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# **Epistemic and Institutional Recognition Work in Changing Conditions of Social Visibility: Anosmia's Journey from the Shadows to the Spotlight**

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## **Abstract:**

This paper explores the complex relationships between recognition, collective action, and social (in)visibility of health conditions. We trace how collective action for recognition changes as conditions of visibility shift. We investigate how the Covid-19 global pandemic thrust one health condition (anosmia) and collective efforts around its recognition from almost complete public invisibility into a sudden spotlight. We show how ‘prepared’ movement actors leveraged this sudden hypervisibility to mobilize resources and change cultural values, noting how prior ‘recognition work’ becomes a resource for new ways to advocate for their condition’s recognition, toward epistemic and institutional recognition: from building a shared epistemic ground and improving relatability, toward resource distribution and finally, creating and institutionalizing new cultural values through policy change. Our findings highlight organizational efforts to mitigate community tensions and dispersions related to hypervisibility, through boundary and integration work.

## **1. Introduction**

Socially invisible health conditions are those that lack social acknowledgment despite their prevalence and the intensity of suffering that they bring to those who live with them (Lonardi, 2007; Madden & Sim, 2006). Examples of such conditions include fibromyalgia (Madden & Sim, 2006), chronic pain and headache (Lonardi, 2007; Pryma, 2017), chronic fatigue syndrome (Brown et al., 2017; Pilkington et al., 2020), and many other invisible impairments (Lingsom, 2008). The literature has explored the multiple challenges that people with socially invisible conditions face, for instance when searching for information about their condition (Madden & Sim, 2006), asking for disability benefits (Pryma, 2017), or gaining support from medical professionals (Edwards et al., 2007; Pilkington et al., 2020). Other work considers how

individuals fight against the various epistemic injustices related to invisible or contested illnesses (Groenevelt & DeBoer, 2023) and how they navigate identity issues between ‘passing’ as normal and living with an invisible impairment (Lingsom, 2008). Overall, in Kempner’s (2017, p.153) words, “invisibility does not just refer to the physiological limits of vision to perceive a phenomenon, but to the state or condition of being ignored”.

Alleviating this state of ‘being ignored’ might also be a common goal around which patients organize into collectives (Tyler, 2019). Such collectives might fight to be ‘seen’ at the level of everyday experiences, but they might also campaign for institutional recognition – that is, recognition of their condition in the health system at large, for instance by the medical establishment, the health insurance system, policymakers, or research funders. Sudden changes in visibility due to external factors, for instance a sudden interest in the condition, bring a heightened ‘social gaze’ (Brighenti, 2007), which can swiftly open new opportunities. Yet, we know little about how collectives organize to benefit from such shifts, especially given that hypervisibility - too much visibility and/or visibility that arrives too suddenly – may not have unambiguously positive effects (Lingsom, 2008; Settles et al., 2019). Addressing this lack of insight, we ask: How do actors organize collectively to foster recognition for their medical condition in changing conditions of social visibility?

To answer this question, we conducted our study in the context of anosmia, the loss or absence of a sense of smell. Unlike other ‘illnesses you fight to have’ (Dumit 2006), anosmia can be biomedically diagnosed (Brown, 1995). Yet, for the longest time, anosmia was virtually absent from public discourse and neglected by medical education and research funders, even though around 5% of the world’s population are suffering from complete absence of smell and another 15% have partial anosmia (Philpott & Boak, 2014). Van Toller (1999, p. 705) argues that

the social invisibility of anosmia has its roots in a ‘hierarchy of the senses’, noting that: “Smell is a sense whose value seems to be only really appreciated after it is lost.” This social invisibility had physical and psychological impacts on those who lived with anosmia, as well as on the ability of scientists or other allies to access resources for research and other institutional support.

We investigated collective action around the recognition of anosmia through primary and secondary research between 2015 and 2022. We interviewed representatives of patient organizations and research bodies, activists, entrepreneurs, and other involved actors at various points in time and geographies (noting that the majority of anosmia-related organizations operate in Europe and the United States). We further collected and analyzed secondary data, including documents, media articles, and podcasts. Our analysis uncovered that for the longest time, collective action around anosmia was aimed at building a community based on a shared epistemic ground. However, the last years of our study brought a radical step change in this collective organizing: the onset of the Covid-19 pandemic. It was only when anosmia gained visibility as a symptom of Covid-19 in March 2020 that large-scale rapid organizing for institutional recognition was enabled. However, as we shall demonstrate, this sudden thrust into the spotlight was not entirely unproblematic for the movement, as its previously hard-fought-for sense of community started to disperse.

Overall, we study how the collective efforts towards recognition, which we refer to as “recognition work”, change as social visibility changes. We found that collective organizing evolves from mobilizing around the formation of a shared epistemic ground – or ‘epistemic recognition’ (Petherbridge, 2022) to mobilizing around institutional recognition, aimed toward fostering a collective’s cultural acceptance and parity of esteem. With these reflections, we contribute to research on collective action around socially invisible medical conditions,

particularly on such movements' institutional contexts and their ability to access resources. By introducing a focus on recognition in terms of resource distribution and institutional esteem, we also further help prize open the 'black box' of collective action in healthcare (Geiger, 2021; Rabeharisoa et al., 2014, p. 121; Vidolov, Geiger, & Stendahl, 2023).

## **2. Collective action in healthcare and recognition struggles**

In Brown's (1995) classic schema of the social construction of illness, collective action is most likely to arise in cases where there is either an absence of or conflict over the biomedical definition for a specific condition and/or where the condition is not generally accepted by the medical establishment or policymakers. In other words, collective action is likely when there is uncertainty either in the diagnostic or the social definition of an illness. Within these categories, however, a wide range of action is possible, and we claim that sensitivity to the conditions of social visibility and recognition dynamics is helpful in more fine-grained analyses of different modes of collective action.

