# Transformative Netnography: Combining Representation, Social Media, and Participatory Action Research

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## Abstract

*How can systems science researchers leverage qualitative social media research methods to address cultural and social issues in a way that involves participants and researchers working together? To address this question, this paper proposes transformative netnography, an adaptation of netnography that combines social media representational affordances with participatory action research techniques to offer unique communication benefits for transformational research. It examines some of the practical and theoretical underpinnings that have guided various forms of action research and links them to representational concerns and qualitative social media research. The paper proceeds to present a detailed example of transformative netnography that pioneers the use of social media's accessibility, organizational, and consciousness-raising affordances, combining them with collaborative ethnography to create a novel and digitally enabled form of representative advocacy research. The paper concludes with some implications for further transformative research using social media affordances and the ongoing development of transformative netnography.*

**Keywords:** action research, ethnography, netnography, representation, social media

## 1. Introduction

The "transformative paradigm" (Mertens, 2007) and transformative forms of science and research have been advocated as approaches to systematically study, include, and address issues of social justice, human rights, and environmental crises (Crockett et al., 2013). The action research paradigm (e.g., Ozanne and Saatcioglu, 2008), which has a long history in systems science, shares many similarities with the transformational research paradigm (Mick, et al. 2011). As Avison et al. (1999, p. 94) explain, "Action research combines theory and practice (and researchers and practitioners) through change and reflection in an immediate problematic situation within a mutually acceptable ethical framework. Action research is an iterative process involving researchers and practitioners acting together on a particular cycle of activities, including problem diagnosis, action intervention, and reflective learning."

Although there is significant diversity between the different action research approaches applied in information systems research, they share a basis in interpretive research, researcher intervention, naturalistic settings, participatory observation, and the study of change (Baskerville and Wood-Harper, 1998). Numerous innovations in these areas have helped advance both theory and practice in information and systems sciences. For example, the development of "Participatory Action Design Research" was proposed as a way to combine urban informatics, design science, and participatory action research [PAR] to confront contemporary issues of everyday life in urban environments (Bilandzic and Venable, 2011).

This paper considers the principles, roles, forms, and implications of these interventionist forms of investigation as they are applied to netnography, which is a systematic qualitative research technique that uses online traces, elicited, and observed data to gain cultural understanding. In netnography, the representation of groups, issues, topics, and individuals are key elements. These representations and representational affordances are important aspects of social media content and context, and they profoundly affect the conduct of qualitative social media research. In fact, netnography has been termed a "representational practice" and described as "a way to rethink the role of scholarship, communication, understanding, and academia in a social media environment" (Kozinets, 2015, pp. 242-3).

Because representational practices are an important part of both netnography and the social media environment, there is significant potential to develop action research methods that leverage these practices in pursuit of research deliberately involving the people who are affected by their representations. To develop this approach, we examine some practical and theoretical underpinnings to guide research in this area. This requires a deepening of the linkages between netnography, videography, and PAR. We thus overview prior PAR and related action research

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approaches such as community action research with an eye to leveraging them to address social issues in a contemporary social media environment.

The heart of this paper is the presentation of a detailed example of a transformative netnography that investigates and represents people with facial differences who utilize social media to face the world with a new impression of themselves and their social reality (e.g., Cavusoglu and Belk, 2023). We conclude with implications for further transformative netnography and consider what these developments mean for the future of collaborative research between systems science researchers and research participants.

## 2. Principles and philosophical assumptions

Chief among the collaborative approaches to scientific social investigation is participatory action research, which is often also called action research within the systems science field. PAR is based upon "a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview" (Reason and Bradbury, 2001). It generally begins with the practical problems of specific groups. It tends to focus on the specific and the local. PAR has also focused on helping people gain expertise in the conduct of research (Cleaver, 1999), building, informing, and validating social science theory (Reason and Bradbury, 2001), and inducing changes in public opinion and perhaps also in public policy (Lewis, 2001).

