

“Please don’t put a price on our lives”:

Social media and the contestation of value in Ireland’s pricing of orphan drugs. Gillian Moran and Nicola Mountford, Maynooth University

Social media play an ever-increasing role in the organization of collective action where property rights, actors, networks, and governance are enacted and contested by political, cultural, and social institutions (Dacin et al., 1999). Social media’s role in building community (Kaplan and Haenlein, 2010) and facilitating advocacy (Obar et al., 2012) is well charted, as is the ubiquity of social media in our daily lives (Hewett et al., 2016).

Our goal is to understand how organizations and individuals alter definitions of value within the pharmaceutical market through their actions and interactions on social media. We examine social media influence in two case studies in the context of Irish drug pricing. The drugs in both cases fall into a special category – that of orphan drugs. In the European Union, orphan drugs are classified as those that are designed for the diagnosis, prevention or treatment of life-threatening conditions that affect no more than five in 10,000 people¹. Their special status means that those who develop and produce orphan drugs benefit from a wide range of supports including public funding for basic science, tax incentives, extended patent protection, and market exclusivity.

In 2013, the Irish government gave full statutory powers to the Health Service Executive (HSE) to make decisions on the reimbursement of medicines through the Health (Pricing and Supply of Medical Goods) Act 2013. The Act specifies the criteria to be applied in assessing the value of all new drugs including the clinical and cost effectiveness of the product, opportunity costs, and impact on resources available. The HSE is required to take the advice of the

National Centre for Pharmacoeconomics (NCPE) in making its decisions. Our first case deals with the provision of the drug Orkambi for cystic fibrosis (CF) patients. Orkambi was approved for access in Ireland following eleven months of public debate and social media campaigning by people living with CF, their loved ones and their advocates. The second case concerns the provision of the Spinraza drug for patients with Spinal Muscular Atrophy (SMA). Spinraza was also approved for access after “a lengthy campaign by patients and their families”¹. In both cases, the HSE and NCPE had initially refused reimbursement.

In the wake of these and other similar campaigns, Bill 33 of 2018, an amendment to the Health Act (2013), was debated in the Irish parliament (Dáil). The Bill was an attempt to change the existing reimbursement decision-making process for orphan drugs only. It proposed “...guidelines which include a threshold cost-effective incremental ratio or similar assessment, shall not be relevant in the case of Orphan Medicinal Products.” In other words, the objective clinical/cost assessment process outlined in the original 2013 Act would not be applied to orphan drugs. This proposal was not universally popular. Indeed, Professor Michael Barry, Director of Ireland’s National Centre for Pharmacoeconomics, has argued that “it will not help a single patient” and will only lead to massive hikes in the cost of medicines: “What it is saying, is the highest cost drugs that we look at every day — that cost more than half-a-million euro per patient per year — we are not allowed to ask about cost-effectiveness?”²

We ask what role social media activism played in this new bill that aimed to alter the processes by which value was calculated for this subsection of drugs. This chapter is structured as follows. We first review and synthesize the social media literature, linking it to its use in the

¹ RTE News, 11th June 2019, <https://www.rte.ie/news/health/2019/0611/1054770-spinraza-drug/>, accessed 9th August 2019

² Prof Michael Barry, Director of the National Centre for Pharmacoeconomics, addressing the 2018 Irish Medical Organisation AGM

contestation of value, particularly in the context of healthcare markets. Secondly, we describe how we used social media data to build a picture of social media influence on reimbursement decision-making within the Irish market for orphan drugs. We focus in particular on the use of social media for information circulation, community building, and mobilization towards action within an online advocacy campaign. The following section presents the results of this research in the form of two case studies on the Orkambi and Spinraza campaigns. Drawing on these case studies our fourth section discusses the insights for healthcare market activism arising from our research.

[The Role of Social Media in Healthcare Market Advocacy](#)

The increasing role of the market in healthcare

Marketization often causes fields such as healthcare to seem like markets – subjugating other institutional structures such as state, community, or professions to the market in terms of how value is defined (Thornton, 2002). The result is that social relations between doctors and patients may be simplified to that of supplier/consumer (Giroux, 2004). The contractual arrangements and monitoring processes that frame the modern healthcare field – such as the reimbursement decision-making process at the heart of our cases - are often shaped by market logics and thus serve to diffuse market principles (Djelic & Sahlin-Andersson, 2006). The public sector increasingly commissions while the private sector delivers, resulting in the marketization of healthcare services (Acerete, Stafford, & Stapleton, 2012). Acerete et al. offer evidence from Spain where a 2011 report called for management reform in hospitals and a move to a market-based system (Fundación Bamberg, 2011) and the UK where, in 2012, a private healthcare partnership won a £1 billion 10-year deal to run clinical and non-clinical services at Hinchingsbrooke Hospital, Huntingdonshire. This reflects an increasingly prevalent

“culture of markets” in healthcare where value is perceived through the more efficient allocation of most if not all goods and resources (Djelic, 2012).

As Geiger in her introduction to this volume suggests, however, this process is potentially incompatible with civic values and accountability as it places little or no value on democratic ideals such as fairness and justice (Eikenberry & Kluver, 2004). Public actors, therefore, continue to bring the state into the market through both legislative and non- legislative methods (Mountford, 2019) while other actors including affected patients work to have their voices heard within such ‘concerned markets’ (Geiger, Harrison, Kjellberg, & Mallard, 2014). Within healthcare markets the State can play multiple roles – it may act as one large buyer or seller (Ahrne et al., 2015), it can seed and manage relationships (Mountford, 2019), and it legislates and makes market rules. This means that, even within a marketized healthcare field, the state remains a target for advocates or activist networks who wish to change the way purchasing decisions are made, challenge the relationships between organisations, or overturn the rules that govern both market and field (Mountford & Geiger, 2020). Hoffman (1999) portrayed the field as a centre of debate where reconfigurations and reorganisations result from events that trigger new debates or new forms of debate. Patient groups in the US, for example, advocated for the passage of the American Orphan Drug Act in a bid to encourage the pharmaceutical and biotechnology industry to develop treatments for rare diseases (Novas, 2009). Value can become an issue for debate, where new valuation categories go beyond immediate economic valuations to include more complex approaches to valuation that can include emotion, longer-term horizons, or wider impact evaluations (Dubuisson-Quellier, 2013). Moreover, social media offer new virtual discursive spaces where texts that shape such new valuation categories can be produced, distributed and consumed (Hajer, 1995), and be contested by multiple voices (Hauser, 1999).

Social media and healthcare activism

Social networking sites (SNS) bring together like-minded individuals, separated by geography or other barriers, to connect and converse over a shared interest or issue (Kaplan and Haenlein, 2010). In the healthcare field, patient communities are flourishing on social media (Attai et al., 2015). Virtual patient communities are important sources of emotional support, advice and camaraderie among those facing comparable illnesses and challenges (Smailhodzic et al., 2016), such that patients may feel “an intrinsic connection toward other members” of the online patient community (Bagozzi and Dholakia, 2002:5). Community members utilize social media as discursive spaces to share latest research and facilitate patient-specific discussions (Dholakia et al., 2004). Social media thus fulfil important identity, community building and support functions for patient communities – functions that, as Rabeharisoa and Doganova in their chapter suggest, have always been important to patient organizations and that are now much facilitated through the ubiquity of online tools.

Of late, social media have moved from connecting and exchanging information to becoming central to the instigation and coordination of contemporary advocacy campaigns (Velasquez and LaRose, 2015). Advocacy here refers to the “systemic effort by specific actors who aim to further or achieve specific policy goals” by informally influencing public policy (Obar et al., 2012: 4). They facilitate the forming of advocate communities due to their inherent open access, their ability to allow individuals to forge social connections with similar others (Tajfel, 1978), and their provision of access to essential resources such as knowledge-sharing, advice, and the opinions of experienced others (McAlexander et al., 2002). This empowers users to leverage social media networks to “influence their peers and thus contribute

to broader public advocacy efforts that may in fact have real, if indirect, macro-level policy effects” (Penney, 2015:53).

