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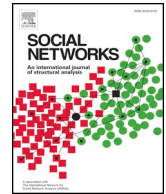
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Whose results are these anyway? Reciprocity and the ethics of “giving back” after social network research

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ABSTRACT

Bridging the social networks, field methods and ethics literatures, I make the case that the process of reporting research findings is an ethical issue, and recommend elevating it in the research design. I draw on a reflective account of three research experiences with settings in, respectively, online health communities, economic organizations, and the mainstream media. I proceed in steps, discussing release of personal network results to individual participants, of whole network results to the researched community, and finally of general results to wider audiences, under a unifying idea that a reciprocity obligation underlies the reporting process. I claim that communication should follow an iterative rather than a linear approach to reach all relevant stakeholders, thereby mitigating the vulnerabilities that arise from research.

Introduction: communicating research results as an ethical problem

What ethical issues may arise in the process of communicating the results of a social network study? I faced this question when I was researching the online and face-to-face social networks of persons living with anorexia nervosa and other eating disorders. The study looked at the linkages between their health condition and their social environment, showing that relationships offer support complementary to treatment, and that web-based groups could be particularly helpful (Tubaro and Mounier, 2014). One day I received an invitation to speak at a popular TV show, whose success relied on a sensationalist approach – juxtaposing people at opposite ends of the body weight spectrum and chastising their unhealthy eating habits. The producers had heard about “pro-ana” websites and expected me to warn viewers about the potential risks of online networking and social influence allegedly triggering disordered eating behaviours. Accepting would certainly earn wide visibility for my study, but would also indirectly endorse the show’s problematic concept – while I knew from my research that judgment and stigma could be far more harmful for sufferers than any contact with (and even influence from) peers. After some hesitation, I eventually declined the invitation, explaining my reasons in a long letter to the show’s producers.¹

This is just an instance of a more general, but largely overlooked, research ethics problem: where and in what contexts should we, as

researchers, draw on our research results to provide feedback to members of the social group we investigated, and more generally to the public? Standard ethical guidelines provide relatively scarce guidance on such issues. Surely, there are general principles that recommend dissemination (see for example Iphofen, 2011, chapter 12), and several research institutions, publishers, and learned societies have created organizations and adopted codes of conduct (such as COPE, Committee on Publication Ethics) that cover matters such as authorship, originality, acknowledgement of sources, declaration of conflicting interests. Nevertheless, most of these initiatives concern *scientific* publication, while communication with stakeholders outside the world of research is seldom discussed. Ethical approval procedures usually do require researchers to take into account these stakeholders, but they are undertaken before a study starts and focus on the early stages: key concerns are anonymization, informed consent, and any distress that might occur during data collection, but it is more difficult to anticipate reporting and communication issues that might arise long afterward. Neither is it practical to go back to ethics review boards later for one-off advice: their procedures are too lengthy for media requests that typically come at very short notice, or for unanticipated stakeholders’ reactions that require rapid responses. Further, board members may have limited knowledge of the specific setting and circumstances. In the end, the researcher is to make a decision alone, often in no time.

Reporting social network research outputs is especially tricky insofar as, in recent times, ubiquitous online social networking services

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¹ I made public an anonymized version of the letter (now only available in the Web Archive): <https://web.archive.org/web/20131217023109/http://www.anamia.fr/reponse-a-un-journaliste-tele-ayant-sollicite-une-interview-sur-les-troubles-alimentaires-et-les-sites-pro-ana/>.

<https://doi.org/10.1016/j.socnet.2019.10.003>

and the blurring of boundaries between “public” and “private” spheres (Tubaro et al., 2014b) make people’s relationships widely visible. In the wake of internet-mediated communication at both local and global levels, people have progressively learned to recognize their connectedness and to attach values and status to it (Christakis and Fowler, 2011; Rainie and Wellman, 2012). The potential benefits of an extended range of social contacts are now widely understood, and are among the motivations for using social platforms and applications, so much so that people sometimes overestimate the extent and reach of their online social capital (Dunbar, 2016). Thus, any research results that make people aware of the relative richness (or poverty) of their social networks are likely to have an effect on their personal life satisfaction and well-being (D’Angelo and Ryan, 2019).

Another reason why in present times, reporting research outcomes is a particularly sensitive part of social network research is that stakeholders who hold setting-specific knowledge may well re-identify study participants and misuse results. In their influential 2005 contribution to the *Social Networks* special issue on ethical dilemmas, Stephen P. Borgatti and José Luis Molina made precisely this point, in the case of organizational network research that managers may use to reward or penalize employees. Today, increased visibility of relationships through digital technologies extends this challenge beyond workplaces. Using the above example, websites on eating disorders might expose to unwanted viewers (including potential future employers) not only their authors, but also their readers.

