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## **Navigating the cartographies of trust: how patients and carers establish the credibility of online treatment claims**

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### **Abstract**

Digital media offer citizens novel ways of ‘enacting’ health and illness, and treatment and care. However, while digital media may so ‘empower’ citizens, those searching for credible information will be confronted with various, often-conflicting claims that may have ‘disempowering’ effects. This article uses Gieryn’s concept of the ‘cultural cartography’ to explore the criteria that patients and carers employ in establishing the credibility of information on alleged treatments. Drawing on data from interviews with Australian patients and carers who have travelled or considered travelling abroad for unproven commercial stem cell treatments, the article examines how individuals assess rival sources of epistemic authority—science-based and non-science based—as they search for credible information. As we argue, in a context where conventional treatment options are perceived to be limited or non-existent—which is likely to be the case with those suffering severe, life-limiting conditions—and the credibility of sources uncertain, matters of opinion and belief are prone to being interpreted as matters of fact, with potentially far-reaching implications for citizens’ health. Revealing the mechanisms by which individuals ascribe credibility to health information, we conclude, has become crucial as digital media assume a growing role in health and healthcare and

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governments encourage citizens to become 'digitally literate'.

**Key words:** trust, credibility, hope, stem cell tourism, cultural cartography, digital technology

## **Introduction**

For those newly diagnosed with a chronic illness or disability, the internet offers a panorama of possibilities in regards to information about their condition and options for treatment and care. The internet may be the primary or sole source of information for people or it may be used to supplement health and medical information initially gained from practitioners or other sources (European Commission, 2012: 58). Surveys undertaken in the US, Australia and other economically rich nations with a high level of internet penetration reveal that a significant proportion of those who seek health information begin, at or at some stage use, a search engine such as Google, Bing or Yahoo (Pew Research Center, 2013; Wong, et al., 2014). Further, citizens may use social media to produce and share content, such as experiences of health, illness and treatment or care options, and to collectively organise to promote research, gain access to treatments, and raise funds to support these activities (Sosnowy, 2014; Shim, 2014). They may combine credentialed expertise and lay knowledge to form 'epistemic communities', and thereby become influential policy actors or 'evidence-based activists' (Akrich, 2010; Rabeharisoa, et al., 2013). However, while digital media may 'empower' citizens in these ways, their routine use in health and healthcare raises questions about the credibility and trustworthiness of information that is relied upon for decisions about treatment and care. This is particularly pertinent in a context of direct-to-consumer advertising where commercial providers offer therapies yet to be recognized by the established medical authorities.

This article explores the criteria that individuals employ in establishing the credibility of information on claimed treatments as they encounter different sources, and it considers the implications for conceptions of trust in increasingly digitally mediated healthcare. We focus on the experiences of those who have travelled or considered travelling abroad for advertised stem cell treatments (SCTs). This is an area of medical research with a particularly complex topography ranging from proven treatments for a limited number of specific conditions, to clinical trials where promising interventions for additional conditions are evaluated for safety and efficacy. In addition, there are a growing number of interventions being offered outside clinical trials and marketed directly to the consumer where there is little scientific justification for their use. Here we ask: how do advertised 'treatments' that have been assessed by conventional medical standards to be clinically unproven come to be perceived as credible therapeutic options? On what basis is information about these options and those that provide them judged to be trustworthy or not? The

paper draws on interviews with Australian patients and carers (parents or partners of patients), and uses Gieryn's (1999) concept of the 'cultural cartography', that he employed in his analysis of the credibility contests that characterise science, to reveal the mechanisms by which claims come to be judged as having epistemic authority and thus credible or as lacking such authority and thus not credible.

As we argue, in a context where conventional treatment options are perceived to be limited or non-existent—which is likely to be the case with those suffering severe, life-limiting conditions—and the credibility of sources uncertain, matters of opinion and belief are prone to being interpreted as matters of fact, with trust based on a 'leap of faith' or investment in hope. In the article, we explore these complex dynamics of credibility and trust, including their temporal dimensions, as they manifest in the accounts of those with various chronic and acquired conditions who decide to travel and those who decide not to travel for advertised SCTs. As we conclude, understanding the criteria by which citizens ascribe credibility to health information has become crucial as digital media assume a growing role in medicine and healthcare and governments encourage individuals to take a greater responsibility for their own treatment and care. We begin by briefly charting the rise of the market of alleged SCTs, which relies heavily on promissory discourse and online advertising techniques, before introducing our theoretical perspective and the research data upon which we draw.