Rabeharisoa (2006) distinguishes between identity, epistemic, and political claims as interrelated motors for collective mobilization in healthcare. Claiming a common and distinct identity of those living with a particular condition has been well-researched in the literature on 'new' health social movements (Brown et al., 2004). A prominent example is the early identity work of breast cancer survivors (Klawiter, 2008). Epstein (1995) sees this type of 'identity politics' as a struggle around symbolic and cultural resources, representations and meanings.

The epistemic motor closely relates to what Rabeharisoa et al. (2014) have called 'evidence-based activism' - collective action that seeks to insert the patient experience as a valid source of knowledge claims into medical research, diagnosis, and treatment. This type of activism is prevalent in biomedically contested illnesses such as ME/CFS, where tensions

between patient experiences and medical orthodoxy can be particularly acute (Dumit, 2006). But the paradigmatic case for this type of collective action is HIV/AIDS activism (Epstein, 1995) - a condition that at least in its early days suffered from hypervisibility and simultaneous under-recognition: while ubiquitous in the media and public discourse, it was a highly stigmatized condition that was slow to gain institutional recognition by funders and policymakers. As Epstein describes, gaining ‘credentialed expertise’ allowed patients to enter previously closed institutional spaces; but this epistemic recognition related to a relatively circumscribed institutional realm – medical research. Mobilizing for epistemic recognition is often interrelated with identity work. The recent example of ‘naming and framing’ (Brown, 1995) of Long Covid illustrates how a patients’ collective organizing to create visibility of their experiences went hand in hand with struggles around acknowledgment of a name and identity of the condition (Callard & Perego, 2021).

Rabeharisoa’s (2006) political motor pertains to collective action that seeks to alter often deeply ingrained institutional arrangements such as insurance codes (Dumit, 2006), research funding (Callon & Rabeharisoa, 2008), medical training (Scott, 1990), or industry practices (Geiger & Stendahl, 2023). A paradigmatic case was charted by Scott (1990) in the case of post-traumatic stress disorder (PTSD), where protracted collective action by a range of actors aimed at the political and medical establishment finally succeeded in inserting PTSD into the Diagnostic and Statistical Manual (DSM III).

In short, collective organizing in healthcare is about searching for recognition, where this quest can manifest as a social acknowledgement of a collective identity, a patient group’s knowledge base, or the political importance of a certain condition. In this paper, we draw on recognition theory to shed more nuanced light on how these three motors may interrelate in the

context of a socially invisible condition, emphasizing the importance of epistemic and institutional recognition through the prism of Fraser's status model of recognition.

There are two different conceptualizations of recognition: Axel Honneth's identity model and the "status model" of Nancy Fraser. In the "identity model", being recognized means that one's identity is seen as worthy of concern and acknowledgment (Islam, 2013). Under-recognition can drive a sense of invisibility and alienation (Honneth & Margalit, 2001). It can become a 'psychological injury' (Fraser & Honneth, 2003) that damages individuals' self-perception and prevents them from building a healthy identity. A quest to redress this injury yields scope for collective action if the same injury or suffering is shared by others. Social change, from this perspective, 'is rooted in the factual demand for recognition of facets of one's own identity...on the part of a person or social groups' (Fassauer & Hartz, 2016, p. 176).

People who suffer from socially invisible conditions, such as anosmia, experience this under-recognition in their everyday life, for instance when they have to constantly explain their condition to others who do not know about it, or when they have to continuously reflect on whether they wish to 'pass as normal' or disclose their impairment (Lingsom, 2008). People often turn to those who experience the same struggles; they become visible to one another as "epistemic subjects" who, "together, can better make sense of their own experiences and are better able to convey their experiences to others" (Groenevelt & DeBoer, 2023: p. 6). A collective identity thus often builds less on personal characteristics and more on a shared basis of experience, which highlights 'social suffering' as an important driving force for collective action (Honneth, 1996).

The status model of recognition moves beyond this conceptualization, contending that identity models of collective action underplay the material consequences of the 'social gaze'

(Fraser, 2000; 2018). According to this model, to be recognized is to be granted parity of participation in social life as an equal and full partner at all cultural and institutional levels. By contrast, misrecognition happens when “institutionalized patterns of cultural value constitute some actors as inferior, excluded, wholly other, or simply invisible, and hence as less than full partners in social interaction” (Fraser, 2018, p. 89). Fraser notes that the struggle for recognition is situated in the context of material inequality, advocating that social justice needs to include recognition *and* redistribution of resources (Fraser, 2020). In a healthcare context, institutional under-recognition may refer to conditions that are ineligible for disability support or insurance coverage (Dumit, 2006) or deemed unimportant by medical researchers, educators, or funding agencies (as in the case of anosmia before Covid-19). While emphasizing such access to institutional resources, this quest for material recognition needs to go hand-in-hand with cultural values that constitute patients’ “status as a full partner in social interaction at all levels” (Danermark & Gellerstedt, 2004, p. 346). The struggle for recognition, consequently, is one that tackles “institutional social relations” (ibid.); it is at its very core a social politics (Siebers, 2017).

We argue that a status model offers value in conceptualizing collective action around socially invisible medical conditions. On the one hand, it highlights the importance of the political motor in Rabeharisoa’s (2006) distinction. It redirects the struggle for recognition toward the concrete institutional structures that prevent certain groups of patients or sufferers from participating fully in society – a quest that has long been at the core of disability movements (Zurn, 2003). At an analytical level, it allows researchers to draw linkages between patient organizations’ struggles for identity, those for epistemic justice and those for material resources. At a more pragmatic level, a status definition of recognition allows for heterogeneous identities of patients to exist within a larger community organizing for recognition – something

that has been criticized for instance in relation to the prevailing template of ‘survivorship positivity’ in many breast cancer organizations (Cheded & Hopkinson, 2021). Indeed, a singular collective identity related to a health condition is rare, as Rabeharisoa’s (2006) case of muscular dystrophy shows. More commonly, there are multiple ways of experiencing a medical condition (Brown, 1995), including those that are socially invisible. The status model of recognition thus acknowledges differences within patient groups all while focusing on their (collective) ability to access resources and seek epistemic and distributive justice.