A related challenge stems from the common confusion between social networks as our research community construes them – as structures of relationships, interactions or interdependencies between individuals and groups – and social networks popularly interpreted as digital tools for social networking (or social media). This is a common source of misunderstandings, especially for those of us who study non-technology-mediated networks, and calls for very careful word choice at every step. Charles Kadushin’s point that “the social network field may have become a victim of its own successes” (2005, p. 139) is still, and perhaps increasingly, true: we benefit from improved visibility but struggle more to get our message through.

This paper aims to advance social network scholars’ endeavour to comprehend the conditions for responsible return of research results. It draws on a reflective account of three cases from my social network research activity. All three concern communication to laypersons: thus, scientific presentations and peer-reviewed publications fall outside the scope of my analysis. I share my field experiences as a step towards a collective effort to co-construct an appropriate ethical framework, in the belief that researchers can (and should) take an active role.

To achieve this, I set out to bridge different literatures, in addition to research ethics strictly interpreted. Particularly in field methods, there is a large and mature tradition of reflecting on, and developing best practices for, returning results to the community where the researcher originally collected the data, and on which those results might exert an effect. At the crossroads of these different lines of thought, I frame return of results as a reciprocity obligation – a way of “giving back” to society in exchange of the resources (be they informational, financial or other) that it made available to research. Accordingly, return of results addresses not only informants in the field, but also a wider range of stakeholders, including funders and promoters of research projects, partners, policymakers and the general public. Instead of a linear progression in which reporting is just the final stage of research after data collection and analysis, the process I envision is a feedback loop between stakeholders and researchers that forms an integral part of research design since inception.

I argue that social network research is an ideal setting to develop these ideas. While other domains, especially biomedical research, notoriously shaped some of the key principles of ethics for all disciplines, the social sciences may benefit from fresh perspectives that take into account both their substantive and methodological specificities. Social

network research is particularly well suited to serve as a terrain of experimentation as, unlike clinical trials, its focus is not on individuals taken independently of one another but on interpersonal relationships that link individuals and groups. It thus introduces fundamental dependencies across people’s behaviours and is capable of providing unique insights into society seen as a cohesive whole, rather than as a sum of separate entities.

In addition, social network research helps answer a fundamental question that the literature often leaves open: what is the “community” to which researchers should return results. If it is not limited to the narrow circle of study participants, where should one draw the boundaries? Network studies suggest that a community may be understood as the set of social relationships that are meaningful to a focal individual or group (Wellman et al., 1988), and prove that mapping such relationships very precisely and assessing how actors make sense of them, can be very helpful. For example in my above-mentioned study of the networks of persons with eating disorders, doctors and other health professionals appeared as alters together with friends and family members, and were therefore targets of my communication as part of participants’ “personal communities” (Chua et al., 2011).

Bridging literatures

While frequently ignored in established research ethics guidelines, presentation of results has begun to receive a greater deal of attention in recent times, notably in the literature on clinical trials. Returning results to patient participants becomes a greater priority as part of the ongoing shift in healthcare toward participant engagement and “patient-centred care” (see e.g. World Health Organization, 2007). At the very least, this means communicating aggregate research results to general audiences, in summary form and using language that is understandable and usable by non-specialists. Some regulators have already adopted policies and processes to this end: both the US Food and Drug Administration, and the EU Clinical Trials regulation, require publication of summaries of results for laypersons.

There is also an emergent, though less consensual need to give clinical study participants access to their *individual* research results, that is, the outcomes of any tests (such as blood tests, scans etc.) performed on them individually. The hope to get such results is a primary motivation for many patients to participate in a clinical study at all, especially in a context in which digital self-tracking devices and the services of commercial companies such as 23andMe have accustomed people to easily accessing, handling and visualizing their own health data (Wong et al., 2018). Ethically, return of individual results is a way to ensure participants receive the greatest possible benefit from their contribution to the study. Research bodies such as MRCT in the United States (2017) are issuing guidelines to support release of individual outcomes, although there are disagreements over the optimal timing, the extent to which results can place a burden on patients, and the need to withhold findings in some circumstances. One contested issue is report to the family, including after the death of the research participant, notably in the case of genomic research (Wolf et al., 2015).

Calls for open science and open access reinforce the expectation of accessibility of research results to even wider communities – not limited to research participants. Recent debates on open access rely upon the moral framing that requires the outputs of publicly funded research to be freely available to those who paid for it – the taxpayers. This is an argument about obligations of reciprocity (Parker, 2013), whereby researchers receive (financial) resources from the community, and give knowledge to it in exchange. In this perspective, dissemination of knowledge is a key responsibility of researchers and grounds their social legitimacy. The public is implicitly supposed to participate in the process, although this current of thought focuses mostly on scientific publications as such (with issues such as replicability), rather than on outreach to lay audiences (Cahill and Torre, 2007).