The history of PAR has been local, based in neighborhoods and regions, and the method has been applied most often by anthropologists and sociologists. "Action researchers seek change across individual, group, and national behaviors and develop solutions in collaboration with consumers that are also sensitive to their needs and desires" (Ozanne and Saatcioglu, 2015, p. 424). Although some PAR studies have been attuned to the uses of media, for example in influencing public opinion (Lopez, 2015) or designing and delivering information systems (Bilandzic and Venable, 2011) or communication systems (Hearn and Foth, 2005), most tend not to be centered on systems or media, although often their core topics relate to issues of representation. However, utilizing representational practices for emancipatory purposes is often a key elements of extant action research, community action research, and PAR methods (Ozanne and Anderson, 2011).

Transformative, community action, action, and PAR researchers all follow interpretive and social constructionist assumptions about the nature of reality. Their ontology views the social world as contextual, historically constructed, and driven by specific cultural and historic interests and trajectories that often define reality along political, economic, ethnic, racial, gender, age, and disability related lenses (Mertens, 2007; Murray and Ozanne, 1991).

The transformative netnography approach is novel and distinct from prior approaches such as PAR, critical and humanist netnography, and social media action research in several important ways. First, it is new in the extent to which it emphasizes how *people's definition of reality is reflected and influenced by media, particular social media, and their representations of individuals, groups, situations, organizations, facts, and issues*. Second, transformative netnography is novel in that it takes as an ontological foundation the assumption that *social media are often a form of self-representation by the dispossessed themselves* that can and should be leveraged throughout the conduct of the research. Third, it is novel in its epistemological aim of specifically utilizing social media to *bring together self-representations by multiple people in the category of dispossession being studied (with their permission and involvement)* for the purposes of social and individual betterment through the provision of more control over representation.
In terms of epistemology, transformative, community action, action, and PAR researchers situate knowledge in a complex sociocultural context wherein the interactive links between researchers and participants are crucial for knowledge development. Prior developments in netnography have emphasized the role of social media in the creation and representation of knowledge. In particular, Kozinets (2015) situates netnographic research practices as involving discourses of representation simultaneously for the researcher, the researched, and the research topic. Transformative netnography explicitly extends these principles to the representation of the deprivileged or dispossessed.

Methodologically, PAR, and other action researchers tend to emphasize qualitative and interpretive methods, but mixed methods that legitimate findings to relevant figures in power have been increasingly advocated (Crockett et al., 2013; Ozanne and Anderson, 2010; Mertens, 2007). This aspect also fits well with netnography, which is primarily a qualitative research technique, but some researchers have developed quantitative aspects using other methods such as content analysis, social network analysis, and natural language processing quantification (Kozinets and Gambetti, 2021).

The axiology of action researchers promotes social issues and causes such as human and ecological rights and social justice, focuses on consciousness-raising, reflection, challenging

embedded discourses of power, and envisioning new social forms that challenge power structures. Representational concerns are important or even central to these issues, in which they often converge. For example, Martello (2008) examines scientific and political representations of Arctic indigenous people as expert, exotic, and at risk. In public and political conversation on traditional media and social media, these representations shape climate policy and science.

Beyond its interventionist aims, action forms of research are used to develop theories that may usefully transfer to other contexts. Although communicated in scholarly publications, researchers who work in these areas are also often concerned with the ownership and culturally appropriate modes of representing and sharing the knowledge that has been collaboratively constructed between researchers and participants. Communication modalities have also been a frequent topic of discourse in these research endeavors. For instance, scholars have communicated findings from PAR and action research investigations using performed scripts (Lee et al., 1999) and songs (Lewis, 2001), among many other modalities.

Hall (1981) suggests that education, research, and action are inextricably intertwined in action research. As it begins 1), this form of research engages community members in the definition and initial analysis of their social issues. In his development of a social media focused form of critical research, Bertilsson (2014) recommends that research be conducted with "a critical but micro-interactionist approach," one that can capture and uncover" the existence of open and hidden "conflicts, tensions and hierarchical relationships" (p. 139). As the research process unfolds 2), it results in the questioning of old assumptions and the careful construction and representation of novel understandings. These the very essence of both the pedagogical and the consciousness-raising functions of critical theory and PAR. Finally, 3), as the research and the implications of the action research findings are understood, they inform the decisions and actions that affected persons and/or identifiable community members can take to better their situations. These three stages are common to action, PAR, and community action research and we purposefully incorporate them into the development of transformative netnography and extend them explicitly to use social media affordances and contexts.