### **3. (Hyper)visibility and collective organizing**

How do social visibility and institutional recognition of a medical condition relate? While social visibility and recognition are often used synonymously, we argue that there are important conceptual differences. Social invisibility is often defined as a “lack of acknowledgement” (Lonardi, 2007) or awareness for a condition, whereas the lack of recognition refers, as described, to a lack of institutional esteem and parity of participation. The distinction between visibility and recognition becomes significant when considering that social visibility may not automatically lead to societal appreciation (Brighenti, 2007). Just as invisibility may lead to social or institutional exclusion (see Callard, 2020), visibility or hypervisibility, for instance as a disabled person in a highly ableist environment, can lead to situations where one is ‘scrutinized but not recognized’ (Settles et al., 2019). For example, disabled mothers may seek visibility as a way to resist everyday stigmatization, yet engage in hidden labor to mitigate the unwanted consequences of such visibility (Frederick, 2017). Moreover, both hypervisibility and invisibility are often exacerbated at specific intersections. For instance, for a Black woman, the struggles with fibromyalgia may stem from an invisibility both related to her condition and her race (Kempner, 2017; Pryma, 2017).

While it can be empirically challenging to disentangle social visibility from recognition, we were in a fortuitous position to explore this relationship by following one particular patient collective before, during, and after the Covid-19 pandemic, which radically altered the social gaze on this particular condition. There are important conceptual insights to be gained from shifts in visibility such as the one the anosmia community experienced. Sudden shifts in visibility may be leveraged to strengthen collective organizing and/or access to resources (Ozkazanc-Pan, 2019). At the same time, they could also prove counterproductive by leading to hypervisibility without recognition (Abes & Wallace, 2018; Settles et al., 2019). In addition, while recognition should ideally be based on symmetry – that is, two parties holding each other in equal esteem - social visibility is often a one-way gaze (Brighenti, 2007). Therefore, visibility or hypervisibility without recognition may exacerbate power asymmetries. In relation to women’s health, for instance, the ‘discovery’ and categorization of premenstrual dysphoric disorder pathologized normal human feelings and behaviors such as aggression or anxiety as symptomatic, thus further fortifying social control over how women ‘ought’ to behave (Conrad & Barker, 2010).

## **4. Methods**

### **4.1. Research context**

Our research design was driven by the question of how actors engage in collective action around the recognition of socially invisible medical conditions. We situated our study around anosmia, a condition that can be biomedically diagnosed but for which there is currently no cure. People with olfactory dysfunctions such as anosmia are facing major challenges in everyday life, as they cannot detect certain types of environmental danger (gas leaks, burning or spoiled food), and they often suffer from social anxiety (Croy, Nordin, & Hummel, 2014). Even though the

absence of smell has been known since the 19<sup>th</sup> century (van Toller (1999) reports that a first scientific observation of anosmia was made in 1837), for a long time, collective action around anosmia consisted only of a handful of actors who were scattered, often isolated, and only weakly (if at all) supported by research institutes.

Attempts at driving collective action around the condition started in the early 2000s, as a handful of organizations and individual actors started to interact, and it grew very slowly over the following decade. This low level of mobilization changed dramatically in March 2020 when anosmia was recognized as a primary symptom of a Covid-19 infection. Serendipitously, we had been researching the struggles for recognition of anosmia organizations for five years at that point and were able to continue this research into this completely new phase of the movement's fortunes.

#### **4.2. Data collection**

The first author started to immerse themselves in this field in late 2015 and collected data in several waves through to 2022, through five main sources (see Table 1).

--- Insert Table 1 here ---

**Interviews.** We conducted semi-structured interviews with representatives of patient organizations, activists, research and medical organizations, entrepreneurs and companies in four waves: 2017, 2019, 2020, and 2022. In total, we completed 41 interviews: 12 interviews with individual patient activists, 12 with patient organization leaders, and 17 interviews with entrepreneurs and researchers. To identify research participants, we first contacted the major patient organizations in France and the UK and interviewed their representatives, and we used snowball sampling to identify further participants. All participants provided informed consent to participate in the study; they were informed about the purpose of the research, the procedures

involved in data collection and analysis, and steps undertaken to ensure participant anonymity. Interviews were semi-structured, lasted from 45-60 minutes, were recorded with interviewee consent, transcribed and pseudonymized. For one interview, where consent to record was declined, we took notes and subsequently used information from this interview for contextual purposes only. We also gathered 77 secondary interviews with different actors in the field of anosmia by the publicly available Smell Podcast, one of the leading patient-led anosmia podcasts.

**Archival data.** We collected extensive secondary data, including from the websites of the patient organizations such as press releases, blog entries, newsletters, and project pitches. This allowed us to trace activities before the start of data collection, reaching back to the late 2000s, as well as more current events. We also downloaded and transcribed 30 videos produced by different organizations, which included virtual conferences, practice demonstrations, and panel conversations between different actors in the field.

**Newspaper and other databases.** Using the Nexis database, we searched for articles containing the term “anosmia” in the English-speaking news. After eliminating unrelated and duplicated results, we created a database of 3477 articles. We complemented this media search with the Google trends tool to understand the popularity of the search term anosmia over time. We also analyzed two clinical trials databases, ClinicalTrials.gov and the EU clinical trials register, to understand how the recognition of anosmia impacted the number of clinical trials conducted. In addition, we searched the PubMed database to ascertain medical interest in anosmia over time.

**Observations.** The first author participated in four conferences between 2015 and 2019 and two digital seminars in 2020, taking extensive notes on the presentations and activities and

conducting multiple informal interviews. At all times, the author revealed her role to the participants and explained the objectives of the research. She also became a member of the Global Consortium for Chemosensory Research (GCCR) in 2020 and gained access to a Slack working group where the members of the consortium shared ideas, documents, and work plans that included issues related to the recognition of anosmia. In addition, the first author was a member of four Facebook spaces related to anosmia (one private group where she disclosed her identity to participants and the group moderator, one public group, and two pages) in the period between 2016 and 2020 and followed important social media hashtags.