These approaches have the merit of replacing presentation of results at the centre-stage of research ethics, shifting from a focus on data collection and data management to a more comprehensive view that covers all phases of a scientific study. Yet report of research results is not an unprecedented outcome of patient-centred care, as the idea that researchers have a duty to engage in conversations with wider audiences predates the current movement toward open science. Traditional approaches to the social sciences, not always framed as ethics, have long taken strong normative stances in this matter. [Pierre Bourdieu \(2015\[1980\]\)](#) believes researchers have a duty to expose the power relationships that shape society, while [Michael Burawoy's "public sociology" \(2004, 2005\)](#) advocates dialogue between researchers and diverse audiences beyond academia. However, these arguments are often cast in too general terms to help answer specific, practical questions: what is the relevant community? What results can be made available? What is the appropriate format?

More to the point, ethnography and field methods have long reflected on "giving results back" to the community where researchers originally collected the data. Field study design encompasses not only entry into, but also exit from, the target community, so that sharing of results is naturally constitutive of it. While firmly grounded in methodology, this literature raises issues that have a strong bearing on ethics. For example, what is the place (if any) of the researcher's autobiographical experience and emotions in the field ([Ellis, 1995](#))? Do participants have a say on narration of results concerning them? What information can intermediaries, community leaders, and any other non-participant stakeholders expect to receive? How should the researcher address any criticism or disagreement? Especially within participatory and advocacy research ([MacKenzie et al., 2015](#)), it is increasingly recognized that researchers have an ethical obligation to share results with the community under study, in order for it to reap a maximum of benefits from participation. Indeed the potential effects of research on stakeholders may vary from shedding light on a problem they are facing, to giving them more voice in the policy process, or to facilitating work towards a solution ([Reyes-García and Sunderlin, 2011](#)).

[Schurmans et al. \(2014\)](#) broaden the concept of reporting results, to address not only informants in the field but all who may be concerned, including funders and promoters of research, partners, and fellow researchers. One may also add policymakers, for their role in steering both research and social action, as well as associations and other civil society bodies, according to the teachings of public sociology ([Burawoy, 2005](#); [Jeffries, 2011](#)). This approach requires re-framing report of findings not as the last stage of a linear process that starts with data collection and terminates with scientific publication, but as a cyclical one with multiple feedback loops. Continuing dialogue with a range of relevant audiences enables researchers to validate their work, builds trust with participants and other stakeholders, and may lead to maintaining relationships over time, possibly through multiple projects ([Chavis et al., 1983](#); [MacKenzie et al., 2015](#)). Some social science traditions like action research already operate in such a cyclical mode. In this long-run perspective, social network research may benefit from its capacity to identify the relevant community of stakeholders, as discussed above, to establish what results to return to each of its different components at what time.

These approaches draw on different perspectives and types of disciplinary expertise, but resonate with, and complement, each other. Both the field methods and open science currents build on a principle of reciprocity. Bringing them together enlarges the range of stakeholders to consider: ideally, all those relationships that shape the social environment in which the research is undertaken, and on which it may have an impact. At the crossroads of ethical, scientific and political issues, such a comprehensive view accounts for the multiple commitments that researchers have to diverse actors and the difficulties that arise in the effort of reconciling diverging agendas ([Tubaro, 2017](#)).

Social network research and case-based reasoning

So far, the social networks literature has not addressed these issues explicitly. The 2005 *Social Networks* special issue on ethical dilemmas touches on them only indirectly and partially, in terms for example of potential misuses of results and of commitments to problematic sponsors such as the military. Yet social network research exemplifies at best some of the ethical issues that the above discussed literatures highlight. For example, there are specific concerns regarding report of individual results to participants, insofar as revealing the set of ties surrounding a person may jeopardize confidentiality and more generally trigger consequences. Social network research also raises specific problems as a consequence of the power and growing popularity of visualizations, which constitute an effective tool to communicate results but may be deceptive or distressing under some conditions. Further, the common confusion between social networks and online social media adds to the difficulty of communicating results clearly and unambiguously.

Conversely, social network research provides excellent material to work toward, and test the efficacy of, possible solutions that draw on the integrated approach proposed above. Return of individual (ego) networks is already practiced and, with appropriate ethical safeguards, may pioneer extensions of this practice to the social sciences at large. Similarly, work on visualizations may improve researchers' capacity to communicate to audiences beyond academia – and again, social networks may be a test for solutions of general applicability. Also as mentioned above, network research can help us identify more precisely the community of stakeholders – who have an interest in the research or on whom the research may have an effect – whom researchers should interact with.