Patient-led advocacy campaigns use SNS to present patients’ own personalized experiences and struggles to the public, thus putting a human face on a social issue to gain support and solidarity from peers and the wider public. Patient advocates confer both moral authority and public trust on the advocacy cause through the depiction of their ongoing battles with illness (McDonnell, 2016). Personalized, emotionally charged health messages propagate quickly online, activating others to get behind an advocacy campaign to help amplify those messages and call for policy change to better the lives of patients (Meng et al., 2018; Berger and Milkman, 2012). Online platforms such as Facebook and Twitter facilitate the high-speed diffusion of user-generated information in real-time to support such calls for action. This instantaneous communication medium lends a sense of urgency to a campaign, while a community of active members can broadcast and amplify a tidal wave of issue-specific information to attract the attention and influence of multiple public stakeholders (Rost et al., 2016, Obar et al., 2012; Poell and van Dijck, 2015).

SNS conditions, for instance a dense, well-connected network of people sharing similar interests, provide an incubator for social challenges and online advocacy (Housley et al., 2018). A coordinated campaign that focuses on a specific topic, such as patient welfare, can create a disproportionate presentation of that topic in the social media environment (Johnen et al., 2018). This helps to create a narrative for the advocacy campaign through the development of consistent patient-centered messages. When content such as this gains traction and ‘trends’ across social media sites it signals the popularity and importance of the information, which focuses public attention on the campaign’s central issue (Meng et al., 2018). Routine social

media reactions, such as liking or retweeting content, easily engage people in information exchange, raising awareness and visibility of an advocacy campaign among previously uninformed peers (Moran et al., 2019; Housley et al., 2018; Penney, 2015). In essence, a social media advocacy campaign gently nudges peer connections to advocate for a worthy cause in a participatory, bottom-up approach that garners grassroots social support to subtly shift public opinion (Housley et al., 2018; Penney, 2015; Zuckerman, 2014).

The relationships between the pharmaceutical industry, state agencies, and patient organizations are key in the framing of the healthcare market (Abraham 2009). Social media have the capacity to transform power relations within the public and civic spheres by bringing in new voices to effect change in regulations or market activities (Housley et al., 2018; Soule, 2012), thus “activist organizations are increasingly seeing the value of social media for recruitment, public engagement, and campaign organization” (Murthy, 2018:2). Patients, through activities such as “lobbying, hypermedia campaigns and marches”, can leverage social media to influence power holders (Acosta, 2012:159; Kraemer et al., 2013). As we will see below, collective action by patient communities can extend to efforts to change field rules as social media provide discursive spaces for patient groups to have their voices included in debating and reframing the meaning of value in the healthcare market.

We argue that these new approaches to, and definitions of, value are developed by community collective action in new social media-based spaces through bringing market-specific issues into the public domain and highlighting competing definitions of value between the patient community and other market actors. A patient community view of value may serve to displace traditional economic valuation in the healthcare market. The social media literature builds a strong case for the role of social media in creating patient communities within healthcare and

active communities in markets beyond healthcare. The literature describes how healthcare has become more subject to market culture and how actors can act to shape that market. This chapter seeks to build on both perspectives to focus in on the role of social media in patient advocacy campaigns within the healthcare field (Housley et al., 2018; Penney, 2015; Obar et al., 2012).

Research Design

Case studies have been shown to be particularly suited to how and why questions, to real life contexts, and to the building of theory (Eisenhardt, 1989). Following the case study approach (Yin, 2014), we present two cases depicting how the decision-making process for reimbursement approval of orphan drugs in the Irish healthcare market was influenced, and eventually overturned, by a small group of active patients using social media to inform, activate and mobilize support for their advocacy campaigns. Below is a brief overview of the two cases at the centre of our study.

Orkambi

“For all intents and purposes, cystic fibrosis is an Irish disease. We have the highest incidence worldwide. We have some of the most severe CF genotypes... Therefore, we have a duty and responsibility to lead from the front when it comes to CF treatment and care.”

Prof Barry Plant, director of the Adult Cystic Fibrosis Centre at Cork University Hospital, chairman of Cystic Fibrosis Ireland's medical and scientific committee³.

Cystic fibrosis (CF) is an inherited chronic disease caused by a defective gene that leads to life-threatening lung infections. In 2017, there were 1,237 men, women, and children living with CF in Ireland with a median age of 20.6 years (70,000 worldwide).⁴ The outlook for patients suffering from cystic fibrosis has changed dramatically over the past 60 to 70 years. As Cystic Fibrosis Ireland (CFI), states: "In the 1950s, few children with cystic fibrosis lived to attend primary school. Today, advances in research and medical treatments, including in Ireland, have further enhanced and extended life for children and adults with CF. Many people with the disease in Ireland can now expect to live into their 30s, 40s and beyond."⁵ The number of cystic fibrosis patients in Ireland and across the world is, therefore, forecast to increase as survival rates improve (Burgel et al., 2015).

In 2015, Orkambi, a new drug to treat CF, was brought to market by Vertex Pharmaceuticals and received approval from the FDA. Rather than treat the symptoms of cystic fibrosis, Vertex claims that Orkambi deals with the underlying genetic defect that causes this disease. In Ireland, Orkambi was initially submitted for review to the NCPE on 26 November 2015, and the rapid assessment concluded that December with a recommendation for a full pharmacoeconomic evaluation. This full evaluation commenced on 11 March 2016 and completed on 1 June 2016 with the recommendation that the drug not be reimbursed at the submitted price (€159,000 per patient).

³ Roche, Barry, "Ireland should lead in cystic fibrosis care, says consultant", *The Irish Times*, Friday, March 31st, 2017

⁴ The Cystic Fibrosis Registry of Ireland, Annual Report, 2017, https://www.cfri.ie/docs/annual_reports/CFRI2017.pdf, accessed 9th May, 2019

⁵ Cystic Fibrosis Ireland website, <https://www.cfireland.ie/about-cf>, accessed 9th May, 2019

Spinraza

Spinal Muscular Atrophy (SMA) is a rare disease affecting the motor nerve cells in the spinal cord. SMA is “a life-threatening and debilitating disease that causes progressive muscle weakness and loss of movement due to muscle wasting”, from the same family as motor neuron disease⁶. SMA makes it difficult or impossible to walk, eat, or breathe. SMA affects approximately 1 in 11,000 babies, and about 1 in every 50 Americans is a genetic carrier⁷. If untreated, one type of SMA (SMA1) can be fatal and is considered the number one genetic cause of death in infants⁸. Most sufferers are confined to a wheelchair and may require mobility/feeding/breathing assistance. In Ireland, 25 children and 18 adults are currently living with Spinal Muscular Atrophy⁶.

Spinraza, brought to market by Biogen, is a treatment for spinal muscular atrophy, described by the SMA patient community as “the first-ever approved treatment that targets the underlying genetics of SMA.”⁹ The European Medicines Agency in its approval of the drug therapy referred to studies in early onset SMA patients that have demonstrated its effectiveness in improving movement in babies including head control, rolling, sitting, crawling, standing and walking. The babies in this study receiving Spinraza also survived longer and deferred needing breathing support until much later⁹.

⁶ <https://www.thejournal.ie/spinraza-sma-hse-4512136-Feb2019/> , accessed 24th February, 2020

⁷ Spinal Muscular Atrophy Ireland Website, <http://smaireland.com/about-sma-spinal-muscular-atrophy/>, accessed 11th June 2019

⁸ <https://www.curesma.org/type-of-sma/> , accessed 24th February, 2020

⁹ European Medicines Agency, EMA/736370/2017 EMEA/H/C/004312 EPAR summary for the public, Spinraza, https://www.ema.europa.eu/en/documents/overview/spinraza-epar-summary-public_en.pdf, accessed 11th June 2016

In Ireland, the NCPE commenced its rapid review process for the Spinraza drug on 11 July 2017. This review completed on 2 August 2017 and recommended a full pharmacoeconomic evaluation. The NCPE completed its full evaluation assessment on 19 December 2017, concluding with the recommendation that Spinraza not be reimbursed at the submitted price (€600,000 for the first year and €380,000 per patient per year thereafter)^{10,11}.

This Study

We focus on the aftermath of the HSE's refusal to reimburse Orkambi and Spinraza. We analyse social media advocacy campaigns led by Irish CF and SMA patients and supporters to challenge these decisions. We focus on Twitter as the dominant social media platform for facilitating advocacy campaigns and shaping public discourse about social issues (Murthy, 2018). Certain features of the Twitter ecosystem such as retweets, replies and hashtags help to connect like-minded individuals, frame a topic by linking conversations together, and depict the temporal sequence of events as they unfold (Housley et al., 2018). Using a Twitter application programming interface (API), we retrieved and downloaded all tweets sent by the Twitter handles @YesOrkambi and @SMAIrelandCom. These handles represent the patient heart of these advocacy campaigns as they were launched specifically to advocate for the reimbursement of the Orkambi and Spinraza drugs.