### **4.3. Data analysis**

Our data collection and analysis were concurrent and proceeded through several rounds, following an iterative and inductive research design, as follows:

**Creating a chronology.** Following principles for the analysis of process data (Langley, 1999), we created an overall case chronology as we proceeded with our research. We produced a detailed timeline of collective action in the field, including the founding and activities of patient organizations and activists, partnering between different organizations, external events that impacted the field, emergence of new actors, etc. Cutting across this event chronology, we could identify key moments that impacted the recognition struggles.

**Delineating phases.** Cross-analyzing these initial categorizations with our longitudinal case account, we used temporal bracketing (Langley, 1999) to delineate the three phases in the process we observed – (1) before Covid-19, (2) from the onset of the Covid-19 crisis in March 2020, when anosmia was identified as a symptom of Covid, until early 2022, and (3) from Spring 2022, when according to our informants the issue of anosmia receded in prominence due to widespread vaccinations and new variants causing less anosmia-related symptoms.

**Theorizing ‘recognition work’.** Through iterative processes of data abstraction and comparing our findings with extant literature on collective action and recognition, we came to understand the struggles for and around recognition as ‘recognition work’, which we saw changing in the three phases (before, during, and after the crisis). We cross-analyzed these practices in terms of visibility conditions, ways and forms of collective organizing, and goals of the recognition work.

## **5. Findings**

### **5.1. Before Covid-19: Recognition work in conditions of invisibility**

**Invisibility.** Anosmia can be categorized as a physically and socially invisible condition. Indeed, the absence of an ability to smell is not instantly visible. A patient advocate pointed out that anosmic people are invisible to each other, and that he spent years thinking that he was one of the rare individuals who had anosmia. “We do not walk around with a large cane or any visual aid, so people don’t recognize other anosmic people.” (Interview, patient leader 1, 2017). Not only is anosmia physically invisible, but until the pandemic it has also remained socially invisible. Anosmia first appears in the media database in 1980, but interest in it remains low and rises only very gradually until 2020. Only 30 articles were published in total on anosmia until 2000. Between 2000 and 2010, we found 176 articles, while from 2010 to 2019 that number increased to 456. Similarly, anosmia also seemed invisible to researchers, scientists, and medical professionals, as illustrated in this researcher’s reflections on her beginnings in the field:

The chemical senses have been sort of like the black sheep of science for many centuries, since Aristotle maybe. People whose domain it is don’t know much about it. It is always the last chapter in books about the senses. (Interview, Researcher 1, 2022).

**Building a common epistemic ground.** One of the rare news articles on the condition in the New York Times from 2011, entitled “The Nose May Not Know What It’s Missing”,

reported on an anosmic neurologist who wrote a book about his experiences, motivated by the lack of knowledge on the part of physicians who tell sufferers to “live with it.” In the absence of medical acknowledgment and guidance, how exactly to “live with it” – and what exactly “it” was – became an early focal point of collective organizing. This was made more difficult as being “anosmic” did not pertain to a singular identity, as two different groups of sufferers existed: those who were born without their sense of smell (congenital anosmics) and those who lost their sense of smell due to illness or other reasons. As a patient organization leader explained, these different identities often related to different experiences:

I’ve never really come across anything like it, where no two people’s experiences are the same, and you have the extremes from practically suicidal right down to “it doesn’t really bother me”. And all these sorts of different levels in between. (Interview, Patient organization leader 1, 2017)

Yet, the multiple experiences of anosmia did not prevent the emergence of early collective action. Instead of pursuing a seemingly impossible quest for a singular collective identity, the work of organizations mostly revolved around establishing a sense of community based on a shared epistemic understanding of living with the condition. Similar to other patient groups where mobilizing emerges from points of similarity rather than differences (Rabeharisoa, 2006), the aim of this early collective action was to find a shared experiential base for those with the same struggles, even if institutional recognition was lacking.

Virtual spaces such as Facebook groups started to become a venue for these endeavors. Indeed, these spaces often serve patients to find an empathetic community that mutually recognizes the struggles involved in living with a certain condition (Groenevelt & DeBoer, 2023). People shared pictures of burned food, pointing out the safety concerns when living with anosmia, or they shared stories of how their problems were dismissed by the medical professionals and their own family members.

Slowly, physical meetings allowed people with anosmia to meet and interact, with the hope that this would give impetus to more concerted collective action. The patient organization Fifth Sense organized its first conference in 2013, with a program oriented towards sharing experiences, expanding knowledge, and fostering action. As one participant summarized it on the organization's website: "We all came away with a greater understanding of the condition and the sense of just how important it is that we campaign for recognition at the highest level".

In the mid-2010s, the few existing patient organizations also started to seek out researchers interested in the condition. These researchers were struggling too in their endeavors to produce knowledge about anosmia – because of its social invisibility, research funds for anosmia projects were virtually non-existent. To collectively change this state of affairs and address institutional obstacles, organizations started to work together. For example, the patient organization Fifth Sense partnered with Florida University's Center for Smell and Taste research to connect patients and researchers – the invisibility of sufferers also created difficulties in organizing research projects around the condition. Similar events were organized between the patient organizations and a handful of startups that started to be interested in the area.

**Enhancing external epistemic relatability.** Throughout this time, efforts were expanded to make patients' suffering relatable and visible to external communities. As many of our research participants noted, the problem in recognizing anosmia as a debilitating issue is that people cannot relate to it as they cannot imagine living without smell, or how it may present a major obstacle in everyday life. One patient activist explained:

It is a difficult thing to really understand if it does not happen to you. ... If you really want to know how it is to have no eyesight, you close your eyes. It is not quite that simple with smell. Unless you decide to go around for six months of your life with a peg on your nose. (Interview, Patient organization leader 1, 2017).