### **The internet and the advertising of SCTs**

The growth of the market of alleged SCTs has paralleled and been enabled by growing access to the internet and use of social media. This market is one that is buoyed by optimism surrounding the potential of stem cell science and its promise to deliver regenerative therapies for many conditions in the future (Morrison, 2012). And, it is here that the internet has played a considerable role. Since approximately 2006, a burgeoning number of these clinically unproven 'treatments' have been advertised directly to consumers via the internet for various conditions, including spinal cord injury, multiple sclerosis, macular degeneration and Alzheimer's disease (Petersen, et al., 2017: 6-7).

This 'direct-to-consumer' advertising has been found to employ various techniques to effect a positive portrayal of products and their providers and lend them legitimacy, involving strong emotional appeals: patient testimonials and blogs to connect directly with audiences; links to 'Frequently Asked Questions' with responses that offer reassurances about the safety and efficacy of treatments; the use of scientific and news sources (e.g. about developments in the field) that lend credibility to claims; images and descriptions of clinics and hospitals and of providers' qualifications that convey professionalism, competence and care for patients; and the omission of information on uncertainties and risks (e.g. longer-term treatment outcomes and likely additional

costs such as travel and accommodation for patients and carers) that would present a more qualified picture of the state of the field (Petersen and Seear, 2011). Notwithstanding years of commentary on the state of stem cell science and the difficulties of clinical translation, advertising strategies that use positive claims and portrayals regarding the safety and effectiveness of products have been found to be reasonably consistent over time (Ogbogu, et al., 2013).

Commercial clinics have sought to leverage the promise and optimism that surrounds the hundreds of trials currently underway to ascertain the safety and efficacy of the different interventions using stem cells or cells made from them (NIH, 2017). In advertising their products and services, providers are capitalising on the strong ‘translational ethos’ and hopeful discourse that attaches to the field of stem cell science (Maienshein, et al., 2008). At the same time, the rise of the internet and social media has facilitated the flourishing of online communities of patients with various conditions and/or their families, who share information and personal stories and sometimes lobby for research or to gain access to these products on ‘compassionate’ grounds (e.g. Margottini, 2014; Spalleta, 2015).

While science organisations have long argued that the sale of these alleged treatments poses physical and financial risks to patients and potentially undermines confidence and trust in stem cell science (Daley, et al., 2016), the SCT market has thrived. According to the standards of science, credibility rests on the claim to provide a reliable body of knowledge about the world (Stemwedel, 2011). In the case of stem cell science, credibility is founded on the claim that ‘evidence’ of the efficacy and safety of treatments should be established through ‘gold standard’ clinical trials, with findings published in peer-reviewed articles, *before* treatments gain regulatory approval (Timmermans and Berg, 2003). Yet SCTs that may not find application in mainstream clinical practice for many years to come, given the lengthy period and considerable financial investment required to undertake fundamental research and conduct trials before treatments gain approval (Dickson and Gagnon, 2009).

Missing from idealised portrayals of the science is acknowledgement that stem cell-based interventions may need to be tailored for each type of chronic, congenital or acquired condition, and that for some conditions a cellular replacement strategy remains unlikely due to the complexity of the disease. While clinical successes thus far are limited to the use of blood stem cells for the treatment of many types of cancers and diseases of the blood and immune system, and a small number of other applications that capitalise on the presence of stem cells in skin and the surface of the eye, scientific and public optimism for stem cell science remains high, especially with frequent media reports of ‘breakthroughs’, leading to ‘gaps’ between people’s expectations and clinical practice (Cossu, et al., 2017: 1). In Cossu, et al.’s view, this context has created the conditions for the flourishing of inadequately regulated clinics that appeal to patients and their families who, in the

absence of reliable information from trials, cannot be informed of the benefits and risks of advertised SCTs (2017: 1).

While it is difficult to determine the overall size of the SCT market, since there is no systematic mechanism for recording and verifying patient numbers at the country level, the evidence suggests that it is substantial and growing. A 2016 review of the global distribution of businesses advertising stem cells found an increased activity at the global level, with over four hundred websites advertising stem cell-based therapies for a wide range of conditions, a large and growing proportion of which were in rich countries such as the US, UK, Australia, China and Germany (Berger et al., 2016). Regulation of this market has proved difficult for various reasons, including its complex character involving opaque and sometimes highly mobile national and transnational actors, the political and practical difficulty of harmonizing and coordinating multiple regulatory agencies, regulatory exemptions regarding autologous stem cell treatments in some jurisdictions, the myriad array of claimed stem cell products for a huge range of conditions, and the multiple sources and means by which information on treatments may be procured (Cossu, et al., 2017; Sleeboom-Faulkner, et al., 2016). Insofar as individual countries have enacted regulations, these have in some instances been questioned for being insufficiently rigorous. Japan, for example, introduced legislation in 2014 allowing ‘conditional’, time-limited approval that some argue has set the bar too low in terms of demonstrating clinical utility and may result in patients being exposed to unscrupulous providers and removing the incentive to participate in stem cell trials (Sipp, 2015; Chan, 2017: 841-844). Meanwhile, individuals who have exhausted current treatment options are presented with various, often-optimistic claims about SCTs that circulate online and offline.