In the case of Orkambi, the @YesOrkambi handle launched on 2 June 2016 – the day after the HSE's initial refusal decision – with the sole purpose of getting this decision overturned¹². Led by the mother of a CF patient, the Twitter campaign states: “Orkambi is a breakthrough drug

¹⁰ Pre-submission consultation with Applicant 12/09/2017; Submission received from applicant 31/10/2017, Preliminary review sent to applicant 28/11/2017, NCPE assessment re-commenced 06/12/2017, Applicant factual accuracy check 08/12/2017, NCPE assessment re-commenced 14/12/2017.

¹¹ <https://www.thejournal.ie/spinraza-sma-hse-4512136-Feb2019/>, accessed 24th February, 2020

¹² <https://rothco.ie/news/you-pick-on-one-of-us-you-pick-on-all-of-us/> accessed 21st February 2020

that could change the lives of 600 Irish PWCF. We won't rest until we get access to it – you can't put a price on people's lives.”¹³ For Spinraza, the @SMAIrelandCom Twitter handle and advocacy campaign took a little longer to begin, launching on 12 September 2018, nearly nine months after the HSE's decision to refuse reimbursement. It clearly sets out its stall as a campaign to secure HSE funding for SMA-related drugs in Ireland, while its accompanying campaign website reinforces this mandate, stating: “The #SpinrazaNOW campaign is a campaign to ensure that the revolutionary drug Spinraza is available to Irish SMA sufferers through the HSE. This drug is to date the only approved treatment for Spinal Muscular Atrophy and is a lifeline to those suffering from this degenerative disease.”¹⁴

In both cases, we followed the temporal unfolding of these advocacy campaigns on Twitter by analysing their tweets, including replies and retweets, from initial launch until the drug reimbursement was eventually approved by the HSE. In total, we analysed 1,012 tweets by @YesOrkambi and 247 tweets by @SMAIrelandCom. In coding using NVivo software, we followed Krippendorff's (2013) guidelines for quantitative content analysis manifest in the objective observation of deductive coding categories rather than exploration of latent meanings. Deductive codes were adopted from Lovejoy and Saxton's (2012) study of how non-profit organisations use social media to leverage followers and drive advocacy campaigns online. In all, 12 sub-categories of tweets were identified from Lovejoy and Saxton (2012), representing three meta-categories: information-oriented tweets, community-building tweets, and action-oriented tweets. Information-oriented content provides community members and supporters with timely updates on latest developments, patient challenges and CF-specific news. Community building content aims to socialize members and strengthen interpersonal ties

¹³ <https://twitter.com/YesOrkambi> , accessed 25/02/2020

¹⁴ <http://smaireland.com/spinrazanow-campaign/> accessed 25/02/2020

within the community. Action-oriented content concerns mobilizing community members to take supportive actions towards achieving campaign goals. In many cases, tweet content related to more than one category and therefore was dual-coded for richness¹⁵ (see Figures 1 & 2 for a breakdown). In addition, we measured the frequency of tweet behaviour and the sequencing of tweet behaviour across both campaigns.

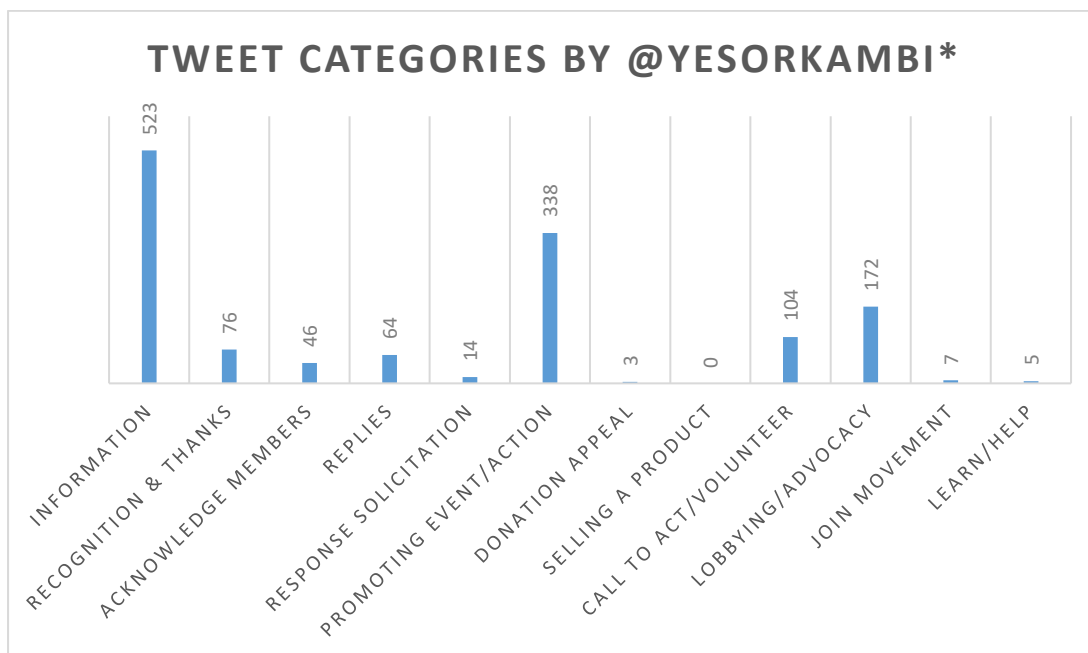


Figure 1: Tweet Categories by @YesOrkambi. *some tweets belong to more than one topic category

¹⁵ Note that numbers/percentages cited for social media statistics do not add to 100% as some tweets belong to more than one topic category

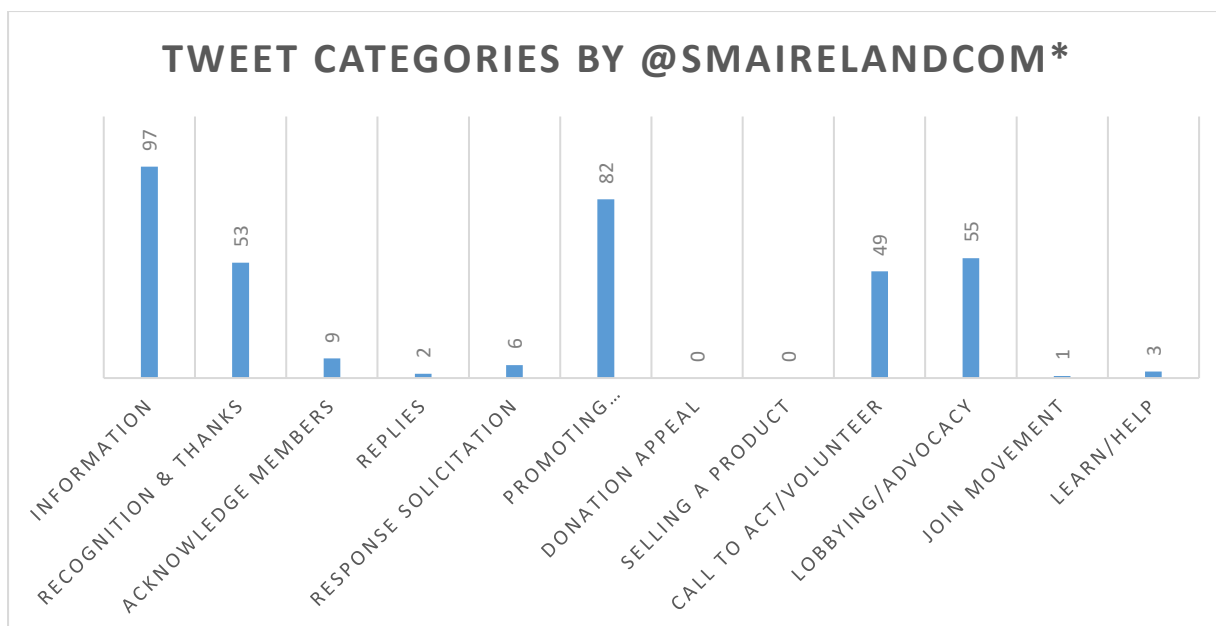


Figure 2: Tweet Categories by @SMAIrelandCom. *some tweets belong to more than one topic category

Study Context – The assessment process

Figure 3 below maps the Irish assessment and approval process – in effect, the process by which the value of a drug is decided. When the HSE receives an application from a pharmaceutical company, its corporate pharmaceutical unit must commission the National Centre for Pharmacoeconomics (NCPE) to conduct a health technology assessment (HTA)¹⁶. This includes a rapid review of the drug’s regulatory status, the clinical condition targeted, the disease it should be licensed for, how the drug will fit with current therapies, comparator or competitor drugs or therapies, clinical evidence, safety, efficacy, and economic considerations. The NCPE review concludes within four weeks and determines whether a full pharmacoeconomic assessment is required. High-cost products, those with significant budget impact, or products where concerns arise in relation to value for money must undergo formal

¹⁶ A health technology assessment (HTA) employs a multidisciplinary research process to collect and summarise information about a health technology including clinical effectiveness and safety, cost-effectiveness and budget impact, organisational and social aspects, and ethical and legal issues that is collected and presented in a systematic, unbiased and transparent manner.

pharmacoeconomic assessment in a full HTA. Here the drug manufacturer is asked to detail the health economics and incremental benefits that justify the drug's increased cost, and submissions by patient groups are facilitated.