In what follows, I explore these ideas with the help of three example cases from my own research experience: one about use of visual sociograms to return individual results, another about whole network representations of the researched community/organization, the third expanding on the TV show dilemma introduced earlier. A case study approach is most suitable to a situation characterized by limited preliminary evidence and a research context that is not yet clearly specified, in an emerging domain of investigation ([Yin, 2009](#)). I do not limit my inquiry to the exploratory level, though, and move forward to using the cases at hand to extract more general arguments, the conclusions of which can be actionable. Thus I make an *instrumental* use of my cases, seeing them as concrete instances of the broader issue of interest, into which they can provide insight ([Baxter and Jack, 2008](#); [Stake, 1995](#)). Cases require in-depth study of the particular empirical contexts in which they are embedded, in order for the researcher to distinguish the general from the specific, to propose interpretations, and to devise new ideas ([Ragin, 1992](#)).

As [Crossley and Edwards \(2016\)](#) maintain, social network research is essentially a case-study method, where focus is exclusively upon a given, well-demarcated social group, especially in whole-network designs. Contrary to classical statistical inference, there is no assumption that the case or cases under consideration are representative, in a statistical sense, of any wider population. This is one reason why social network research has caught on in studies of specific, historically or geographically limited worlds such as organizations and social movements.

In principle, the case study requires engagement with all possible sources of data, methods and analytic strategies that may shed light on the phenomenon of interest. In practice, it is often associated with qualitative research, except in social network studies that draw on a notoriously strong quantitative tradition. Recent approaches lead to greater convergence, whereby qualitative case study specialists use more quantitative methods ([Mills et al., 2010](#)) and network researchers increasingly draw upon multiple data sources, triangulate observations and build richer pictures of their cases ([Crossley, 2010](#); [Dominguez and Hollstein, 2014](#); [Ryan and D'Angelo, 2018](#)).

Giving personal network results to individuals

Social network research makes visible patterns of relationships that would otherwise escape human gaze. Therefore, giving individual-level results back to participants provides them with unique, otherwise inaccessible information about themselves. Should we, then, systematically provide study participants with maps of their own networks – representing their “personal communities” in the case of personal network research, or extractions of their ego-centred subgraphs in the case of whole network research?

This practice is already spreading with the help of network visualizations, which are being integrated into different stages of research, from data gathering to presentation of results (D’Angelo et al., 2016). Researchers who have shown participants visualizations of their ego networks note that they shifted their role from being observed to becoming observers themselves (Molina et al., 2014) and felt the need to explain and justify what they saw (Bellotti, 2016). But if people understand visuals, they may take some type of action as a consequence. This is especially likely in a society that values connectedness (Christakis and Fowler, 2011), and in which individuals are aware of the benefits that might accrue from their relationships (Rainie and Wellman, 2012), so that they will have a sense of themselves as more or less successful networkers. Wide availability of social media visualizations until about 2013 has increased people’s appetite for this type of information, although most digital platforms have recently restricted access to these data (Hogan, 2018). The potential existence of such effects involves a duty for the researcher to anticipate them and as far as possible, to prevent any drawbacks.

A case from my research illustrates some of the ensuing dilemmas. As part of the above-mentioned study of the social networks of eating disorder sufferers, I used a graphical concentric-circles sociogram structure embedded in a web survey to elicit personal networks (Tubaro et al., 2014a, 2016). Participants had to fill in two such sociograms, for their face-to-face and for their computer-mediated ties. The top panels of Fig. 1 are two examples of these sociograms, representing a face-to-face personal network (left), and an online personal network (right). From these images, drawn by participants themselves, were extracted edgelist and tables with alters’ attributes, for use in analysis. My team and I had initially planned to offer respondents an optimized visualization of their full (face-to-face and online) personal networks at the end of the survey, to reward them and acknowledge their participation. The bottom panel of Fig. 1 is the layout of one early option we considered (and eventually dismissed), representing online and face-to-face networks as concentric circles as before, but placing them together in the same image as perpendicular plans intersecting in a three-dimensional space (horizontal: face-to-face, vertical: online).

But there were risks. If participants liked the visualization, they would export it and perhaps post it onto their personal pages and social media profiles. If the visualization included the names of their contacts (alters), anonymity would be jeopardized; but without names (as is the case in this figure), the visuals might appear confusing and little meaningful, especially with sizeable networks and/or major overlaps between online and face-to-face contacts. Another risk would arise if our tool confronted participants to their isolation and loneliness – utterly visible in a graphical representation. At the time (2010), there was no discussion of such a risk in the social networks literature, and the rare previous experiences of sociogram use positively acknowledged participants’ comments on how “interesting their personal networks look” (Hogan et al., 2007, p. 137). Yet ours was a self-administered web survey where no interviewer’s mediation was available to offer reassurance to participants if needed. We were particularly concerned because we were surveying persons living with eating disorders, whose experiences of illness and hospitalization are known to limit their interpersonal interactions and to disrupt their social functioning (Levine, 2012; Patel et al., 2016). We eventually dropped the plan to give individual results back to participants and never developed the tool

depicted in the bottom panel of Fig. 1.