### **The cultural cartography of credibility**

In exploring the criteria used by individuals in establishing the credibility of information on alleged treatments it is useful to consider the ‘cultural cartography’ within which credibility contests occur. According to Thomas Gieryn (1999), the establishment of credibility claims can be envisaged in terms of cultural maps used by individuals to ‘find workable truths about nature and (sometimes) suffer the consequences of practical choices they make based on where epistemic authority is located.’ (1999: 12-13) The mapping metaphor serves heuristically to draw attention to the process by which boundaries between rival sources of epistemic authority regarding particular knowledge or practice are drawn and then redrawn. According to Gieryn, in such a process, credibility claims are contested and overturned, as some claims become persuasive and others marginalized and denounced as matters of faith, illusion, ulterior motive, and so on. As Gieryn argues, those within science may seek to police the boundary of ‘real’ science by highlighting posers’ failure to conform with expected ethical or methodological practice. Those outside science, on the other hand, may

draw different cultural maps, using rival epistemic authorities to curtail the reach of science, by pointing to their inadequacy or liability in regards to certain kinds of issues—subjective, political, and ethical (1999: 22).

As Gieryn argues, mapping the boundaries of credibility ('boundary-work') has different consequences for different actors, both for those who draw them and those who rely on them, in terms of authority, fame, influence, and employment. People's reliance on cultural maps allows them to distribute responsibility for 'facts of nature', some of which may be regarded as provisionally true for the practical choices people make and some fabricated, false or discrepant and therefore disregarded as a basis for action. Decisions may be grounded in science, which is the generally preferred source of knowledge about nature, or some other authority (e.g. religion, personal experience), as people become more convinced of the accuracy, trustworthiness and effectiveness of truth claims, or they may subsequently justify those decisions by reference to the greater expertise and competence of those who are trusted with the truth (1999: 13).

The boundaries of science are 'perpetually contested terrain' since the issues at stake are often significant, in terms of status, power and access to material rewards (Gieryn, 1999: 15). While establishing and maintaining credibility is crucial for all professional areas, this is especially so for new or emergent fields of science, such as stem cell science, where the borders and territories are still being mapped and where legitimacy of practice depends crucially on establishing and maintaining public and policy support. For such fields, at stake is the autonomy over scientists' ability 'to define problems and select procedures for investigating them', which is achieved by 'purifying science' and demarcating it from all political and market concerns (1999: 23). In the case of SCTs, those who profit from the early advertising of clinically unproven interventions are seen to 'pollute truth' and to threaten the boundaries that define the very essence of 'science'. Consequently, scientists have sought to police the boundaries of stem cell science by discrediting SCT providers' claims, pointing to the lack of verifiable evidence of benefit for their products, the health risks associated with the intervention or its administration, and to the exploitative character of their practices.

Gieryn's ideas have found useful application in sociological studies of various professional areas, in revealing how disputes between contending experts are negotiated (e.g. González, 2016; Kurath, 2015; Cadge, 2012; Burri, 2008). In such studies, the application of the concept of 'boundary work', whereby the contours of a field are mapped so as to establish claims in a contested territory of legitimacy, has proved insightful. However, Gieryn's ideas have yet to be applied to analysing the negotiations and deliberations that occur as lay citizens encounter different sources of information during their research on conditions and treatments. As noted, in the age of digital media citizens both produce and consume information, often combining credentialed

expertise and lay knowledge to form their own epistemic communities. By exploring how people respond to multiple, including discrepant claims about health, illness and treatment that they encounter in these different communities, one can potentially learn much about the changing bases for credibility claims and notions of trust upon which they rely in a digitally mediated age.

## Methods

This article draws upon data arising from a four-year (2012-2015) Australian Research Council funded project on 'stem cell tourism'. This project aimed to explore the sociocultural dynamics of stem cell tourism, particularly the factors shaping Australian's views and expectations of SCTs offered abroad. It investigated the contributions of various factors, including informal networks and information sources—such as the internet, print media, treatment providers and other travellers—to the shaping of individuals' expectations and decisions about treatments. We did not set out to explore issues of credibility per se; however, our findings revealed the diverse sources consulted by respondents as they sought to gain credible or trusted sources of information on their conditions and treatment options. As part of the study, interviews were undertaken via the telephone with patients or their carers (generally parents or partners) who had been diagnosed with a range of conditions, including lymphoedema, motor neuron disease, chronic obstructive pulmonary disease, autism, multiple sclerosis, spinal cord injury, and Parkinson's disease, and who had either travelled abroad for treatments ('travellers') (n = 24) or who had considered travelling but at the time of the interview had not yet done so ('non-travellers') (n = 27). While phone interviews have limitations, particularly in not allowing observation of respondents' reactions to questions, they enabled us to include respondents from across Australia, some of whom were remotely located.