All drug assessments (orphan drugs included) are carried out in compliance with guidelines published by the Health Information and Quality Authority (HIQA). HIQA points out that Ireland's health budget is not unlimited and that investing in a particular drug may result in another health technology or service being dropped: "To make that choice, it is important that accurate and reliable evidence is presented to support decision-making. The goal of HTA is to provide that independent evidence"¹⁷. The NCPE considers clinical effectiveness, quality of life benefits, and all relevant costs including potential savings such as lower use of other healthcare resources (e.g. hospital beds) to judge whether the price quoted by the manufacturer is justified. The NCPE then advises the HSE on the value for money and budget impact of the drug. The full assessment report, any commercial negotiations, and other relevant information are considered by the HSE drugs group, which makes a recommendation to the HSE leadership team as the final decision-making body. The 2013 Act provides no distinct assessment criteria for orphan drugs.

¹⁷ HIQA website, accessed 02/09/2019, <https://www.hiqa.ie/areas-we-work/health-technology-assessment>

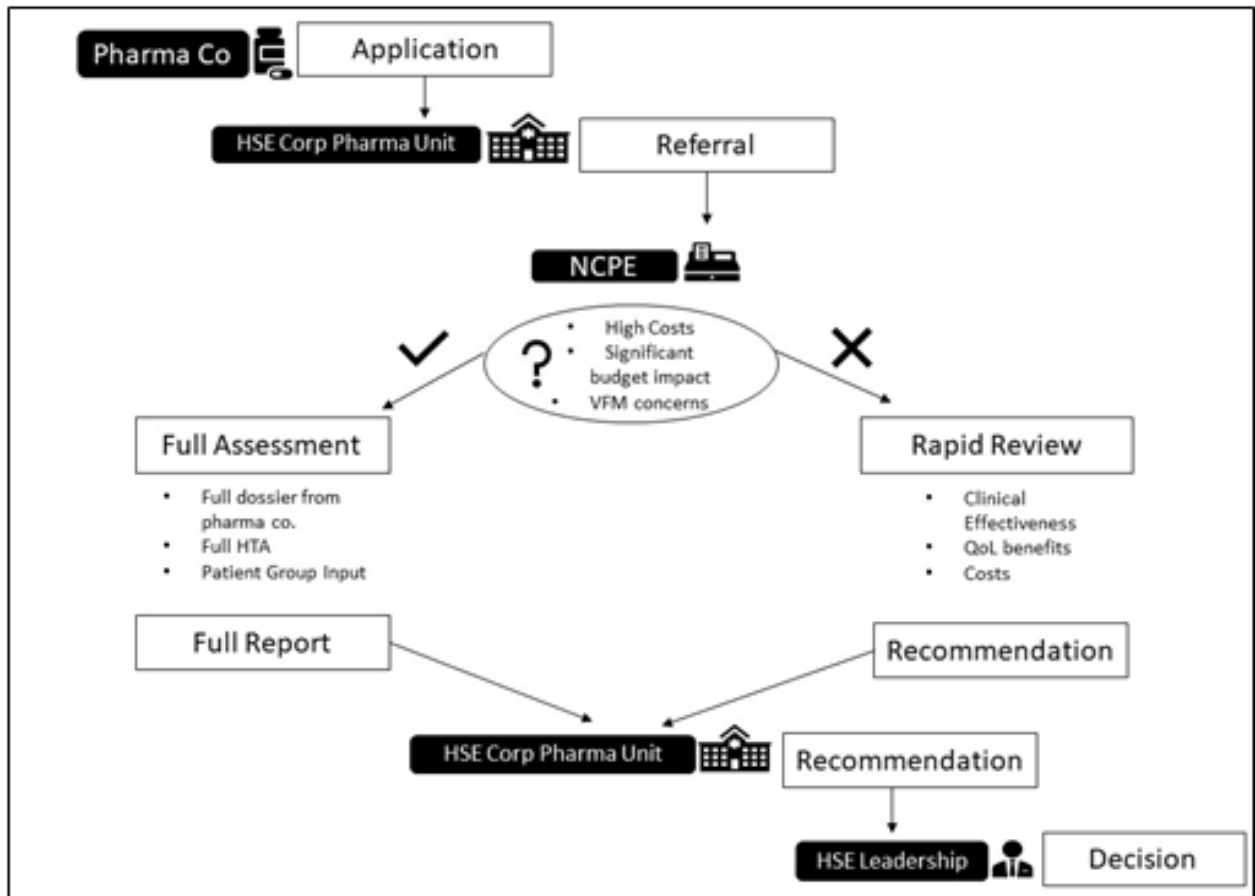


Figure 3: The Assessment Process for Drug Reimbursement in Ireland

VFM: Value for Money; HTA: Health Technology Assessment; QoL: Quality of Life;

NCPE: National Centre for Pharmacoeconomics Evaluation; HSE: Health Services Executive

Below we present findings from two case studies of how the Irish approval process outlined above, designed to remove decision making from the political realm to ensure scientific objectivity, was influenced by a small group of active patients using social media to inform, activate and mobilise support for their causes.

Findings: Influence and decision making in Ireland's drug reimbursement process

The YesOrkambi Campaign

The patient-led, social media-based YesOrkambi campaign posted frequently on Twitter in an attempt to overturn the initial Orkambi reimbursement refusal. Campaign tactics included publicising personalized patient experiences of life with CF, highlighting success stories of those on Orkambi trials, and lobbying local representatives and national government, all reinforced by the hashtag #YesOrkambi. This campaign started strongly, generating 10% of its total tweet count in the first month of campaigning – communicating both the seriousness and urgency behind the campaign. In November-December 2016, we see a spike in tweets in conjunction with offline demonstrations and protest marches outside the Dáil in response to the HSE's second Orkambi reimbursement refusal. Such co-ordinated activities proved fruitful as price negotiations re-opened between the HSE and Vertex Pharmaceuticals in December 2016 and continued into 2017. After a slow start to 2017, the YesOrkambi campaign ratcheted up advocacy activity once again in February when supporters engaged in joint online/offline candlelight vigils, tweeting photos along with the hashtags #YesOrkambi and #CFLivesMatter. These efforts were sustained into March 2017 where once again Twitter activity spiked in line with the campaign's second Dáil demonstration. A timeline of key campaign events is outlined in Figure 4.