Later research provides hard evidence of the issues we intuitively anticipated – even outside the health field and in interviewer-led studies. Ryan et al. (2014) interviewed highly-skilled French professionals in London, many of whom appeared quite self-conscious about the visual representations of their personal networks. Those who thought of themselves as successful, confident networkers experienced a sense of unease when presented with, for example, lack of diversity in their relationships – as a woman who had described her network as “cosmopolitan”, but realized that her visual included almost only co-nationals. Their attitude betrayed a form of vulnerability – that of migrants whose relatively high economic status was not enough to ensure full integration.

In sum, results may reveal (possibly untold) vulnerabilities and trigger reactions that are not observed in more classical participant-researcher interactions. For all their power and appeal, visualizations can be double-edged swords. This is not to say that personal network results should never be shared with study participants. Rather, the lesson learned is that researchers should try and anticipate the conditions that might in some cases lead to distress, and adapt their use of visualizations accordingly.

Giving whole network results to communities

Let us now turn to a second case study, in the context of a research about networking patterns at an international festival of the so-called “sharing economy”, the annual OuisShare Fest, which took place in Paris from 2013 to 2017. At the 2016 edition, I distributed a questionnaire to participants, with name generators that asked them about their relationships pre-dating the event, the ties formed during its course, and those expected to give rise to further contacts or collaborations in the near future. Almost one year after that, and about one month before the following edition of the festival, I approached the organizers with some preliminary results. I did so to give them confidence that the study was producing relevant outcomes, to renegotiate access to the event and re-run the survey again, and to offer them insights – which I expected to matter to them as professional networking was a watchword of the OuisShare experience. Another motivation was the interest of study participants, which I clearly perceived during fieldwork. Asked in 2016 if she would like to see my (aggregate) results, one of them had replied enthusiastically:

I think it will be really interesting. The fact that somebody is interested in studying what’s happening, provides the feeling that what’s happening is really happening, and that it’s big enough to be studied [...] So I think if you do that, it will be really huge (*resp.* 26, 2016).

Indeed OuisShare members were thrilled with the Gephi visuals that I produced from my data. One graph showed that relationships between participants that pre-existed the 2016 OuisShare Fest formed clusters largely disconnected from one another, with many isolates; another revealed that through the new ties formed during the event, most people had become part of a main, densely-knitted connected component.

OuisShare leaders immediately produced an animated gif from my graphs and shared it widely on Twitter.² Two of them went as far as printing my visualizations on T-shirts that they wore at the following (2017) edition of the event, labeling them as “before” and “after”. Interestingly, they advertised themselves to attendees as “human tinders” – the match-makers who, like the well-known app, connect people “in real life” (Fig. 2).

This particular episode happened not to harm anyone, and it was

² Link to the original Tweet: <https://twitter.com/SRoumeau/status/879714234837471232?s=20>.