The sample was self-selected by two principal means: our project's website and through patient organisations, whose representatives distributed (via newsletters) information about our study and contact details to members. In both cases, respondents were able to contact us if they were willing to be interviewed. As noted above, people who underwent treatment or considered undergoing treatment, as well as carers of people, who were often intimately involved in information gathering, decision-making processes and or treatment journeys, were invited to participate. The final sample of travellers comprised 9 males and 15 females, of which 11 were patients and 13 carers; the non-travellers comprised 14 males and 13 females, of which 16 were patients and 11 carers. In the majority of cases, patients (some children) were suffering serious, life-limiting conditions, where prognoses were poor and treatment options limited. Some were developmental or neurological conditions, such as autism or multiple sclerosis, or physical disabilities that affected movement or posture, such as cerebral palsy or spinal cord injury. Many of these conditions involve combinations of symptoms such as loss of motor control, fatigue, and

incontinence. Consequently, our respondents may have been especially open to exploring ‘non-traditional’ treatments. In interviews, they often claimed (and evidently appeared) to have undertaken extensive research on their conditions and in some cases were well versed in their scientific aspects—which may make them atypical of patients and carers in being especially skilled in their ability to make sense of and discriminate between different sources of information.

Interviews were mostly undertaken with individual patients or carers themselves; however, on three occasions, they were undertaken with both the patient and their carer being present. One individual was interviewed on two different occasions—as a ‘non-traveller’ then a ‘traveller’. By interviewing ‘travellers’ and ‘non-travellers’ we aimed to ascertain differences in views on and expectations of SCTs and the factors shaping these. While within Australia there was a growing marketplace for unproven stem cell ‘treatments’ during the time the interviews were conducted, most local clinics limited their services to musculoskeletal conditions (Munsie and Pera, 2014), and were rarely a consideration for our participants.

Questions explored with ‘travellers’ included how individuals learnt about SCTs offered outside Australia, the factors shaping their decisions about treatments, knowledge about treatments undertaken, responses of family, friends, physicians, and others to decisions about treatments, and their experiences of treatments and providers. Questions explored with ‘non-travellers’ included knowledge and perspectives on SCTs, reasons for not undertaking treatments abroad, the influence of family, friends, physicians and others on decision-making, perceptions of risks or other factors shaping decisions, and sources of information (if any) on SCTs. Interviews, which generally lasted one hour, were conducted via phone, and the data were coded and thematically analysed with the assistance of NVivo and Word search. Each member of the research team contributed to the analysis and agreed on the themes, with attention paid to the respondents’ accounts of their decisions to travel or not to travel and of the factors affecting these decisions, including the influence of different sources of information, and to pre- and post-travel experiences, including engagements with the providers themselves. In analysing the data, we were particularly interested in determining differences in travellers’ and non-travellers’ views and expectations and the factors shaping these. Pseudonyms are used to protect individuals’ privacy.

## **The findings**

### *Visiting the internet*

Consistent with earlier studies (e.g. Pew Research Center, 2013; Wong, et al., 2014), our research revealed that, for patients and carers, whether travellers or non-travellers, the internet, Facebook and blogs were major sources of information regarding treatment options as well as on the condition itself. They also provided a means for individuals to connect with other patients and providers. For

some, the internet provided their sole source of information. However, in the majority of cases, individuals combined different sources—both online and offline—with their reliance on each varying over time as they sought to clarify their treatment options and to confirm the credibility of sources and information. Off line sources included print media such as newspapers, and third parties, often personally significant others, typically members of one's family and trusted doctors, but also those met as a result of chance encounters or during the course of one's daily activities, such as other patients and tradesmen. Some also recounted face-to-face meetings with the providers themselves, generally after having first researched their details online. While we acknowledge the significance of these offline sources in decisions, our main focus in this article is on patients and carers as seekers of credible online information in the context of the direct-to-consumer advertising of treatments.