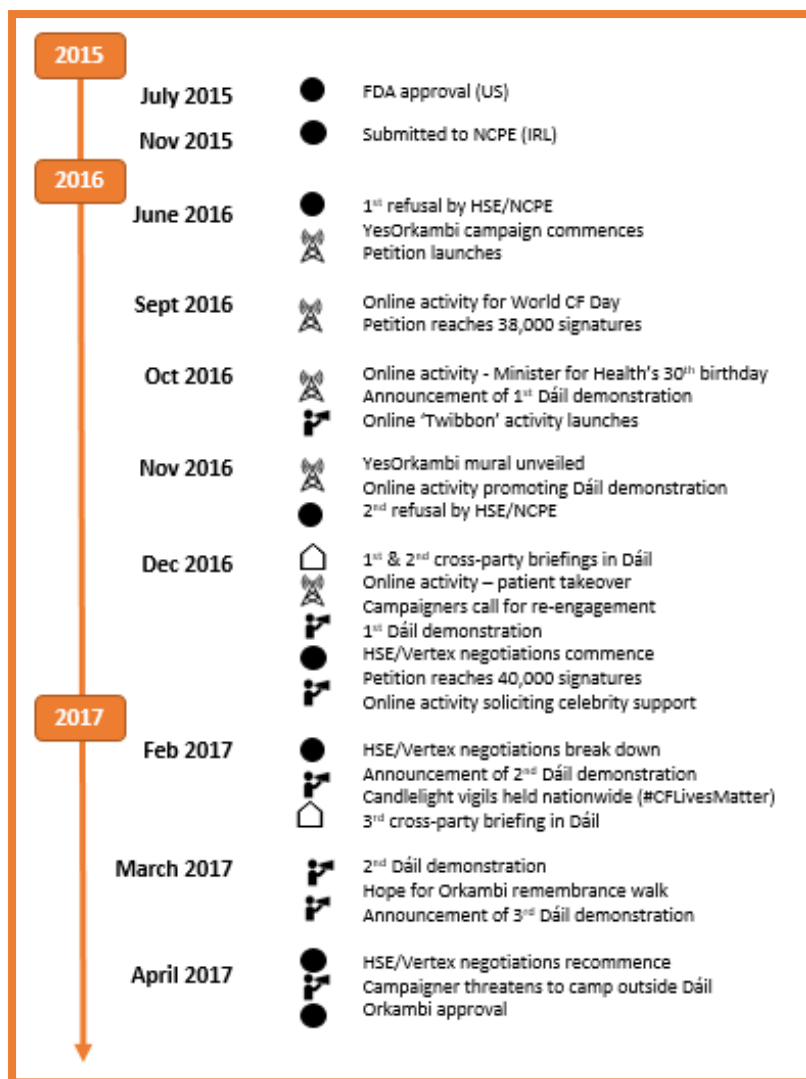


Figure 4: Timeline of key YesOrkambi campaign highlights

Orkambi was approved for reimbursement in April 2017; since then there has been very little activity on the YesOrkambi Twitter account. The advocacy campaign had effectively achieved its aim. We analyse the role of social media in facilitating the YesOrkambi advocacy campaign across 12 content categories representing three advocacy dimensions of communicating with the community, connecting with politicians, and leveraging the media (Lovejoy and Saxton, 2012):

The role of social media in YesOrkambi

The YesOrkambi campaign splits its efforts quite evenly between providing members with information (51.58% of tweets) and rallying for action (50.20% of tweets). It devoted much less time to community building efforts (19.37% of tweets). This is perhaps due to the presence of a pre-existing patient community, as people with CF (PWCF) are already well connected through the Cystic Fibrosis Ireland network. Therefore, it may have been deemed less necessary to socialize members to the purpose of the advocacy campaign than to share important new information and updates, or to organise the campaign's social actions. Information-oriented tweets in this context largely consisted of providing community members with commentary and updates on progress, or lack thereof, in price negotiations, as well as highlighting individual patient experiences with CF. Within the action-oriented tweets disseminated by YesOrkambi, three action topic categories accounted for the majority of this activity: 1. promoting an event/action (for instance a Dáil demonstration) (66.5% of all of action-oriented tweets); 2. lobbying/advocacy activities specifically directed at other market actors (33.86% of action-oriented tweets); and 3. direct calls-to-act/volunteer aimed at mobilizing community members and supporters (20.47% of action-oriented tweets). Community building efforts, while few, primarily concentrated on providing recognition and thanks to members and the wider public for their support, as well as replying to tweets posted by other members (over 70% of all community building tweets).

From this analysis, YesOrkambi organisers undertook a sustained and coordinated advocacy campaign alongside supporting offline social actions such as Dáil demonstrations. This advocacy campaign balanced a largely two-pronged social media approach throughout, informing and mobilizing community members through posting information-oriented and action-oriented tweets. Unsurprisingly, there is an increase in information sharing and calls-to-action in the days prior to organised social actions (e.g. Dáil demonstrations), with a

preponderance of action-oriented tweets on those days, and a return to information-oriented tweets in the days following social actions. In particular, information such as patient stories and media coverage are highlighted to supporters. Community building tweets are peppered sporadically across the campaign timeline, providing multiple opportunities for campaign organisers to maintain support from the community and others.

Throughout the YesOrkambi advocacy campaign we see a concerted effort by campaign organizers and their supporters to politicize their drug reimbursement issue through frequent references to, and direct engagement with, various actors including the government, specific government ministers (Minster for Health, Minister for Finance, etc.), the HSE, NCPE and Vertex Pharmaceuticals. YesOrkambi campaigners use Twitter effectively to confront government politicians and other actors, challenging their perceived complacency/inaction over the drug pricing and reimbursement approval process at the heart of this advocacy campaign. In the first instance, social media permit YesOrkambi advocates to follow and respond to updates from politicians and decision makers, engaging them in dialogue to further the YesOrkambi cause. This feeds into information-oriented tweets where updates are circulated to community members. Replying to politicians, the HSE or Vertex enables campaigners to seek direct clarification and follow up information in the interest of the patient community.

Advocates for YesOrkambi regularly ‘call-out’ perceived political complacency by highlighting the length of time elapsed since Orkambi’s initial refusal, and the lack of progress in the interim – but also offering their willingness to engage in the process. For example: “It’s over 14 weeks. Can anyone give us a timeline? What can we do to help! #YesOrkambi

@VertexPharma @SimonHarrisTD”¹⁸. Such campaign tweets publicly demand increased accountability from those in power while helping to maintain momentum in the advocacy campaign. They accentuate the plight of the patients and reinforce the urgency of their cause: “We’re not going anywhere. 23 weeks is just so wrong. @VertexPharma & @HSElive there are lives caught in the middle. It’s cruel. #YesOrkambi”. The Minister for Health is a particular target for such confrontational challenges. Through retweeting behaviors, YesOrkambi campaigners further draw attention to certain political activities such as highlighting mentions of Orkambi and campaign actions in the Dáil. They thank and recognize members of the opposition for elevating their cause in these political forums, as well as for offering their personal support at organized demonstrations and other events. As this support grows, more pressure is exerted on the decision makers to come to a resolution. A timeline indicating key political actions highlighted by the YesOrkambi campaign is outlined in Figure 5.

¹⁸ Simon Harris was Minister for Health at the time of this tweet.