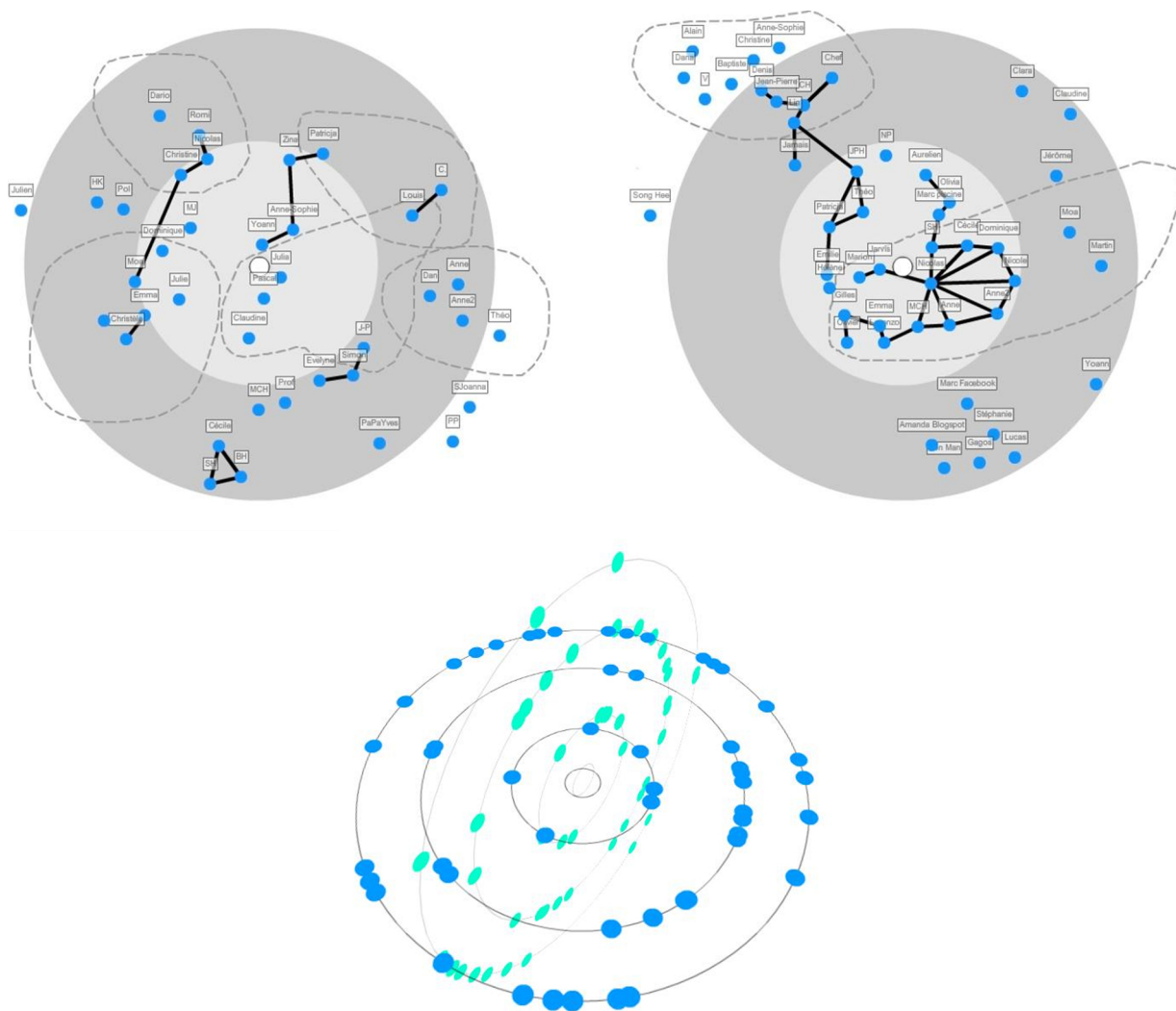


Fig. 1. graphical, concentric-circle sociograms for data collection (top) and planned return to participants (bottom) in a web survey. Top left panel: a face-to-face personal network, right panel: an online personal network, as could be drawn by a participant. The bottom panel is an unfinished (and anonymized) project to aggregate these same data into one image that participants could export at the end of the survey. Horizontal plan: face-to-face network; vertical plan: online network. All the graphs reproduced in this figure are from technical tests and do not represent real persons.

even rather funny; but it alerted me about potential issues. One brings me back to visualization and its power. It was indeed just those two graphs that caught the attention of OuiShare, not the other visuals I provided, nor the explanations I gave on the side. Those two graphs alone were so successful, partly because I deliberately chose a layout that made very apparent the outcome that OuiShare members were so keen to see – the effectiveness of their event in connecting people. The effect was not spurious, but other graphical choices, such as colors or layouts, could have made it much less visually striking. Although there was no deception here, graph visualizations may lead to selective appropriation by stakeholders, and researchers need to be very careful about their use to communicate results.

Another reason for reflecting on this case is that the key users of my results were not study participants individually, but the organizers of the event where the research took place: among the latter, few actually responded to my questionnaire, while many of them appeared in the network as alters (that is, they were nominated by other respondents). This confirms the tenet of the field methods literature that reporting results to the researched community does not simply mean getting back to participants narrowly defined, and that a more holistic perspective is needed. Network analysis can help refine and extend this approach through its capacity to map who matters to whom, so as to account for the full range of relevant stakeholders, whether they are study

participants themselves or not. The fact that my graphs first circulated through Twitter, a social networking service, ensured targeted diffusion to stakeholders within the OuiShare community much more effectively than any publication in a generalist outlet.

When results are shared with a whole social setting rather than with single participants, additional issues may arise depending on the power structure and influence channels within that setting. OuiShare includes prominent community leaders, and their flagship event has played an important role in shaping the “sharing economy”, an emerging and still loosely defined field of activity. They asked me to what extent the results I reported were attributable to their members: were they instrumental in linking participants at the event? From the point of view of their internal management, this would be useful information: “connector” is an official role in their organization and they expect members to be effective networkers. But from a researcher’s standpoint, this was a difficult decision to make. Even if OuiShare prides itself to be a flat, collegial organization of (mainly) freelancers and independent professionals interacting via high-tech digital devices, fear of introducing or exacerbating power relationships prevented me from deanonymizing network nodes to identify the best connectors. Because invisible, informal dominance structures might be in place behind any formal shape (Krackhardt and Hanson, 1993), with potential consequences for individual members, the same issues might arise as those highlighted by