For example, one of the struggles in living with anosmia is the lack of flavor of food, which can lead to eating problems. To make this relatable to non-sufferers, a sensory demonstration to non-anosmic people was organized at one of the patient conferences, to show how much smell plays a role in the perception of the flavor of food and raise awareness about the struggles that people with anosmia may face. Our field notes read:

Organizers distributed small cups containing two jellybeans. They asked us, the participants, to pinch our noses shut and try one. I tried an orange one first. It had an acid-sweet taste. Then I released my nose. It was orange flavored. I tried the other one following the same principle. The taste was spicy, like eating a chili pepper. But the flavor was very surprising: cinnamon!

To further improve the relatability of anosmia, some organizations started to broaden their links to a wider set of organizations, particularly in relation to other sensory losses and other smell phenomena. For example, the organization Abscent connected with the perfumery brand Jo Malone to launch an app on smell training. The research center Monell connected with researchers on deafness to understand the evolution of research in other sensory fields.

In summary, at this stage, anosmia is a socially invisible condition. Invisibility simultaneously drives and constrains collective action; it presents a motivation to organize, but it also shapes the collective action itself by fostering collective action around mutual recognition of living with the condition. In parallel, actors strive to improve epistemic relatability from external actors, but invisibility constrains these efforts substantially.

## **5.2. The Covid-19 Crisis: Hypervisibility reshaping recognition work**

The decade-long recognition struggle that we traced above was laborious and painstaking. Even in our interviews from late 2019, lack of visibility was identified as a persistent problem limiting collective action and impact. Things were about to change dramatically, though, when an external shock made anosmia suddenly visible to the public eye.

**Hypervisibility.** At the end of March 2020, as the Covid-19 crisis shook the world, evidence appeared that an increasing number of Covid-19 patients reported loss of sense of smell and taste as a symptom of the illness, even in the absence of other symptoms. The UK ENT medical community issued a statement to inform the public about this phenomenon, and doctors saw this as a way to detect and manage asymptomatic Covid-19 cases, recommending that people with sudden loss of smell and taste should self-isolate. Public attention was now drawn to anosmia. A Google trends query shows how the popularity of the search term anosmia, relatively unchanged in the last 10 years, reached a massive peak in March 2020 (Figure 1).

--- Insert Figure 1 here ---

Media interest in anosmia also exploded. The media coverage in 2020 amounted to 65% of the total ever media coverage for anosmia until 2020. The research and medical community, and pharmaceutical companies too, turned to anosmia. In December 2020, an article in The Guardian noted that while smell was earlier considered "the Cinderella of the senses", and anosmia "overlooked by the medical community", and "hampered by limited funding", "over the past eight months, traditional medical perceptions of anosmia have changed". This also reflected in an increase in clinical trials related to anosmia. Figure 2 illustrates the rapid shift in anosmia's visibility through search results of three different types of databases: Nexis (for media), PubMed (for research), and Clinical trials databases (U.S. National Library of Medicine Clinical Trials and EU Clinical Trials register together).

--- Insert Figure 2 here ---

Not only did Covid-19 put an unexpected public spotlight on anosmia, but it also fundamentally changed its epistemic relatability: anosmia was no longer a strange condition no one had heard about, but it was something that could affect anyone and that many people

experienced, even if for a short period of time. This patient activist reflected in our interview in 2022 on how the general public finally understood what anosmia was about:

So, I would post quotes that people have said on the podcast and there is one that I posted about how this person's parent had died and she could no longer remember that person through smell. Then I had a family member and I have had anosmia for a really long time who reached out and was like wow I get it. That would have been so hard when this family member's dad died. She was just saying like I understand what it means now because I can't imagine that when my dad died I couldn't go and buy his cologne and smell it. (Interview, patient activist 2, 2022)

Unsurprisingly, the large number of new anosmics and expansion of interest in anosmia translated into a rapid increase in the online community, as the leader of another patient organization noted in an online seminar in early 2021:

The group has grown. To remind you all, at this time last year, there were 1,500 people in the Facebook group. Now, combined across all the Facebook platforms, there are over 30,000.

Clearly, this was the moment for people living with anosmia to be 'understood', as one researcher explained in an interview for SmellPodcast:

It's unfortunate that this pandemic is happening. But one positive thing that has come out of it in my opinion is that there is now increased awareness about the word anosmia itself. I think that the experience of people worldwide who are losing their sense of smell due to Covid-19 gives people with anosmia a moment to be understood.

**Leveraging hypervisibility for epistemic recognition.** The pandemic hypervisibility of anosmia also turned the spotlight onto organizations concerned with this condition. With so much background organizing done in the pre-pandemic period, many of these organizations were now prepared to step into this sudden spotlight and show that they could contribute to solving important questions. A patient organization leader described:

The pandemic changed everything for us. We got registered charity status, which is the legal requirement that you need in this country to work as a charitable organization. That status was granted in May 2019. And within a week we received charitable status we launched our new fully formed website. (...) We had everything prepared and it was just really an ideal situation for when the pandemic hit. (Interview, Patient organization leader 2, 2022)

These actors were in a position to come together quickly into new meta-organizations, such as the Global Consortium for Chemosensory Research (GCCR). After early evidence suggested anosmia as a symptom of Covid-19, a group of scientists proposed urgently forming a global consortium to investigate the link between anosmia and Covid-19. One of the consortium founders recalls:

I think it was a perfect storm of people really having a common goal and the technology being now in place to make that happen fast. I got 165 emails in a three-hour period in the first weekend of Covid, from people all over the world saying we have got to figure this out, we need to study this. (Interview, consortium founder 1, 2021)