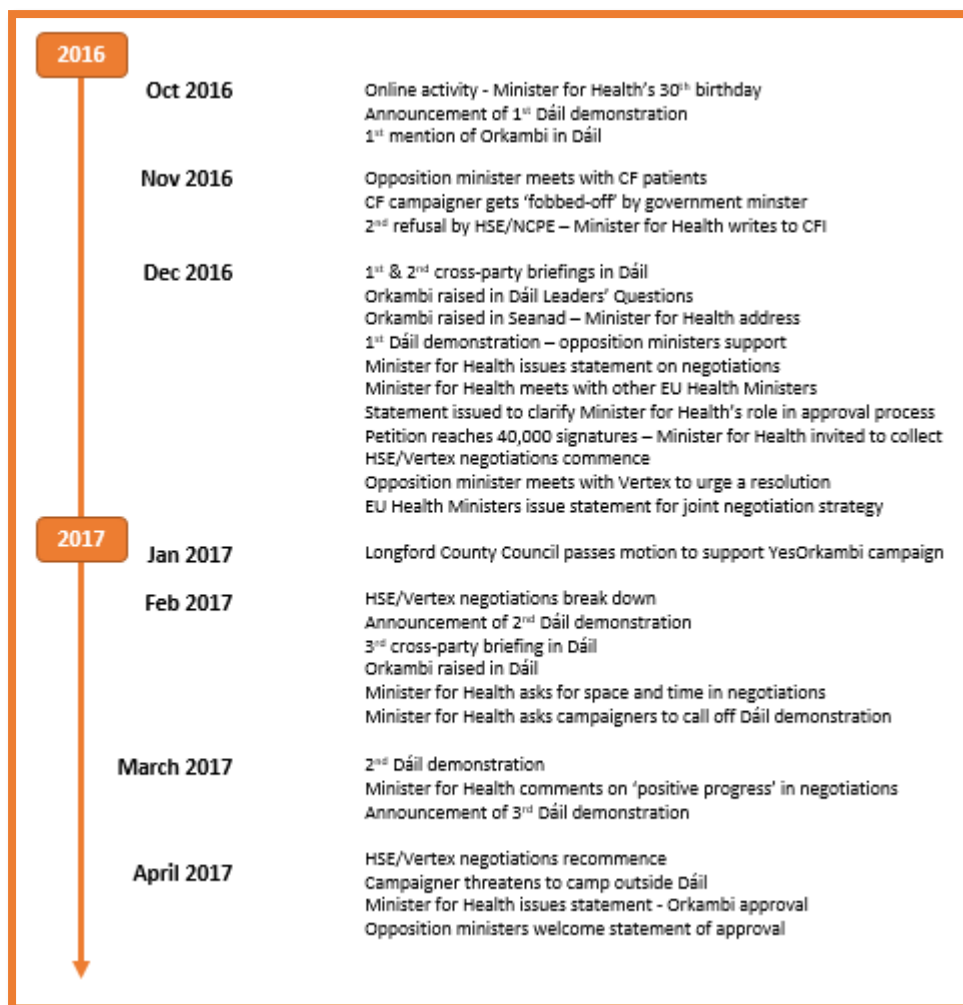


Figure 5: Timeline of key political actions highlighted by YesOrkambi

Through social media, YesOrkambi campaigners also engage with the mainstream media to heighten their advocacy campaign in the public consciousness. Several prominent YesOrkambi advocates undertake mass media activities and participate in public debates in local and national newspapers, on national news and current affairs TV programs, as well as on the radio. They give interviews, write op-ed articles and share their stories. They engage in dialogue with journalists on Twitter, willingly offering their time and experiences for publication. YesOrkambi supporters and campaign organizers readily share and retweet these articles, video clips and podcasts across social media to broadcast them widely and promote the mass media coverage afforded to the advocacy campaign. Through Twitter, campaigners also acknowledge

and thank the media for their support. We see a significant increase in media coverage, and supporter broadcasting of same, in the two weeks prior to the first YesOrkambi Dáil demonstration on December 7 2016, which strengthens the campaign's calls for more decisive action to be taken on all sides. As the demonstration, and its media coverage, gets underway, the mass media also breaks news of the decision by the HSE and Vertex Pharmaceutical to recommence drug-pricing talks with renewed hope for reaching an agreement.

The SpinrazaNow Campaign

Figure 6 outlines the ebb and flow of the Spinraza re-imburement advocacy campaign. The SpinrazaNow campaign launched nine months after the NCPE's recommendation to refuse re-imburement in December 2017, and more than a year after its submission to the NCPE for approval in July 2017. The delayed launch appears to have afforded the SpinrazaNow organisers and their supporters an opportunity to strategize so that their campaign could be as effective as possible. On social media, SMAIrelandCom drove the SpinrazaNow advocacy campaign. Alongside the campaign launched on Twitter, organisers also launched a dedicated campaign website, SMAIreland.com, to provide more detailed information to the patient community, as well as to create a patient database and to communicate with interested parties around how to get involved in its advocacy efforts. For instance, it provided guidelines and a template for joining in with its social media video campaign, along with contact details for advocating directly to decision makers (e.g. Minister for Health, local councillors, HSE, etc.).

Twitter activity across the SpinrazaNow campaign was less frequent and more sporadic than that of YesOrkambi, generating approximately 75% fewer tweets in total – just 247 tweets compared to YesOrkambi's 1,012 tweets. Following a relatively strong start to campaigning and a spike in Twitter activity, there is a significant drop off in online posting and during some

months no online activity at all. Furthermore, we do not see the same intensity in tweeting behaviour at pivotal points during this 10-month campaign, as peaks and troughs are much less pronounced. Nevertheless, this advocacy campaign was highly effective in focusing in on the key reimbursement issue and drawing in a large supporter base collectively throwing its significant weight and influence behind the SpinrazaNow campaign.

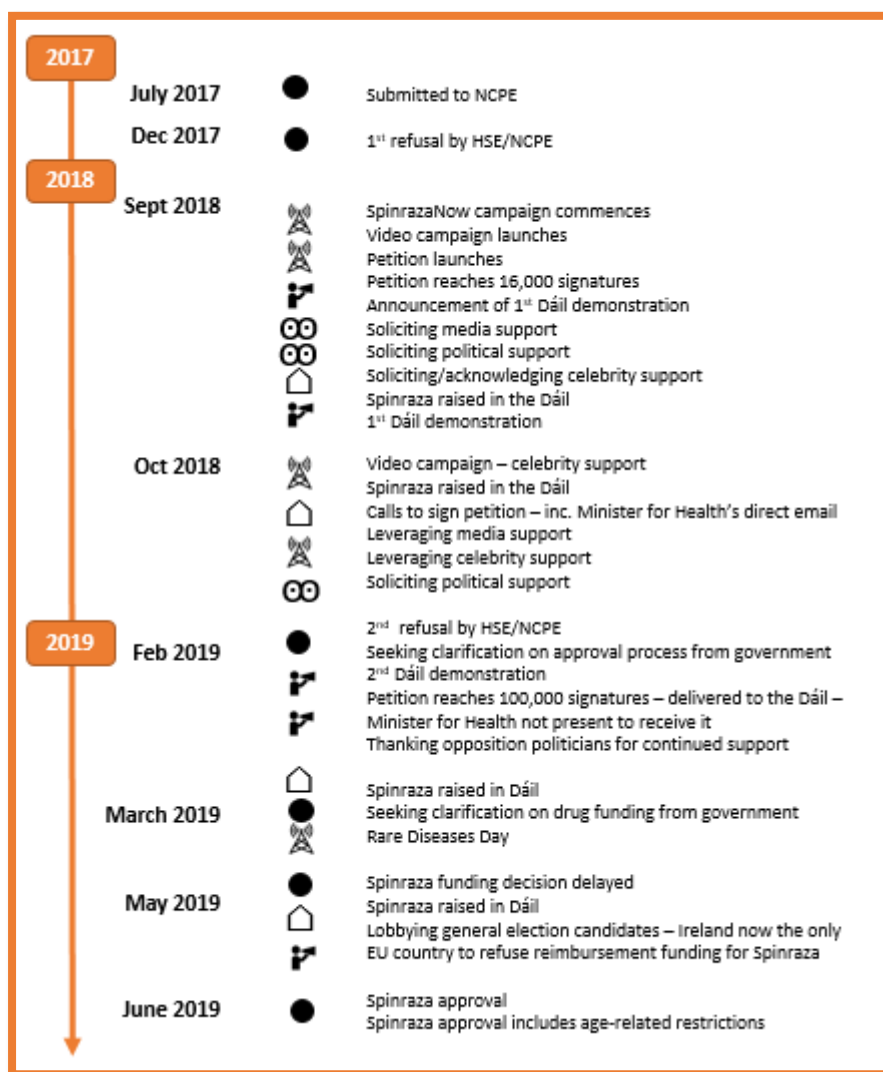


Figure 6: Timeline of key SpinrazaNow campaign and political highlights

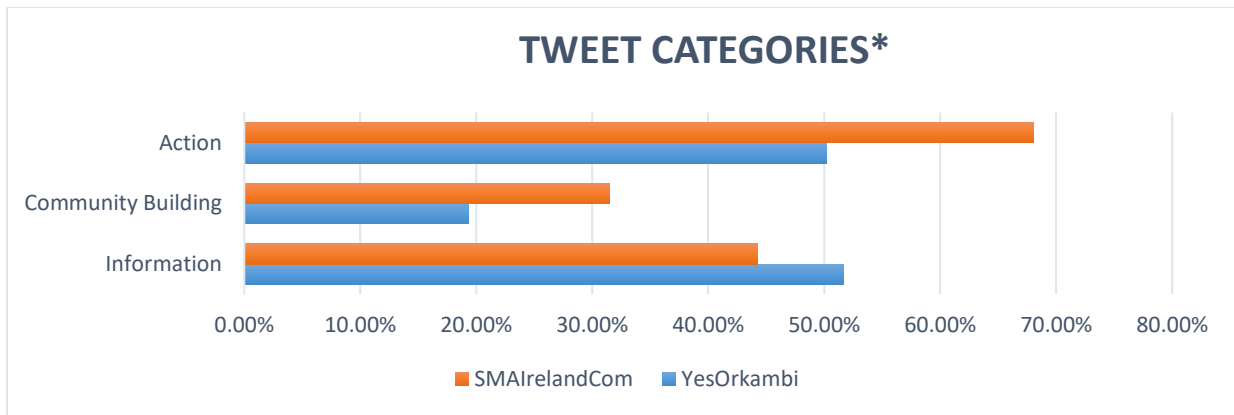
The role of social media in SpinrazaNow

In addition to its delayed start, the SpinrazaNow advocacy campaign took a very different direction to YesOrkambi from the outset. SMAIrelandCom was instantly more focused on using social media to rally its community members into action. Over two-thirds of all tweets posted across this campaign were action-oriented (68.04%), while 44.27% of tweets were information-oriented. Less than one-third (31.51%) of SMAIrelandCom's tweets were concerned with community building efforts. Again, this may have been intentional given the small size of this patient community, just 25 children across the country. It is likely that this patient group already formed a tight-knit support community prior to the launch of this advocacy campaign. Similar to YesOrkambi, this would negate the necessity of spending time cultivating patient support and informing them of the purpose of the advocacy campaign (Lovejoy and Saxton, 2012). Instead, information-oriented tweets were focused on sharing insights into patient challenges and updates on Spinraza's effectiveness.