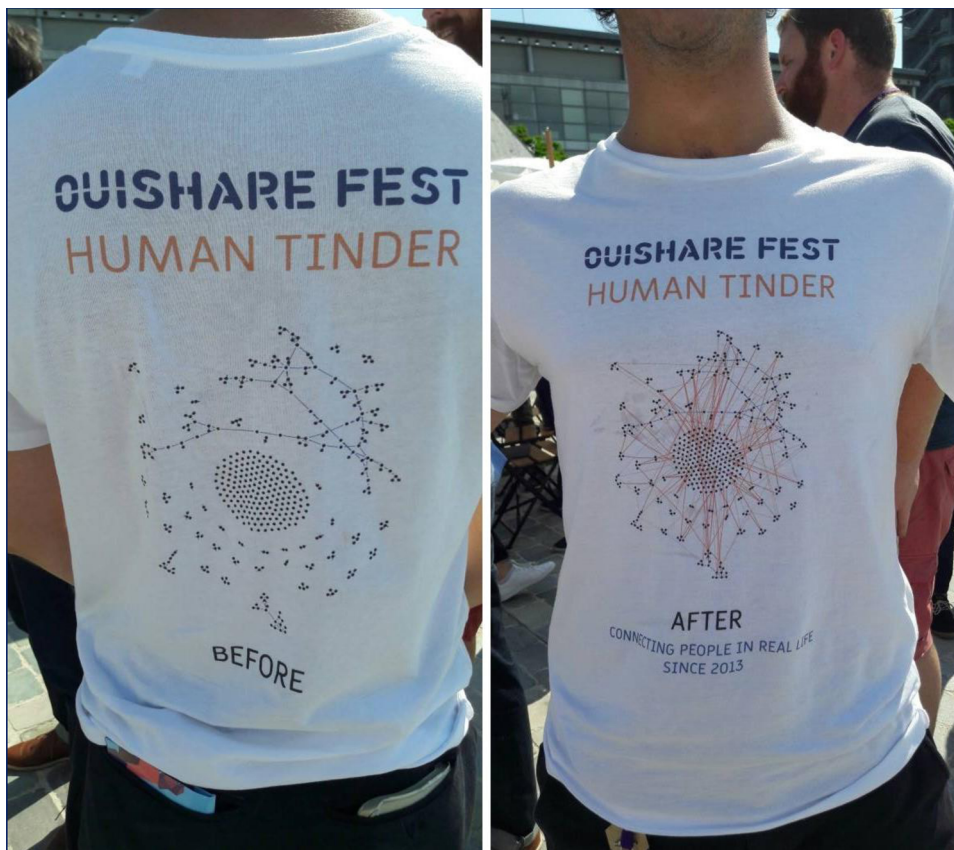


Fig. 2. T-shirts printed by OuiShare members in 2017, with my graphs of networks of ties between participants at the previous edition of the event. The “before” graph refers to ties that pre-existed the event; the “after” one to ties formed during it. I drew the graphs in Gephi using questionnaire data I collected in 2016. The labels, the “Human Tinder” title, and the “Connecting people in real life since 2013” caption were added by OuiShare. Photo: courtesy of Annelise Meyer.

Borgatti and Molina (2003, 2005) in the context of more traditional, hierarchical organizations. As Howard Becker first noted, full consensus does not exist in any community or organization, and the social scientist may end up pleasing one faction while disserving another, so that “the problem is not to avoid harming people but deciding which people to harm” (1978 [1964], p. 330). Even anonymized results would not be neutral, producing potential tensions if, for example, they revealed that it was outsiders rather than insiders who mostly contributed to linking participants.

In a sense, there was also a risk for the researcher. I gave my findings to this community at an early stage to build trust, receive feedback and negotiate a return to the field. But the unexpectedly wide publicity could have backfired, in that any unhappy members could have obstructed my second wave of data collection. In addition, because my authorship was not acknowledged on the T-shirts (although it was in the animated gif that circulated via Twitter), I feared my re-use of such material in future publications would need to be very carefully thought out. In essence, researchers are to be included among those potentially affected, that an ethical approach should take into account – as will be discussed more extensively later.

Extending reporting efforts beyond individual participants is thus a challenge. Visuals can serve as effective and easy-to-understand tools, but they may be distressing or deceptive. When are difficulties most likely to arise? Extant literature (Borgatti and Molina, 2003, 2005) already emphasized the risks that arise in organized settings, and my case appears as an extension of these ideas to looser organizational forms. Even mild power or influence relationships produce specific opportunities and threats that researchers should anticipate as far as possible. My case study also resonates with recent evidence that people attach values and status to connectedness (Christakis and Fowler, 2011; Rainie and Wellman, 2012) – and are therefore keen to demonstrate their role as actors of this connectedness, possibly using research results to this purpose.