## 3. Developing transformative netnography from netnography

Netnography is an evolving approach for gaining cultural understanding involving the systematic, immersive, and multimodal use of digital traces, elicitations, and observations. As a recent edited volume illustrating the varieties of approaches to netnography indicates, the notion of dynamic adaptation is inherent in contemporary netnography (Kozinets and Gambetti, 2021). The method has been combined and extended with auto-ethnography (Howard, 2021), more-than-human approaches (Lugosi and Quinton, 2018), social network analysis (Fenton et al., 2023), and artificial intelligence methods (Shaar et al., 2023) to name but a few recent syncretic innovations.

Netnography is based on the contextually determined combination of three data collection stages or movements: investigation, immersion, and interaction (Kozinets, 2020). Investigative data is collected unobtrusively from existing digital archives or online data traces across various social media or other sites of digital interactions and socialities. Interactive data is elicited from research participants through interviews, online interaction, research webpages, digital diary, mobile ethnography, or other methods. Immersive data is reflexively created by the researchers as they keep an immersion journal of their engaged experience with the phenomenon under investigation. Data that is created, co-created, and/or collected during the process of performing a netnographic research project is subsequently analyzed using qualitative research methods such as thematic, narrative, or discourse analysis, grounded theory, or hermeneutic interpretation. The process of conducting a netnography is systematic, disciplined, immersive, and multimodal.

Early conceptions of netnography as a method for studying particular online communities have been updated in recent years as notions conceptualizing online discourse as forms of community have been increasingly interrogated and overturned across the social sciences (pp. 109-113). However, recognition that netnographic research could utilize the connective and communicative affordances of social media to raise awareness and build organizational links among like-minded individuals was methodologically nascent from its very beginnings. One of the earliest published netnographies engaged the members of several activist newsgroups, involving them in research representing online activists and inviting their feedback through member checks (Kozinets and Handelman, 1998).

However, transformative netnography is a unique extension that develops these nascent tendencies in netnography explicitly and intentionally in relation to social media affordances providing dispossessed persons with voice, inclusion, consciousness raising and catalysis (Kozinets, Ferreira, and Chimenti 2021). We define

transformative netnography as a type of netnography that emphasizes social media affordances and their representational power to effectively channel that power towards action research aims of societal and ecological betterment. Transformative netnography is, thus, a blend of netnography and PAR approaches that extends action research forms by adapting each element to a new digital social reality.

In its first stage, the transformative netnographers will utilize social media and other digital technology to identify and connect with persons, groups, and/or publics who are affected by some important social or ecological issue (these groups may include identifiable community members). Next, the netnographers will (often using social media) engage these persons, groups, and/or publics in the definition and initial analysis of the issue. This research focusing and iterative data collection stage will likely incorporate the initiation, investigation, immersion, and interaction movements of netnography.

Second, transformative netnographers will utilize relevant voice, inclusion, consciousness raising and catalysis social media affordances (Kozinets et al., 2021). to collaboratively work with research participants by combining their perspectives on the issues which affect them with academic research. Together, they will question extant assumptions. This work will result in the re-presentation, or representation, of novel forms of understanding of a social situation.

In the third stage, transformative netnographers will recruit social media and other digital communication affordances and platforms and co-create or co-develop content to present the research findings to a broader segment of the affected persons, groups, and/or publics, and additional feedback and input gained. As with the other action research methods, the intention is that, as the implications of the action research findings are understood by affected groups, they will inform their decisions and actions and help them organize to better their situation.