Searches were undertaken in a context where many individuals felt that the consulting doctors and other health professionals had effectively abandoned them by failing to offer hope in regards to further treatment. However, a range of responses to doctors was noted, ranging from indifference and equivocation to support. For example, some noted that their doctors said that they had read about stem cell treatment and heard that it could be beneficial but were reluctant to pass judgement about its efficacy, choosing instead to adopt a 'non-directive' approach (Petersen, et al., 2017). Many respondents expressed a sense of injustice in being denied the information, or access to trials or treatments that they felt could and should have been made available to them. However, as some expressed it, 'doing nothing' was not an option, and individuals consequently attempted to source information and advice about treatments, using the internet and personal contacts, often forged online, to inform themselves.

While some searched for treatments in general and then encountered advertisements or personal stories about SCTs, others sought to find out more about SCTs after having first heard about them from other sources such as friends or news coverage. During interviews, some respondents indicated that they began searching the internet after discovering that SCTs, clinical trials, or information on treatments were not 'available' in Australia. In telling their stories, respondents presented themselves as being well researched and as seeking to leave 'no stone unturned' in their search for treatments but also in their quest to learn 'the truth' about them. As Alex, who had a spinal cord injury and at the time of interview had not travelled for treatment, said, 'I spent every afternoon for probably two or three years just reading and, and sourcing the information, and as much as I could, and going to meetings and stuff like that.'

### *Navigating different information sources*

During their searches, individuals often explored different information sources, each offering either only partial perspectives on SCTs or views that conflicted with those obtained elsewhere, which served to raise questions about the basis for their belief and trust in the credibility of sources and prompted further investigation. Dan, who had a spinal cord injury and had considered travelling to Germany for SCT because ‘it’s in Europe, it’s got to...have some legitimacy and...it’s got to be good’, but then decided not to travel after further enquiries, offers insight into the often-tortuous route followed:

Well there wasn’t a great deal of information on the web and what was there, thinking about their site, didn’t really...instill a great deal of confidence in you, when you looked at it. So I then went onto another website which was more of a blog type chat forum operated out of the States, and picked up a couple of threads of information there, and followed those, and found a lot more information through this blog site than anywhere else, which led into newspaper reports from the UK on people who had travelled there, who’d had problems, which then also led to another newspaper article, which again I think was out of the UK, that highlighted the fact that they were operating within Germany under a loophole in German legislation ....

As Gieryn notes, when faced with multiple and discrepant accounts of nature, people need ‘still other maps to assign authority over the task of mapping’—that is, ‘second-order boundary work’—to locate ‘credible cultural cartographers’ or sources that can be relied upon to dismiss a rival’s map as ‘unskilled or misleading or deceptive’ (1999: 17-18). While both travellers and non-travellers recounted broadly similar experiences in their quest to confirm credibility claims, the latter appeared to stay more within the boundaries of science in that they expressed concerns about lack of transparency of results and outcomes that would have been found in published peer-reviewed journals. In the above non-traveller’s account, the individual’s suspicions of a website led to investigation of other, in their view more credible, sources such as blogs and news articles that tend to rely less on scientific criteria of evidence than on personal experiences and popularised depictions of science. The use of various media—in the above case, a US blog and a UK news article—was common. Such sources, it should be noted, rely heavily on patients’ stories, sometimes recounting heroic quests to gain SCTs. Patient blogs, for example, involve personal experiences of treatment, and sometimes advocate for ‘compassionate use’ of experimental therapies, thereby bypassing strict rules qualifying patients for participation in clinical trials (Zettler, 2015). In contrast to Dan’s experience, above, of finding critical media reports which preceded the closure of the X-Cell Centre in Germany, the ‘articles’ cited by participants were mostly those appearing in news media or online forums that focus on scientific ‘breakthroughs’ and stories of promise.

On the other hand, only a few respondents mentioned consulting medical or scientific journals or deriving sources of information from articles published therein. Theo, a non-traveller, in

the early stages of motor neuron disease, stated that they read ‘mainly the scientific journals’ and that they were not ‘so interested in individual cases’, while another non-traveller, Len, who had an optic nerve problem following a stroke, indicated that they had ‘been through medical journals which most of which don’t make sense to me.’ However, as the comments of the latter suggest, individuals may struggle to interpret what they read. As Len elaborated, ‘you need to have some sort of medical background or someone that you can rely on who is going to give you... an honest opinion or can sort through what you’re reading because there’s so much stuff out there.’

In short, while individuals sought an ultimate source of authority to adjudicate between contending claims about SCTs, they often felt unassisted and had to rely on their own judgment and resources. While it is hazardous to generalize about differences between travellers and non-travellers in regards to their use of particular sources, since at the time of the interview some of the latter had adopted a ‘wait and see’ approach and continued to explore their options, the non-travellers’ responses suggest that they may inhabit epistemic communities that are more science based in that they were more inclined to question non-scientific claims.