The Consortium rapidly gathered more than 700 researchers, clinicians, and patient activists in 66 countries. This meant stronger coherence of existing actors around a tangible goal – increasing knowledge of the link between anosmia and Covid - as well attracting new actors into the community. The Consortium leadership team included members of existing research centers and patient organizations. These were the actors that had pushed collective action before the crisis and were now prepared to join forces quickly, as one researcher indicated:

As a group we were prepared to tackle an issue that was relevant and of huge public health concern. We had the ability to really organize and put people together. (Interview, researcher 1, 2022)

The consortium started with vigorous internal communication through the instant messaging service Slack and rapid prototyping of study ideas, and it quickly began to produce research output. Subcommittees enabled swift consolidation of different epistemic positions; patient organizations for instance have their own patient committee organized around patient involvement in research projects. As one of the GCCR leaders explained, this patient-oriented subcommittee was an important ‘reality check’ for scientists and a source of quick feedback on patients’ experiences. Zooming in on the participation of one of the patient activists, she recalled:

This person was always in the meetings and was always available for that perspective, saying: “No, that is too crazy”, or “this is what patients want to know”. She was in a very active Facebook group, so she was able to provide feedback on what people are really saying most of the time, rather than us noticing one tweet that gets re-tweeted 200 times.

The GCCR leader posited that feedback from patient activists had a transformative effect on researchers’ work: “one of the really positive things that came out of it is that scientists are now more inclined to first get feedback from patients about their surveys”.

Outreach became central to Consortium activities too. For instance, the I CARE campaign showed a video with different faces of researchers around the world saying I CARE in the different languages used in the consortium. This campaign had an obvious and powerful emotional charge, but it also signaled that simple awareness of the condition was not enough - sufferers needed solidarity.

The overall organizational effort was considerable. From a standing start, throughout 2020, at least 40 webinars and virtual conferences were organized with researchers, patients, clinicians, and activists on a wide range of topics from explaining strategies to live with anosmia, smell-training practices, to sharing research progress.

**Leveraging hypervisibility for institutional recognition.** Importantly, beyond fostering urgently needed research, anosmia organizations also endeavored to leverage hypervisibility to fight for resources. Before the crisis, collective efforts toward external stakeholders focused on creating visibility and relatability for the issue. Now, the crisis served actors as a vital lever to mobilize resources. The GCCR diffused press materials about new studies to larger audiences, highlighting the importance of anosmia in the fight against Covid-19. Through events, it showcased the organizational field that had rallied around the condition, profiled its diverse membership, and signaled the strengths of existing collaborations to institutional actors including

fundors and politicians. In one of our interviews in early 2021, the consortium leader confirmed the rise in interest from funders – at least when it came to Covid-related research:

I definitely see that there is interest outside of the community and this is reflected at a certain point in the number of grants, but the grants usually fall into the category of Covid-specific activities, and smell and taste are high within that Covid 19 framework. (Interview, consortium leader 2, 2021)

A prominent patient organization put forward an application for (not Covid-19 related) research funding that aimed to "bring together patients and clinicians around a particular medical problem and enable them to feed in their priorities for future research". The founder of the organization noted that this funding application was prioritized "because of the situation, because of the level of interest and the need that has been demonstrated, we thought it makes sense to move forward with this sooner rather than later and capitalize on this interest." Thus, actors who had prepared the ground through their interactions earlier on could now access resources that had previously been out of reach.

**Tensions and dispersions.** However, the spotlight on anosmia was not roundly positive. The broader the network that rallied around the condition became, the harder it became to maintain a sense of community and shared epistemic ground – so hard fought for in previous years. Noting some emerging tensions, which had been uncommon within this community before Covid-19 despite the diversity of anosmic experiences, leaders were keen to avoid fracturing:

We have also to be mindful of the people who are affected by longer-term anosmia, that we are not just suddenly going to become an organisation purely for the people who are losing it through Covid-19. What has been really interesting is the reaction from some people who are affected longer term who in some cases are a bit frustrated or a bit sort of like, well, now you know what it's like. We have seen that reaction as well, of people saying well you might only have it for two or three weeks, lucky you. (Interview, patient organization leader 1, 2021)

Indeed, tensions between anosmic ‘newbies’ and ‘long-termers’ became all but unavoidable, as this patient organization leader vividly illustrates in relation to the exponential growth within the Facebook group:

It was like you are having a quiet dinner party and someone rings the doorbell and then in pour dozens of drunk people who then monopolize the conversation and eat you out of house and home. The original members of the group were like excuse us, we have been here for years. That was very upsetting for them. (Interview, patient organization leader 2, 2022)

To deal with these rising tensions, the organization engaged in careful boundary management, seeking to maintain a sense of a collective while accounting for the dispersion of patient experiences. The Facebook groups were separated, and discussions on Covid were only allowed in the Covid-19 related group. However, even more dispersions happened due to the appearance of Covid-19 related parosmia, the distorted sense of smell. As the same patient organization leader stated, this led to further frictions and fractions:

And then I noticed that there was a lot of tension between the people in the Covid-19 group who had parosmia and who didn’t have parosmia. As you may be aware if you have got parosmia you have a slightly better outcome than if you didn’t have parosmia. I separated them and I am also really careful to try and keep that separate, because the people who don’t have parosmia sometimes say “Oh you know there’s nothing but parosmia, parosmia, right now, and not everybody has it. What about us?”

Thus, while external recognition both in epistemic and institutional terms increased, within the community, diffracted socialities of suffering emerged, all of whom demanded to be recognized in their own right.

In addition to boundary work in addressing the dispersion of patient experiences, to stem these divisions, organizations engaged in educating and integrating new members of the community. Videos, webinars, and tutorials were quickly produced for new patients to understand the food preparation and smell training practices that had become a shared stock of

anosmic practices and meanings in the previous period. Anosmia bloggers increased their level of activity to engage with new patients and share new developments in the field.