In the fourth stage, transformative netnographers collaboratively work with participants to continue to refine and develop content with the affected persons, groups, and/or publics with the goal of developing representations to be publics shared on social media and perhaps also through traditional media. These advocacy related representations will be targeted and focused to empower and enable specific change, and the technical affordances of the platforms may be used to monitor and manage the advocacy messages and their reception.

### 3.2. Differentiating transformative netnography from related approaches

Traditional netnography does not necessarily take an interventionist stance towards the groups, topics, and people it studies online. In contrast, transformative netnography encourages a focus on change and the active engagement of the researcher in the promotion of change. This change in roles positions the researcher at the heart of a social transformation agenda. Transformative netnography thereby fosters a more intimate relationship between netnographers and members of the group or groups they study, thereby opening opportunities for collective knowledge production, shared decision-making, and coordinated action.

The primary goal of transformative netnography is to develop social media research with an emancipatory and purpose-driven focus that emphasizes representation and collaboratively engaged participants in content creation that utilizes social media and other digital media affordances sharing this emphasis. As with the ethos of PAR, those who embrace a transformative netnographic approach will seek to empower stakeholders, particularly those in marginalized or underrepresented groups, to critically reflect on their situations, challenge the status quo, and contribute to positive change. However, in transformative netnography the researcher and online research participants embark on a collaborative journey toward social transformation using online connection, content creation and distribution using digital platforms as a core capability and tactic. Transformative netnography's integrative approach uses social media content creation and distribution to elevate an understanding of social media research participants from mere objects of study to partners in a process of technologically enabled social innovation and transformation.

Transformative netnography builds on several related developments. It has a direct lineage to the "humanist netnography" proposed by Kozinets (2015, pp. 263-277). However, it is distinct from this predecessor because it is much more detailed and explicit, adding numerous important methodological particulars, conceptual development, and research procedures. Like "social media action research" (Wang, 2015), it is interventionist; it seeks to explore "the research opportunities opened up by the convergence of social action and social media" (pp. 4-5). But, social media action research is not focused on representation and advocacy affordances, while transformation netnography is. Like "critical netnography" (Bertilsson, 2014), transformative netnography focuses on using netnographic research to uncover and conceptualize "various forms of domination, asymmetry, hierarchy, conflicts, discourses and status positions" (p. 135). However,

transformative netnography incorporates and massively extends this focus into development and advocacy and is thus a much broader and more interventionist approach.

## 4. Transformative netnography: A detailed example

To illustrate and explain transformative netnography, we use a research project in which we investigate the experiences of people with congenital and acquired facial differences (a disfigurement characterized by an unusual, scarred, or asymmetric face resulting from birth defects, genetic disorders, rare diseases, intentional mutilation, assault, or accidental injury). How do people with facial differences navigate society and develop a positive sense of unique self-worth? In pursuing this question using transformative netnography, we seek to understand how facially different people, as a marginalized community, use social media to create personal and collective action that aims to raise awareness about their experiences in public forums, encourage societal recognition of those who are shunned due to societal normativity expectations, and advocate for face equality.

### 4.1. Investigative movement, social media outreach and online depth-interviews / interaction

Our transformative netnography combines two key elements of netnography. The first is investigative data collection, consisting of focused observations and downloads of social media data from participants who agreed to take part in our study and also allowed us to use their posts.

In the first stage, we used a social media platform to find and communicate about our research with socially different participants who were affected by their online and other representations. Before their Zoom interviews, we analyzed each participant's publicly accessible posts related to facial differences as well as their personal profiles on Instagram, Facebook, YouTube, Tiktok, personal blogs, and any online media coverage in which they had appeared. Obviously, platform affordances play a major role in netnography and transformative netnography is no exception. Although the research affordance difference between, say, Instagram and YouTube are too complex and out of scope to delve into in this one paper, they are highly relevant and should be explored by researchers conducting any type of netnography (Kozinets 2020, pp. 69-101).