### *Symbolic significance of science*

Like citizens in general, many of those considering SCTs looked to ‘science’ as the preferred source of knowledge when seeking to establish the legitimacy of claims (Gieryn, 1999: 14). While few respondents consulted medical or science journals or read scientific articles, or talked to scientists, some mentioned that the providers whom they had identified or contacted had research published in medical or scientific journals or displayed other attributes of scientific expertise or distinction, which they evidently saw as an indicator of their legitimacy. For example, when asked whether he talked with his treating doctor about his previous experience, Benjamin, who was in ‘the final stage’ of scleroderma, an autoimmune rheumatic disease, replied:

He’s got 400 or so peer-reviewed articles or 500 peer-reviewed articles. He got names at one stage **one of the** leaders in chemotherapy treatments in all of Europe. So it wasn’t like I was going to some back-shop operator.

When asked about how they judged the credibility of the doctors in a Panamanian clinic whom they contacted, Faye, the mother of a child with cerebral palsy, responded:

...Mostly just reading their bios and just doing some research on-line then, just Googling the names, Googling the hospitals they used to work at, that sort of stuff. Just tried to authenticate, to a certain extent their credentials. And they all sort of checked out. A couple of them, one of the doctors that I read about at the clinic in Panama has written an article in a medical journal which made me go, ‘Yeah, okay, well they wouldn’t just let me write in their medical journal and call myself a doctor.’

Comments such as these suggest that individuals saw these articles as lending credibility to the claimed treatments and in some cases the provider, since it offered evidence of a link to legitimate medical research. As noted, advertisements for SCTs have been found to make considerable reference to scientific articles and other symbols of science (e.g. assurances of ‘accreditation’, the citing of professional qualifications, images of clinics) as an indicator of their legitimacy, along with testimonials recounting positive experiences and assurances of competence and care, as techniques for establishing credibility for treatment and engendering trust in providers (Petersen and Seear, 2011; Lau, et al., 2009; Ogbogu, et al., 2013).

That evidence of links to legitimate or reputable science may carry considerable weight in credibility contests is supported by some respondents’ references to hospitals or websites being ‘university-linked’ or ‘university-run’ and to ‘trials’ being undertaken, when recounting why they decided to proceed with SCTs or visit particular clinics. Respondents were, in short, drawing on the symbolic resources used by scientists to demarcate the boundary between legitimate and illegitimate knowledge (Gieryn, 1999: 17). However, interestingly, while respondents’ accounts suggest that these symbols of science may carry considerable weight in the assessment of credibility claims, in framing their accounts individuals relied heavily on subjective, non-scientific points of reference—the ‘evidence’ referred to being one’s own or others’ experiences or impressions. References to other patients’ (generally positive) experiences, to national stereotypes and to ‘gut feeling’, for example about the ‘sophistication’ or otherwise of providers’ websites, were common. This reflects a more general tendency for epistemic authority to be decided ‘downstream’, in the local, episodic and contingent rather than the universal, involving formal criteria and actual practices in the lab or clinic (Gieryn, 1999: 27).

#### *Subjective, non-scientific criteria*

The deployment of such subjective, non-scientific criteria in evaluations of credibility were strongly evident in the story of the following individual, Janet, a carer for their partner, a health professional, who had a genetic condition affecting muscle function. In this case, the role of local, contingent factors in decisions was also apparent. As they said, they had starting looking into SCTs in the previous two years as they were ‘willing to take a few more risks than they would have before’ because ‘all [my husband’s] cousins have died quite suddenly and [my husband] is actually commenting that he’s feeling worse’ than he was when he was first diagnosed sixteen years earlier.

We Googled stem cell therapy which is probably the usual thing that most people do and then we came up with different sort of websites and a lot of India stuff. And we’re sort of, even though my husband is from [Asian country] and we’re not anti-Asian medicine, we did feel that India may be pushing boundaries or a bit of a rip-off just because that’s how we perceive

that country.... We then found an American website which we felt, seemed a lot more credible, and...I sent an enquiry thing out and it, I guess my little alerts were they rang me. Why would somebody ring STD or internationally to try and get you to do their treatment? That seemed a little odd.

As this excerpt clearly conveys, subjective impressions of credibility may be established during initial searches of websites. However, the process of establishing credibility or implausibility generally involves a series of interactions and observations over time, sometimes entailing engagements with various media. As this respondent elaborated, they received a telephone call from a woman who said her daughter had been treated with cerebral palsy and had made 'great steps'. Further, the doctor at the clinic selling the treatment whom they interviewed 'had very poor command of English and seemed to be reading from a script, which sent up an alert at me'. Their suspicions were further heightened when the provider said they 'offered a discount to doctors'; however, 'the final piece de resistance was, "On the day of your treatment, we take you across the border to Mexico"', when 'I thought, "Oh okay. You're getting us to go outside of a country for treatment because it's not legal"'.