The hypervisibility of the condition in the general media also meant that the community lacked control over the narratives surrounding anosmia. Disparate and often false information circulated widely, and patient community leaders had to weed through a great deal of confusion. Facebook conversations, for instance, proved increasingly difficult to curate:

Then came the whole nightmarish problem of Ivermectin. And then people believing that the vaccine had caused them to lose their sense of smell. Or the other thing that they believed is that the vaccine either cured their parosmia or caused their parosmia. But of course, there is nothing going on there, that is merely an accident of timing. .... Which is difficult, people getting really emotional and angry, and using foul language, and threatening me, and I had to deal with all that. (Interview, Patient organization leader 2, 2022)

Tensions also appeared in the collective organizing of the GCCR. Due to the rapid pandemic organizing, epistemic tensions arose for instance between a quickly broadening set of researchers and patient organizations: for a large survey researchers were looking for people who had anosmia for “at least a two-week period”. But when the survey was posted in the patient Facebook group, ‘long-termers’ felt disappointed and ‘unseen’ by the researchers.

To summarize, pandemic hypervisibility becomes a double-edged sword for the community. The recognition work done in the previous period becomes an important resource as patient organizations and researchers can swiftly organize into larger collectives.

Organizationally ‘prepared’ actors thus leverage hypervisibility by accelerating existent projects and extending networks. Recognition remains a driver for actors, but the mode of collective action changes: actors can now focus their attention on resource mobilization and institutional recognition. Yet, new recognition struggles arise as the community widens. While anosmia was always a condition that incorporated different experiences, the magnitude and diversity of new experiences complicate the previous period’s epistemic goals.

### **5.3. Beyond Covid-19: Precarious visibility and institutional recognition**

Beyond the crisis, our data demonstrate how ways and aims of collective action have shifted once again: it now predominantly focuses on building on the pandemic momentum towards institutional recognition and on tackling deeply ingrained cultural ‘recognition orders’ (Honneth, 1996).

**Precarious visibility.** The longer-term impact of the crisis was twofold: a social consensus emerged that anosmia is an important issue; and the condition had become ‘known’ to many at a visceral level. As the pandemic settled, anosmia’s new-found epistemic relatability was clearly reflected in the media, with stories of struggles becoming embedded into the collective knowledge. For instance, The Washington Post published a story about a brave toddler who saved his family from a house fire as he woke up his parents who could not smell the smoke. The Telegraph and The New York Times warned about the impact of anosmia on work and industries related to smell and taste, such as wine-growing and perfumery. Overall, our media analysis shows that the number of articles in 2021 has remained high (1200) but the interest slowly started to fade, with 393 articles published in the first 6 months of 2022. Similarly, when we examined the popularity of the search term two years before and after the onset of the crisis, we saw it starting to dwindle in 2022 (Figure 3).

**Institutionalizing new patterns of cultural value.** Toward the middle of 2022, as results of the GCCR’s collaborative efforts started to be published and researchers went back to business as usual, collective research activities slowed down. Yet, the previous period’s organizational efforts did not completely dissipate. Even as the consortium contracted, researchers and patient organizations found new ways of fostering institutional recognition and directing resources towards anosmia:

I think the profile has been raised. In order to get money, you need to demonstrate that there's anguish, people are suffering. That is now extremely evident. (Interview, patient organization leader 2, 2022)

In addition to resource mobilization, organizations started to heavily leverage their new-found visibility to achieve lasting institutional impact, especially on health policy. One researcher we interviewed in 2022 called the pandemic 'the revolution of the smell'. She highlighted the need to keep smell and taste on the public agenda and not have it become a "one-hit wonder". The collective work done through the crisis became a starting point for developing new projects for changes in education and implementation guidelines. As a researcher stated in 2022, the work during the crisis "allowed for the concept of universal smell testing to emerge". She further explained that:

Most of us have had vision tests throughout their lifetimes, even hearing tests if you think of babies, but the majority of the world population has never had a smell test .... but we know that smell is a sentinel for health in many different scenarios, not just Covid. (Interview, researcher 2, 2022)

Researchers have initiated multiple discussions around universal smell testing in healthcare. A French patient organization outlined a series of projects, including an open letter to the Minister of Health to include smell-testing and education in schools, similar to existing tests for vision and hearing, and to push for anosmia to receive disability status.

The intense period of collective interaction during Covid-19 also gave rise to new collaborations around highlighting the cultural values of smell and taste, thus tackling long-held theorizations of the 'hierarchy of senses' (van Toller, 1999). One such actor, the Smell and Taste Association, worked toward recognition not only of the absence of smell and taste, but toward appreciation of these senses in themselves:

We started with other folks in many different industries a new organization which is called the World of Taste and Smell Association. Last year we started on September 13<sup>th</sup>. It is the day to celebrate and elevate smell and taste. ... We have people who are working in the perfume industry, in sensory marketing, in community building around smell and taste,

scientists, chefs. Any person that you can think of that has a connection with smell and taste, we want to bring them under this wider umbrella. (Interview, researcher 2, 2022)

One of leaders of this new association, who had campaigned for anosmia before and during the pandemic, explains their change in focus:

What shifted for me was that I was trying to let people know that there was something called anosmia, that this was a condition, because nobody had heard of it. Now, my focus is really about elevating and celebrating the sense of smell and taste. So, my own focus has changed because now people broadly know about the condition. So, it's kind of the next phase. (Interview, leader Smell and Taste association, 2022)

Thus, with the waning of the pandemic, the public gaze drifted away from anosmia. Yet, rather than returning to obscurity, the condition and the organizational actors rallying around it now exist in what we label as precarious visibility, which orients actors toward buttressing institutional recognition by creating and institutionalizing new cultural values. This work aims toward anchoring anosmia firmly into the cultural, medical, scientific, and public landscape as a condition that is recognized at every one of these levels. In its 'celebration of the sense of smell', mentioned by our interviewee above, the quest for recognition for an invisible condition has thus found its broadest expression to date.