We utilized the visual, tagged (#facequality, in this case), and often empathy-inducing, affordances of Instagram to discover and then reach out to people and ask them if they were willing to participate in the research by consenting to an in-depth interview. We sent direct messages to more than seventy Instagram users across five continents. Interviews were conducted via Zoom. No one was excluded on the basis of geographic location or demographic factors. The only disqualifying factor was age. We only recruited adults aged 18 and older. We preferred to recruit English speakers. For non-English speakers, we used a qualified translator. We also recruited four people from India and four from Turkey through non-governmental organizations (NGOs) focused on people with facial differences. Nineteen participants gave written or oral consent to participate the study. Figure 1 shows five of the selected participants. Because the normalization of presentations of people with facial differences is the objective of this research, we decided that it was important to present these people visually in our research, including in this paper.

It is important to recognize that these representations are not presented to exploit these people. They are participants in the research who wanted us to use their images and names in order to further awareness of them and their community. The act of representation in this paper is an act of empowerment on their part. If the appearance of different faces makes the reader uncomfortable, that may be a good outcome, because becoming aware of our own discomfort with representations of bodily and facial different people is an important initial step to changing our reactions. This awareness is a key goal of the research. In fact, engaging with our discomfort may be necessary for most forms of social change.

**Figure 1. Selected participants**

The second netnographic movement we employed was interaction. Our interview protocols were modified based on information obtained from this investigative data. For example, we knew that one of Duane's (see Figure 1) YouTube videos had over 1.5 million views and that he is a corporate branding business owner and podcaster, despite severe cranial-facial differences including having no ears or ways to hear without Cochlear implants and

hearing aids. This knowledge led us to elicit autobiographical information in the interview about how he navigated Treacher Collins Syndrome.

We were also able to obtain a "behind-the-scenes" perspective by asking participants to film aspects of their daily lives in a variation on the netnographic technique of mobile ethnography. As suggested by Patton (2015), prior to interacting the participants, we prepared an interview protocol. We sought the input of two volunteers with facial differences to review the interview protocol and ensure that the language we used when interacting with participants was devoid of offensive terms and otherwise appropriate. As a result of the feedback we received, we made changes to our interview guide to ensure that we always used the preferred term "facial difference" instead of "facial deformity or disfigurement" for more positive and inclusive representation in our research. The terminological shift is instructive and also salient to our interventionist efforts, which is why we share it here.

Combining investigative and interactive data allowed us to connect what we were seeing in social media with what was going on at other levels we could not observe online, verify, or modify through depth interviews.

As well, because netnography values researcher reflexivity, an immersion process was central. The second and third researchers reflected on our own social, intellectual, emotional, historical, and other tangential situations, relating these insights to our research following each interview. As an example of our efforts to establish trust with participants and demonstrate our commitment to reflecting on their experiences, our second author shared a personal story about her husband's battle with Bell's Palsy – a condition that results in paralysis of one side of the face.

## 4.2. Ethical procedures and inclusion challenges

Physical ability and appearance are socially sensitive research topics that have the potential to affect participants by being both intimate and incriminating (Renzetti and Raymond, 1993). The nature and complexity of transformative netnography required sensitivity to ethics and the concerns of confidentiality. We needed to design and implement data collection protocols that met the highest standards of ethical research and provided participants with enduring protection. If this work was going to serve as the basis for ongoing efforts to move public opinion and, we hoped, affect regulatory structures, its research ethics had to be as unassailable as we could make them. We closely followed the extensive ethical guidelines established in Kozinets (2020).

After obtaining IRB approval from two universities, we took the initial step of recruiting participants by reaching out to NGOs for assistance. We sent requests for help via email to more than twenty-five NGOs across ten different countries. Ultimately, we received responses from fifteen organizations, but only two of them agreed to participate in the project.

Although each of the three researchers has conducted multiple qualitative research projects, using in-depth interviews, netnography and videography on vulnerable and sensitive topics such as marginalization, discrimination, and stigmatization, one of the major ethical concerns expressed by the organizations was the absence of a team member with a facial difference who could better identify with the vulnerability of the participants and their concerns for privacy and ethical treatment. Fortunately, netnography contains very detailed and explicit guidelines for the ethical conduct of a wide range of different types of projects, and these guidelines served us very well in our second step of recruiting participants over Instagram. However, we note the inclusion of a member of the dispossessed group as a full research team member as an ideal situation.