This case reveals how a variety of criteria and rival sources of epistemic authority may shape credibility assessments. Thus, giving weight to non-scientific criteria did not mean that they were oblivious to physical risks and safety—indeed, as noted, the words 'risk' and 'safety' were used by the above respondents, as well as some other respondents—however, these criteria were often considered alongside other factors, including subjective impressions of providers. References to national stereotypes, clearly evident in the above example, were common.

### *Confirming credibility*

In the effort to confirm 'credible knowers and authentic claims' (Gieryn, 1999: 22), respondents generally sought to confirm their online impressions through personal recommendations or by contacting providers directly. The role of other patients' stories communicated via blogs, face-to-face meetings and testimonials linked to clinics' websites were evidently of crucial importance in the hierarchy of credibility claims, since they were seen as untutored and authentic. Thomas, who had a rare acquired immune inflammatory disorder, who travelled to the US for a bone marrow-based SCT, reasoned that it was once difficult for patients with a rare disease to 'talk to another patient about their problems, especially when you got a rare disease' and if they did 'they normally lived quite close anyway and they'd normally have the same doctor or they would be treated in the same sort of circle'. However, 'with the internet and on-line forums...I'm talking to people from all over the world...from Hong Kong to Europe, to America. And we're all seeing different doctors and we're all being exposed to different methodologies and different things.' As this and other

accounts highlighted, obtaining a range of perspectives, including personal contacts with other patients and providers, was seen to offer a more comprehensive picture of both the patient experience and of the likely benefits or otherwise of SCTs than that offered by single sources.

A number of respondents recounted personal contacts with providers before deciding on SCTs, sometimes travelling to their clinics to confirm their impressions, after first learning about them on the internet. Meeting providers face-to-face in their clinic, they said, gave them confidence about their decision whether or not to proceed with a SCT.

#### *Who or what to trust?*

Assessing credibility claims can be time-consuming and frustrating, and may ultimately prove fruitless in the sense of being offered no definitive evidence or advice on who or what to trust. Obtaining disinterested information was a challenge, as Phillipa, a carer for her partner with dementia, who, at the time of interview had not travelled for treatment, explained:

Our concern is establishing the efficacy of the treatment, the clinics and the practitioners.

And that's the stumbling block because the information comes either from the providers who have a barrow to push or from scientists and academics who are...and the Australian medical profession who are naturally cautious.

While feelings of uncertainty, doubt and suspicion were especially pronounced in the accounts of non-travellers, they were evident to some extent in the accounts of virtually all respondents.

Individuals often showed acute awareness of the tricks and traps associated with the advertising of SCTs, some using terms such as 'shonky', 'dodgy' and 'cowboy' to convey their impressions of providers whose credibility was deemed suspect. As Benjamin observed, 'there are very, very shady operators out there that'll cut corners and just collect the money and don't care about the consequences.' Suspicions were heightened when providers seemed overly eager, especially in regards to finalising payments for SCTs.

When commercial considerations were seen to take priority, individuals saw this as providing grounds for doubt. On the other hand, demonstration of professionalism and of concern, for example, in positive replies to enquiries, generally served to instill confidence. As was clear from the accounts, assessing credibility is a far from dispassionate matter. Many expressed that they hoped for at least some improvement in their own or, if carers, their partner's or child's condition, which evidently played a role in the decisions of many of the travellers. Despite the frequent failure to uncover definitive information after extensive research (in the above case over approximately three years), and sometimes contrary to the advice of their Australian doctors, family or friends, many decided that the potential benefits outweighed the risks or that the risks were small, and embarked on SCTs. Gabrielle, who travelled to X-Cell Center in Germany before it was closed in

2011, was at first suspicious of its website ('Oh no, that looks too good to be true; I don't trust it') and was warned by her 'best friend', a nurse, about 'the power of the placebo effect'. However, after talking to other people, including another friend 'who's a doctor', they 'threw caution to the wind, and went.' In this case, as in others, respondents recounted hearing or reading about others making miraculous improvements or recoveries after receiving SCTs, which they found encouraging, if not persuasive. While they themselves may not have expected 'miracles' from SCTs, the power of hope in shaping actions was a pervasive theme in interviews.