The SpinrazaNow Twitter campaign adopted a concerted action-oriented approach by immediately promoting community action from its very first tweet. One of this campaign's defining characteristics was the seeking out of supporters with influence (e.g. Irish sports stars and celebrities) to tweet on its behalf to raise greater awareness. Campaign organisers provided supporters with online templates and advice on how to create advocacy messages and supporting videos to share with their social networks across social media. This approach resulted in over 55% of all action-oriented tweets specifically focusing on promoting a variety of key campaign events and actions. In addition, almost one-third (32.88%) of action-oriented tweets also included a direct call-to-act, designed to encourage more supporters to get involved in campaigning efforts. Furthermore, 36.91% of all action-oriented tweets involved lobbying and advocacy efforts explicitly aimed at state and corporate market actors.

In terms of community building efforts, SpinrazaNow campaign tweets largely consisted of recognising and thanking those who participated in the advocacy campaign (76.81% of all community-related tweets). In particular, gratitude was extended to celebrities and others for their support, thus further amplifying this support while encouraging others to get involved through embedding specific calls-to-act. As such, a number of community-building tweets were also considered action-oriented tweets as campaign organisers adopted a dual-purpose in showing their appreciation and recognition of community members and supporters.

The SpinrazaNow advocacy campaign adopted by SMAIrelandCom appeared to follow a clear strategic intent, perhaps due to learnings gained from the YesOrkambi campaign that took place a year earlier. The YesOrkambi campaign favoured a dual-orientation approach, balancing information- and action-oriented tweets (51.68% and 50.20% respectively). YesOrkambi focused much less on community-building activities than SpinrazaNow (19.37% versus 31.51%); however, it did have a much higher incidence of replying to tweets from members and others to acknowledge their campaign involvement. In contrast, SMAIrelandCom concentrated on sharing action-oriented bite-sized content with followers to encourage their engagement and advocacy support (68.04%). In fact, the SpinrazaNow campaign included a direct call-to-action in 22.37% of tweets, compared to just 10.28% of YesOrkambi's tweets. In addition, the lobbying/advocacy efforts of SpinrazaNow were proportionally much greater than those of YesOrkambi, at 25.11% and 17% respectively. Perhaps this reflected a lesson learned from the earlier YesOrkambi campaign, which empowered SMAIrelandCom to be more forthright in its social media campaigning for SpinrazaNow.



*Figure 7: Comparison of Tweet Categories *does not add to 100% as some tweets belong to more than one topic category*

Throughout the SpinrazaNow advocacy campaign, we notice a distinct politically focused activity not evident in the YesOrkambi campaign – direct solicitation of politicians requesting their support in securing funding for Spinraza in Ireland. SMAIrelandCom and SpinrazaNow supporters frequently tweeted government ministers and local councillors, as well as Irish Ministers of European Parliament (MEPs) and presidential candidates asking them to engage with the advocacy campaign’s efforts by attending events (e.g. Dáil demonstrations) or signing a petition, amongst others. Campaigners lobbied politicians by tweeting them directly to seek their support, exploiting the platform architecture of Twitter to bring this advocacy campaign in front of powerful actors and decision makers. Social media solicitation is an activity that recurs throughout this campaign.

For those politicians who do engage, for example by raising the case for Spinraza in the Dáil or by creating advocacy videos as part of the social media SpinrazaNow video campaign, SMAIrelandCom retweeted this information in order to acknowledge, show appreciation for, and amplify political support. Similar to YesOrkambi, broadcasting political backing bolstered the SpinrazaNow advocacy campaign by signalling a growing support, and therefore strength,

behind the campaign. As more members of the opposition get involved, their clout gives credence to the campaign's demands, and again raises the issue of drug pricing reimbursement in broader civic and public domains.

In addition, the SpinrazaNow campaign actively used Twitter to denounce perceived political complacency in relation to the reimbursement of drug funding. Campaign organisers launched and frequently promoted links to a petition to bring this issue to the steps of Dáil and collected in excess of 100,000 signatures along the way by leveraging supporter networks across social media. Moreover, SpinrazaNow campaigners took to Twitter to vent their frustration when Ireland became the only outstanding country in the EU not to reimburse funding for the Spinraza drug. Going further than YesOrkambi, SpinrazaNow campaigners called on their social networks to avoid voting for present government ministers in national elections running during the campaign's timeframe. In all, social media was crucial to initiating and sustaining political pressure for the SpinrazaNow campaign.

SMAIrelandCom also used social media to solicit support and coverage from the mainstream media. Through actions such as tweeting journalists and current affairs programmes, SMAIrelandCom and SpinrazaNow advocates offer interviews and appearances to bring wider attention to their cause, for instance: "Willing to talk to anyone who will listen.. community groups, media. This morning our [campaigner] left [local] church in silence when she addressed them. THANK YOU for taking time to listen and help #SpinrazaNOW @RyanTubridyShow @joeliveline". Such online actions were particularly evident in the days leading up to Dáil demonstrations in an effort to create as much advocacy 'noise' as possible in order to draw attention to the campaign, for example: "@ghook Be great to have your coverage of

#SpinrazaNOW campaign for SMA sufferers in Ireland. We're coming to Dublin on Thursday.”

Coverage gained by mass media outlets was publicly acknowledged and appreciated on social media by the SpinrazaNow campaigners. Retweeting of news articles and video/audio clips helped to amplify the mass media's coverage and encouraged more media support for the advocacy campaign. The importance of mass media coverage was clearly understood by the SpinrazaNow campaign organisers as having the potential to refocus public awareness of and support for funding Spinraza. This leveraging of mass media support is reminiscent of the approach adopted by the YesOrkambi advocacy campaign a year earlier.

Lastly, SpinrazaNow campaigners also solicited the support of Irish celebrities and sports stars via social media. Individuals who participated in the SpinrazaNow video campaign (calling for funding using a refined video template/script issued by SMAIrelandCom) were recognised and thanked for their support. Again, leveraging this support through tweets and retweets helped to amplify the SpinrazaNow campaign message while reaching vast secondary audiences consisting of all those following these well-known Irish stars on social media (Kaplan and Haenlein, 2010). Similar to leveraging mass media coverage, leveraging celebrity support also helped bring the campaign for Spinraza funding into the limelight, drawing public attention towards this issue. This added publicity re-invigorated and emboldened campaigners to continue to advocate for Spinraza.

Discussion

The multiple roles of social media

Social Media Enrol New Actors

Social media enrol other media in the debate. Much of the social media literature speaks of social media as ‘open access’ platforms (Hoffman and Novak, 1996:51), implying an open door through which interested others can gain access to the campaign. Our data shows a less passive role for social media in the campaign. Our social media campaigns actively reach out and enroll others within, including mainstream media and celebrities. Although it is a small sample of only two cases, our data appears to indicate an increasing use of social media to perform such active enrolment within the healthcare market in Ireland, with the Spinraza campaign exceeding the Orkambi campaign in this regard.

In our data we see the campaigns, particularly that of SMAIrelandCom, reaching out to mainstream media and weaving mainstream and social media narratives together to reinforce the campaign. Mainstream media must, to a certain extent, maintain an objective presence ‘above the fray’ so to speak. It has checks and balances in terms of editorial policies and verification processes. Social media have no such limits and facilitates pure advocacy “to further or achieve specific policy goals” as outlined by Obar et al. (2012:4). Our cases demonstrate how social media are used to harness the apparent objectivity of the mass media and utilize this in the social media campaign. The moral authority and public trust that is conferred by the direct patient voice bearing witness to their struggles (McDonnell, 2016) is exponentially strengthened by the apparent objective endorsement of the mass media.