We considered it vitally important for the project to interpret all information, including interview data and social media posts using a lens attempting to understand and empathize with participants' languages, cultures, genders and their medical conditions and histories. For non-English speaking participants from India, Turkey, and Brazil we used native speakers or professional interviewers whom we trained for the project to better understand the participants in their own unique cultural, social, and medical context.

## 4.3. Transformative netnography interviews and relevant early discoveries

Each initial interview lasted 60-70 minutes and was conducted on the two-way Zoom platform. Our main focus was social change and how to best enact it using a representational focus and relevant social media platform affordances. We wanted to conduct this research to advocate for the facially different community, affect public opinion through proper representations, and impel policy change. We were also conscious of the fact that our research might be covered in the news in the various countries we were investigating. An advocacy group like the facially different community often involves working with journalists to support their efforts and get the word out. In this case, our transformative netnography's PAR perspective meant that our

research might be used to affect public opinion and gain public support.

We had to deal with hidden information and a quickly changing social media landscape where digital traces that appeared one week were often gone the next. The project required us to connect the dots among a prodigious amount and diverse kinds of online traces produced by and about the research participants. Nevertheless, after several weeks of concentrated effort, the patterns became clearer and clearer. Eventually, through a type of investigative data collection research familiar to those who practice ethnography, videography, and netnography, we discovered that the facial equality movement on social media often involves community events. These events have names such as "International Face Equality Week" or then "I am Not Your Villain" movement. Posts on Instagram contained advocacy, disappointment, frustration, reproach, and calls-for-action and were labelled with hashtags such as #FaceEquality, #FacialDifference, #VisibleDifference, #RepresentationMatters, #PositiveRepresentation, #AllFacesAreBeautiful, #WeWillNotHide, or #TreatMeRight.

### 4.4. Presenting insights through a co-created videography

Every participant granted us permission to collect supplementary material from their social media accounts. Hence, after a thorough examination of each participant's social media posts, which often included video. Combining these traces with our recordings of interactive netnography interview elicitations, we accumulated sufficient data to produce a short film.

The notion of a collaborative research partnership stands as the ideal in participatory action forms of research. However, in practice, the partnership often requires negotiation of the roles and amounts of decision-making power that will guide the research, its implementation and the particulars of its communication style, tone, and content. Since our project is about facial differences, disabilities, and disfigurement, we deemed it important to show some faces, but only with multiple permissions by participants. After the interviews, which used a multimedia release form, we asked each participant for his/her consent to release their photo, interview recordings (audio and/or video). We also asked for consent for the particular ways in which they would or would not allow the researchers to use their information (audio, video, and/or photo used in a conference, academic journal, online, and/or broadcast setting, etc.).

Furthermore, we followed-up with most of our participants, and asked them to reflect on whether they had ever attempted to conceal their facial differences and how they felt about wearing face masks in the COVID-19 pandemic. We had them film themselves reflecting on these requests and we used some of the resulting videos in the short film we produced. We subsequentially showed our resulting rough-cut film to participants and sought their reactions, comments, feedback, and amendments. Their reactions were universally positive (see Figure 2).

During our initial interviews we sought to delve deeper into their reflections regarding what Goffman (1963) referred to as the use of masks to hide "spoiled identities." We asked them to video record themselves responding to these questions as well. We also asked them, if possible, to document their daily activities through video journals, and provide us with childhood photographs, as well as any significant milestone photographs or videos they would be willing to share with us, such as their wedding pictures or videos, photographs with their loved ones and children, travel, or graduation moments, and so forth.

In the resulting co-created film, the research participants explain who they are, their experiences with various crises in their lives, and how they cope with inappropriate reactions. Upon completing the collaborative film, we uploaded it to Vimeo and secured it with a password. We then shared the link with all our co-creators to review, provide feedback, and approve the final product. Figure 2 illustrates their feedback on the short film (Vimeo link: https://vimeo.com/813448542, password: ACR2023LR). Additionally, two of our participants expressed their interest in personally participating in the academic conference where the short film will be shown and answering audience questions.