## **Discussion and conclusion**

Using Gieryn's (1999) concept of the 'cultural cartography', our analysis highlights the often tortuous, emotionally fraught paths taken by those who are seeking to establish the credibility of claims about SCTs. Drawing on the experiences of patients and carers who travelled or contemplated travelling overseas for SCTs, our study reveals that individuals encountered diverse sources, both online and offline, as they sought to clarify options and to confirm whom and what they should trust, with the internet and social media being especially significant in regards to information about conditions and treatments. In telling their stories, individuals relied heavily on non-scientific criteria of credibility, with references made to third-party recommendations, other patient stories, and their own personal 'feelings'. Scientific sources were infrequently cited although, for many, science evidently held considerable symbolic value, despite the fact that, for many applications, the scientific justification for the treatments offered was nascent or in some cases non-existent. While we have no way of knowing whether our respondents' actions were consistent with their accounts, these non-science criteria may carry considerable weight in credibility contests. Where such contests are yet to be settled and the stakes in their outcomes are high, as is the case with claims about SCTs, matters of opinion and belief are liable to be interpreted as matters of fact.

Gieryn's ideas offer the basis for a dynamic portrayal of the development of science knowledge, highlighting the 'boundary-work' undertaken and contestations occurring at the margins of science as rival groups seek power and influence using different sources of epistemic authority. Such a dynamic portrayal is highly pertinent in the age of digital media characterised by numerous, rapidly circulating claims about health and treatments. We suggest that in markets for new, clinically unproven treatments, such as SCTs, where the boundaries of the field are highly contested and unstable, those who have exhausted their treatment options may be especially vulnerable to the appeals of those who portray themselves as competent and caring. The suspension of doubt or 'leap of faith' in deciding to embark on treatments was a common response to the context in which individuals found themselves; namely one of limited clinically proven options,

often inconsistent or conflicting information about alternatives, and the promise and hope offered by SCTs.

In revealing these dynamics of credibility assessments our study contributes to a growing body of sociological and other social science literature on citizens' engagements with digital health technologies (e.g. Adams and Niezen, 2016; Lupton, 2016). It highlights that, contrary to the many optimistic portrayals of such technologies as 'tools of empowerment', the potential impacts of their use on users' subjectivities, including sense of agency, are far from uniform, positive and absolute. By enabling access to a wider range of often-discrepant information that is difficult to reconcile, digital media may actually serve to 'disempower' users by making them vulnerable to certain claims. Understanding how people assess whether information on therapies is credible and trustworthy is of great significance in an age when digital media play a growing role in forging affective relations and political identities (Barassi, 2016).

While research reveals that consumers are often aware of the limitations of online health information and may question its credibility (e.g. Sillence, et al., 2007; Silver, 2015), investigations thus far have focused largely on traditional health websites rather than on social media (Dalmer, 2017). As the Pew Research Center observes, in its enquiry into 'The fate of online trust in the next decade': 'the rise of the internet and social media has enabled entirely new kinds of social relationships and communities in which trust must be negotiated with others whom users do not see, with faraway enterprises, under circumstances that are not wholly familiar, in a world exploding with information of uncertain provenance used by actors employing ever-proliferating strategies to capture users' attention.' (Rainie and Anderson, 2017: 2) Scientists have increasingly recognised that 'fostering trust' in science is crucial for maintaining public support for promising research, yet scientific debate has focused mostly on how to communicate the value and workings of science to citizens and on 'correcting any misunderstandings' of previous work (e.g. Cossu, et al., 2017). This assumes that 'facts' will necessarily carry most authority in credibility contests and provide the foundation for engendering public trust. As our work highlights, in their search for information, citizens are likely to encounter claims that may rest on criteria that are very different from those of credentialed experts and traditional trusted authorities.

Given the growing emphasis on enhancing 'digital literacy' among citizens (e.g. Australian Digital Health Agency, 2017; NHS, 2017), greater attention should be given to how individuals assess the credibility of the diverse sources of health information that they may encounter and how this may shape their conduct, including in relation to alleged treatments. While the issue of establishing credibility is not unique to digital media, the vast quantity and accessibility of online information in the market of healthcare means that the origins of information, its quality and veracity are less clear than they once were (Metzger and Flanagin, 2013). Providers can now use the

internet and social media to advertise directly to consumers using strong emotional appeals and promises of self-transformation, while citizens may employ the same media to share stories, mobilise their networks, raise funds and access treatments. These new market relations unsettle accepted criteria of credibility and trustworthiness. As Salter, et al. observe, in their analysis of the global political economy of stem cell therapies, hegemonic biomedical expertise, governance and values have come into collision with the demands of increasingly informed health consumers who are pursuing their own interests (Salter, et al., 2015). The need to develop forms of ‘digital literacy’ that will enable citizens to safely navigate this treacherous terrain has never been more urgent.

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