association La Fenice, in support of their petition to suppress Bill C. 2472, 5 Sep 14: <https://www.change.org/p/petizione-diretta-a-deputati-e-senatori-della-repubblica-italiana-ritirate-il-disegno-di-legge-n-2472-della-on-marzano/u/8059055>
8. Supporting statements by health professionals and representatives of associations:
 - (a) Jean-Luc Plavis, on behalf of Coordination of Health Associations of the Greater Paris Area (Collectif Inter Associatif Sur la Santé en Ile-de-France, CISS IDF), 25 Nov 19;
 - (b) Brigitte Remy, Medical Doctor and former Secretary General of AFDAS-TCA (French eating disorders professionals' association), 25 Nov 19;
 - (c) Danielle Castellotti, President of FNA-TCA (National Federation of Eating Disorders Associations, France), 27 Nov 19;
 - (d) Nicolas Sahuc, dietician, France, 28 Nov 19;
 - (e) Nathalie Godart, Professor of Medicine and President of FFAB (French Federation on Anorexia and Bulimia, the professionals' association), 12 Feb 20.