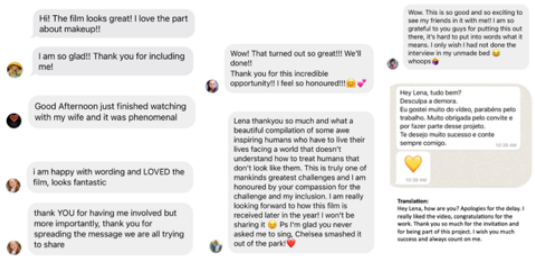


**Figure 2. Participants' reactions to the co-created film**

### 4.6. Theoretical implications

In sum, our findings challenge Goffman's (1963) theory that individuals use masks to conceal a flawed sense of self and Belk's (1988) idea of the extended self as a form of compensation through

possessions. In contrast to Goffman's perspective, our co-creators have largely abandoned cosmetic surgeries, laser treatments, heavy makeup, and other methods of concealing their differences. Instead, they celebrate their unique features, connect with others who share their facial differences, and reclaim their stigmatized identities in a world that is often rude and unsympathetic.

Many participants, including but not limited to Megan, Chelsey, and Brittany (Figure 3) began posting their selfies and portrait photography on social media platforms to show their pride in their faces. They call themselves "advocates" or "activists" on their social media profiles. They use TikTok, Instagram, or YouTube channels to offer support to those going through similar experiences and to educate the public about facial differences (Figure 4). Our videography and the transformative netnography that underlays it added to these interventionist efforts. Although Belk's (1988) initial formulation of the use of possessions to extend sense of self was not supported, his subsequent (Belk 2013) update of extended self in a digital age was well-supported.

**Figure 3. Selected social media bio(s) of participants**

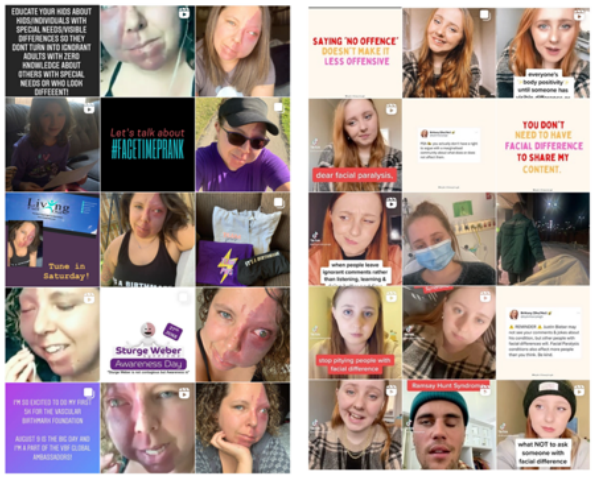


**Figure 4. Selected educational social media content of participants**

For various reasons, prior social media research may have over-emphasized the communal feel and ostensibly harmonious social orderings of social media groups, as detailed by Kozinets (2020, pp. 107-9). This likely occurs at the expense of research that would have focused on oppressive power relations in social media, and on the "conflict, tensions, the reproduction of hierarchical order, and status positions" that are also present in these social arrangements (Bertilsson, 2014, p. 139). However, transformative netnography seeks to expose these hidden conflicts and relations of power, and then to help social actors transform them.

The realization that they were not alone and that others with similar facial differences are having similar experiences was a pivotal moment for most of our participants. For example, Duane (see Figure 1), who was once shy and had difficulty with speech, had even started a video blog on YouTube. In some cases, we helped participants to similarly recognize the power of social media to connect with others who had similar conditions in order to help others as well as themselves.

Similar to Duane, several participants proudly reclaimed their stigmatized identities and even went on to become micro-celebrities and models. For example, Mariana (seen in Figure 1) became a fashion model in Brazil after gaining a substantial following on social media platforms like Instagram (141K) and TikTok (389.8K). Similarly, Reagan (also seen in Figure 1) began collaborating with brands as a fashion and beauty influencer, with a significant following on TikTok (366.5K).