The mass media are not the only ‘other’ to be enrolled by social media. The Spinraza case also demonstrates the recruitment of celebrities and sports stars in support of the SpinrazaNow campaign. These celebrities are used to amplify the calls and claims of the campaign as their social influence is harnessed via the social media campaign. This not only lends weight to campaign statements in a form of endorsement, it also extends the campaign as those who follow these celebrities become aware of, and active in, the campaign. This is seen in the dual coding of a number of our case tweets that refer to celebrities as both community building and action-oriented, where the social media campaign organisers extended thanks to, and highlighted the actions of, these enrolled celebrities. These celebrities are neither similar to (Tajfel, 1978) nor more knowledgeable or experienced than (McAlexander et al., 2002) the patient advocates who are behind the social media campaigns. This therefore extends the previous view of patient-led advocacy campaigns that use SNS. While our cases do, as previously catalogued, present patients’ own personalized experiences and struggles (Yang, 2016; Penney, 2015), they go beyond this to enroll and mobilize non-patient influencers in the campaign.

Social media mobilize actors offline

Beyond that, social media act as coordinating tools for offline action. The social media literature builds a strong case for the role of social media in creating patient communities within healthcare (Obar et al., 2012; Zuckerman, 2014; Penney, 2015; Housley et al., 2018). The literature describes how healthcare has become more subject to market culture and how actors can act to shape that market. Our research demonstrates that certain social media campaigns actually spend little time or effort on community building amongst the patient community but rather focus on the provision of information and rallying for action. In the timelines presented

in our findings above (Figures 4,5,6), the connection between online social media activities and offline activities such as marches, vigils and petitions is clear. Social media campaigns are used to publicize these activities, facilitate engagement in the offline activities, and actively recruit existing and new actors to these offline activities. Post-fact, social media campaigns are used to amplify the offline activities, posting commentaries on or images from the relevant march or vigil.

Social media are used to challenge powerful actors

The platform architecture of Twitter facilitates users to connect, follow and address others without the need for reciprocation, a unique feature among most social media sites. Such a feature assists campaigners and advocates coming into direct contact with power-holders and decision makers, a difficult feat under other circumstances. Both cases demonstrate how social media are used to solicit, criticize, confront, or question, various actors including the government, specific government ministers (Minster for Health, Minister for Finance, etc.), the HSE, NCPE and Big Pharma. Social media are used to hold such actors accountable and question their definitions of value. As such, social media facilitate patient voices more readily entering the market approval process, which so markedly affects them. Social media strengthen patient voices in their criticism of actors involved in the approval process. Moreover, community advocates use social media to broadcast their appreciation for support gained from politicians. This encourages more supporters to get involved in campaigning and singles out those ministers who enable this process to continue.

These three roles are mutually reinforcing. The relationship between mass media and social media assists in the mobilization of actors as mass media publicize and subsequently report on offline protests and vigils. The mobilization of offline protests adds weight to the challenge of powerful actors – bringing the protest to their door both literally and metaphorically. Likewise, the challenging of powerful actors provides further fodder for mainstream media coverage and offers a focus point for offline action. Social media act as a thread that weaves these elements together so that they become a coordinated campaign. Figure 8 below summarises the roles and impact of social media.



Figure 8: The roles and impact of social media within healthcare

Social media extend the community and definitions of value are re-negotiated

As the mass media become involved in the market the number of people participating in the issue snowballs. This is particularly evident in the Spinraza case where the initial affected public extended to just 25 children and their families. By the end of the social media campaign, hundreds of new advocates supported the call for SpinrazaNow. This new weight of supporters, combined with the ability to tackle powerful actors such as government and ‘big pharma’ in a public arena, generates greater ‘noise’ and elevates the issue of drug pricing and reimbursement from a market challenge to a larger societal issue. In doing so, a two-way influence is forged

between the market and wider society - social media bring market-specific concerns into the public domain, and societal concerns must be dealt with at the market level. These concerns challenge the legislation-based method of defining value within the market. Throughout the legislative rule-based process, information as to value is provided based on the probability of cost effectiveness at a range of thresholds. For example, a value is placed on the quality adjustment per year of a patient's life on the drug in ranges: €20,000 per quality adjusted life year (QALY); €45,000 per QALY; and €100,000 per QALY. As the title of this paper suggests, however, social media advocacy campaigns seek to change the definition of value that underpins current market rules asking that legislators and decision makers 'do not put a value on our lives'. However, in both of our cases these changes in value definition appear somewhat time-bound and last only as long as the advocacy campaigns themselves. Despite efforts to introduce changes to the drug reimbursement legislation on the back of such campaigns, no real policy changes have been implemented. An amendment to the Health Act (2013), raised in 2018, proposed "...a threshold cost-effective incremental ratio or similar assessment, shall not be relevant in the case of Orphan Medicinal Products."¹⁹ Yet as of January 14 2020 this proposed amendment to the Health Act (2013) has now lapsed, and no such changes have been enacted²⁰.

Conclusion

We set out to examine how social media campaigns might affect drug reimbursement in Ireland in the particular case of two orphan drugs. Our data suggests that social media play three key, interrelated roles within that context – enrolling new actors, challenging powerful actors, and mobilising offline action. Together these three roles combine to extend the range of actors

¹⁹ Prof Michael Barry, Director of the National Centre for Pharmacoeconomics, addressing the 2018 Irish Medical Organisation AGM

²⁰ Health (Pricing and Supply of Medical Goods) (Amendment) Bill 2018
<https://www.oireachtas.ie/en/bills/bill/2018/33/>

involved and introduce societal concerns into the economic evaluation process. This in turn opens up new discussions as to what constitutes value that challenge existing definitions of value within healthcare. We offer indicative findings and thoughts as to the role of social media in healthcare that raise more questions as to the complementary or contradictory roles that mass media and other actors may play alongside social media. We therefore suggest that future research examine the intersection between mainstream media, social media, and legislative action in shaping value in healthcare to better understand the relationships between all three.

In addition to contesting definitions of value by enrolling and mobilizing new actors, social media have produced a further outcome in the power dynamics of market actors. Social media activism shone a spotlight on the orphan drug reimbursement process and the economic assessment of value underlying it. By challenging public discourse on what constitutes value through social media activism, patient communities in essence, have served to strengthen the hand of ‘big pharma’ – arguably already the most powerful player in this market. Through demanding access to orphan drugs, patient influence has gone further to instigate a change in altering the process for calculating value in terms of orphan drug cost-effectiveness. Bill 33 of 2018, the amendment to the Health Act (2013), seeks to remove the Government’s right to question the objective cost-effectiveness of orphan drugs prior to their reimbursement. Should this Bill pass through the Irish Parliament (Dáil), it would undoubtedly benefit patients, yet it would also serve to line the pockets of drug manufacturers who would face less scrutiny. Here the enrolment of patient communities into the reimbursement process arguably leverages the weakest market player to do the bidding of the most powerful. This raises the question as to which market actors benefit most from social media-led activism campaigns.

The global pharmaceutical market is reliant on orphan drugs for much of its predicted future expansion. Between 2018 and 2024, orphan drugs are expected to outperform the market, accounting for 20% of total prescription drug sales and forecast to almost double in size to \$262bn in 2024.¹⁹ One industry report comments that this reflects the pharmaceutical industry's focus on "small groups of neglected patients with high unmet need and to benefit from traditionally reduced payer scrutiny on orphan drugs, as well as regulatory and financial incentives." (Evaluate Pharma, 2018:8). It is these two points – the high unmet need of the patient, and the review and negotiation of drug prices, that form the basis of our cases. These counterpoints mean that although there is great promise in new therapies that successfully treat the rarest of diseases for the smallest patient populations, market processes, and particularly approaches to pricing and reimbursement, must keep pace with pharmaceutical innovation in order to ensure access, equity, and sustainability of supply – in short, to reconcile market and civic logics within the provision of orphan drugs. "The promise of these new therapies will only become reality if the innovation of drug companies is matched by innovation in the drug pricing and reimbursement systems." (EvaluatePharma, 2019).

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