## **6. Discussion and conclusions**

This study sheds light on the recognition struggles around anosmia, a condition that was biomedically recognized yet socially invisible within the medical and research community and the public at large. Healthcare sociologists have been exploring the struggles of patients and patient collectives aiming to improve the recognition for their socially invisible health conditions (Groenevelt & DeBoer, 2023; Lonardi, 2007; Madden & Sim, 2006; Pilkington et al., 2020; Pryma, 2017). We draw their insights and our empirical findings together with theoretical debates on recognition, proposing that recognition revolves not only around gaining a social identity and credentialed knowledge, but importantly also about institutional participation and

parity of esteem (Fraser & Honneth, 2003). We highlight that what we call ‘recognition work’ in patients’ collective action is a cumulative relational and positional practice: it aims toward the formation of a community based on a shared epistemic ground, and, importantly, at having this validated through external epistemic relatability and equitable partaking in resource distribution and health policy. Which of these vectors of recognition work will more strongly color collective action, in our analysis, depends both on previous recognition work done – hence the ‘cumulative’ nature of this work – but also on how the ‘social gaze’ enables or inhibits it, hence its relational character.

We show that recognition work changes with changing conditions of visibility. As long as anosmia was socially invisible, recognition work was oriented toward building an internal empathetic community, while fostering relatability of the condition to the outside world proved difficult. Once conditions of visibility shifted, organizations leveraged hypervisibility to move the focus of recognition work toward externally-facing epistemic and institutional recognition in order to build the knowledge of external actors and improve access to resources. At the same time, the internal epistemic ground built previously began to shift and fracture. Finally, once social visibility (however precarious) was established, collective action engaged with broader cultural recognition work to address the underlying patterns of value that had rendered their condition invisible in the first place – in our case, the ‘hierarchy of senses’.

Our longitudinal insights shed a nuanced light on how actors may try to leverage hypervisibility for longer-term institutional change. As work in disability studies and HIV/AIDS has demonstrated, hypervisibility is not always beneficial to collective action causes (Epstein, 1995; Lingsom, 2008). In Epstein’s recounting of early collective action around HIV/AIDS, for instance, lay experts had to work particularly hard to overcome prejudices related to the media

portrayals of those living with the virus to gain epistemic recognition. While our case relates to a condition that is less stigmatized, we show that even in this case hypervisibility is not roundly positive. Our findings suggest that when visibility conditions change, fortune favors the prepared – in our case, organizations that had built up an epistemic community of patients and allied researchers. These ‘prepared’ collectives were able to seize their ‘moment in the spotlight’ through rapidly shifting gear in their mode of collective organizing. Our research thus demonstrates how the work done in the early moments of the emergence of a healthcare movement sets the stage for benefitting institutionally from sudden shifts in visibility. In the context of anosmia, this preparedness enabled actors to leverage early organizational bonds to engage in joint production of knowledge and simultaneously open up opportunities for resource mobilization. Patient organizations that had ‘prepared’ by establishing a shared epistemic base could now also better absorb newcomers and help prepare these patients to ensure more equitable interactions with the healthcare system and practitioners, further moving anosmia and its sufferers from invisibility toward equity in the care received (Wagner, 1998). The final stage, at least in our narrative, is one where collective action pushes for broader cultural change and thus focuses on more fundamental changes in society’s recognition orders – in our case, that associated with the hierarchy of senses.

But our longitudinal study also allows us to add valuable nuance to these potential benefits of (hyper)visibility. Specifically, we highlight that the sudden influx of actors gathering around a ‘hypervisible’ condition may dilute the very basis upon which the movement may be able to gain institutionally from the step change in visibility - its sense of community based on shared epistemic ground. In such situations, dispersions may divert energy from a rapidly closing window of opportunity, and organizations need to balance boundary work with efforts to

integrate the experiences of new patients. Our findings thus extend those of Roth and Gadebusch-Bondio (2022) on collective action around Long Covid and its relationship to the ME/CFS community in highlighting that collective action to expand a movement's reach needs to be carefully balanced with boundary work to retain shared epistemic ground and avoid too great a dilution of the collective, which could subsequently inhibit institutional recognition. This also reflects issues earlier raised by Scott (1990) in his study on PTSD: while a core of veterans and researchers continuously collaborated to 'create' PTSD and have it medically recognized, careful expansion to other trauma experiences reaffirmed the condition as 'real' and 'objective'.

We acknowledge that our case insights, straddling the extraordinary times during Covid-19, may not be directly comparable to other instances of sudden changes of visibility. Yet, at a broader societal level, the social turbulences associated with the Covid-19 pandemic offered a particularly interesting context for a study on collective action and recognition even beyond the healthcare realm, as the pandemic shifted many ongoing recognition struggles, invisibilizing some further and bringing others into the spotlight. This was the case for example for the recognition struggle involved in the Black Lives Matter (BLM) movement, tragically made hypervisible through the murder of George Floyd in May 2020 (Mullard, 2023). That visibility in turn triggered recognition work to raise attention to the disproportionate effects of Covid-19 on already marginalized communities (Mullard, 2021; Mullard et al., 2023). At the same time, the Covid-19 pandemic also brought on new misrecognitions for that very community (Aspinall, 2021). More proximate to the healthcare domain, the rapid rise and media prominence of Long Covid may have increased cognizance in the medical establishment that a myriad of socially invisible illnesses exist and cause great suffering and that they deserve institutional recognition - for instance through "equitable care pathways, inclusive diagnostic criteria, [and] employment

rights” but also through research funding and medical education (Alwan, 2021, p. 492). We hope to have contributed to this aim by deploying Fraser’s recognition framework, highlighting the material as well as personal hazards of prolonged misrecognition, and emphasizing how patient communities may work toward epistemic and institutional recognition. Overall, we argue that recognition theory brings crucial nuance and political import to Rabearisoa’s (2006) three motors for patient movements – identitarian, epistemic, and political – by demonstrating how these can be read as entwined and cumulatively built facets of recognition work and by highlighting the social conditions of visibility under which each of these facets may be most beneficially pursued.

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