### 4.7. Ongoing advocacy action

Our research attempted to uncover what was carefully hidden by the fashion, beauty and entertainment industry's obsession with ableism and ideal beauty. We attempted, and are still attempting, to raise popular awareness about the need for regulation, addressing lookism bias among companies and technology platforms. For example, many facial recognition systems do not work on people with facial differences. Many social media platform filters have similar problems identifying facial characteristics. This presents facially different people with a myriad of problems. For example, some airline gates or border security systems cannot recognize them. Such problems also often exclude them from using Snapchat filters that others take for granted. A core reason for these challenges is because technologies are not developed, and software functions are not trained, using datasets that include people with facial differences. Similar problems have been identified in recognizing faces with dark skin.

These sections show how research, education, and action, extended by the representational and empowerment affordances of social media platforms, served as the basis for our transformative netnography with the facially different community.

## 5. Implications: The outlook for transformative netnography

Representations are realities. The study of social media discourses and images and the influencers and creators behind them can help us to better understand how depicted versions of reality are often stratified along political, economic, ethnic, racial gender, age, and ability/disability related lines. Armed with this understanding, researchers can work collaboratively with those who are affected by these realities and seek out effective communication and representational strategies to counteract them. Without a doubt, contemporary information, and communication technology transforms relations of power and civic life. As this investigation has shown, its power to represent and connect is equally formidable and full of potential.

The transformative netnographic research example in this paper demonstrates how the connective affordances of social media can be used to confront representational issues among a group that has insufficient visibility and which, as its history shows, has the unfortunate potential to be misrepresented and misunderstood. By combining the institutional privilege and academic soapbox of our positions as researchers, and by utilizing our capacities as connectors, content creators, and knowledge distributors alongside our research participants and co-creators, we have begun to both organize and connect divergent voices in the facial difference community online and to aggregate and amplify those voices through several social media channels.

This research describes and illustrates how transformative netnography extends three research traditions—netnography, collaborative research, and PAR—into novel terrain by leveraging relevant social media platform affordances of empowerment and representational advocacy.

Collaborative research emerged out of the crisis of representation that began in anthropology in the 1960s. It has developed into a powerful tool for understanding self-representation or etiology, together with professional theorizing (Belk, 2017; Bennett and Brunner, 2022). And PAR has proven useful whenever the needs for advocacy and community needs overpower the needs for distance and objectivity (Toombs et al., 2017; Vaughn and Jacquez, 2020). We feel strongly that this is the case in the facial difference community that served as the core illustration of transformative netnography in this paper. Transformative netnographies such as this one benefit from the synergies achieved by applying this rigorous new methodological approach for outreach, connection, content co-creation, and distribution of a new academic and public-facing representations of dispossessed groups and peoples.

Describing the humanist netnography which is a forebear of this paper's transformative netnography, Kozinets (2015, pp. 265-275) explicitly advocated for future approaches that might make academic knowledge more accessible and available. The study related in this paper finally provides a systematic development and example of these long-nascent idea(l)s. This paper's videographic representation was co-created through the collaborative efforts of the second and third authors and the facially different research participants. The fact that many of these participants were skilled content creators with significant followings on social media provided particularly strong abilities for this transformative netnography to develop. Although these factors suggest that our sampling may not have been representative of the general group of facially different people (likely, it was not in terms of social media ability and presence), they were highly advantageous from a transformative netnography research perspective.

Transformative netnography may one day become an important tool in the toolbox of multimodal, multidisciplinary, and multimethod researchers in the systems and social sciences. It may be useful for those seeking to leverage the affordances and near-ubiquity of information and communication technology to build alliances between researchers and dispossessed community members and to use these technologies to address issues relating to their realities and representations. Once these alliances are forged, the resulting researcher-research participant collaborations can pursue a wide variety of projects that not only lead to the development of knowledge and useful theory but also help contribute to the furtherance of social justice, peace, human rights, ecological, and other urgent needed and worthwhile goals.

## 6. References


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