The key is to ensure reciprocity criteria are met, at least to some extent: the fact that they were in the OuiShare Fest case (the organizers gave me access to the field, I gave results to them), kept potential risks under control and gave me a second access to the field, and even further logistical support, one year later (after which I also returned results to them as I had done before). But in other cases, such conditions are not met and return of results is more problematic, as discussed in the next section.

Beyond networked communities: sharing results with the media and wider audiences

What about communicating general results to publics that are larger than the specific social setting in which a study was run (such as the OuiShare community)? Research institutions increasingly encourage outreach to wider non-academic audiences who are indirect financial contributors (notably through public funding schemes) and/or potential beneficiaries (for example, families, neighbourhoods or communities of interest). Ethical issues arise as sensitive decisions must be made, such as choice of sufficiently accurate wording when technical language cannot be used. So far, only a few institutions and learned societies have published ethical guidelines for responsible press communications (for example the Society for Neuroscience³).

As before, I draw on my own research experience to stimulate a discussion. I already mentioned a case in which I declined to speak at a TV show to avoid risks of distortion of my findings on online networks and eating disorders. This is a far-too-common trade-off between two ethical imperatives, one that urges researchers to reach out to the public, and one that invites to caution in light of the potential negative

³ See <https://www.sfn.org/Membership/Professional-Conduct/Guidelines-for-Responsible-Conduct-Regarding-Scientific-Communication> (accessed on 27 July 2019).

consequences of any misrepresentation of results, notably when they have health implications. Other challenges related to this case speak expressly to the social network research community. The producers of the show implicitly endorsed the idea that online relationships are somehow less valuable than face-to-face ones. As network scholars, we know this is a more complex matter. A long-lasting debate has opposed those who stress the “internet paradox” (Kraut et al., 1998) of a communication technology that drives people apart and undermines human propensity towards face-to-face conversations (Turkle, 2012), and those who emphasize seamless integration of the two (Wellman and Haythornthwaite, 2002; Wellman and Gulia, 1999). Even young people are not all savvy with technologies, and down-to-earth inequalities persist online (Hargittai, 2010).

What’s more, the show producers took for granted that social influence through peers on the web triggers imitation of unhealthy eating behaviours and is therefore undesirable. Beyond its neglect of influences from non-computer-mediated relationships (Valente, 2010), this view puts the blame on personal networks, without considering the responsibilities of mainstream media that can reach out to much larger audiences. My own research showed that personal networks mediate the reception of media contents, sometimes attenuating their effects, sometimes amplifying them, with different strength and significance depending on individuals’ body size (Pallotti et al., 2018). This very insight from my social network research suggested that, with little time to elaborate and no control on the social environments of the show’s publics, it would be wiser not to communicate widely on such sensitive matters.

Alternatively, I could have chosen to attend the show and explain myself; but even if I had been given sufficient time to make my point, my approach could be seen as *lecturing* others, as if I were in a position of higher standing, rather than just engaging in a mutually beneficial conversation.

This brings me to the reciprocity argument I introduced above. Broadly defined, dialogue with stakeholders is a way for researchers to give back to their social environment in exchange of what they received from it – not just the financial resources they ultimately obtain from taxpayer money, and not just responses from participants to a study, but any form of information and social support. The problem is that the conditions for reciprocity must be in place for it to happen. In the case of this TV show, I could not ensure appropriate “giving back”, as the risk of distortions and sensationalism was too high. Besides, reciprocity was made difficult by the lack of common language and shared understandings of the matter at stake.

Discussion: dual vulnerability and reciprocation

Building on the thought of Emmanuel Levinas, philosopher Pierre-Antoine Chardel, who was a partner in my eating disorders study, describes the mirroring of instability and risks in respondents (or other stakeholders) and in researchers as *dual vulnerability* (Chardel, 2012, 2013). First, vulnerability concerns study participants: in our research on eating disorder networks, it was mainly due to their health condition, exposure to social stigma, and relatively young age. The second vulnerability is that of researchers who take human, scientific and ultimately legal responsibility when they handle sensitive information which participants (especially if in situations of illness or distress) entrust them with. Chardel’s notion of researcher vulnerability stems specifically from French data protection law, which had stringent requirements even before entry into force of the GDPR in May 2018, all the more so when data contained sensitive information (e.g. on health). Yet this notion can be easily transposed to regulations in place in other countries, where researchers are subject to Review Boards, with further constraints coming from the legal and risk management services of their institutions (Molina and Borgatti, 2019). Chardel’s view has the advantage of taking into account various sources of researcher vulnerability, deriving from the broad range of ethical and even scientific risks

that arise from interactions with multiple stakeholders. These extra sources of vulnerability are looser and less recognizable, but their effects are no less forceful.

Some aspects of my case studies can be understood in these terms. The first (return of personal networks to individuals) suggests that not only participants, but also researchers are vulnerable if presentation of results fails to protect anonymity, because their status and reputation in the profession may suffer. Perhaps in a subtler way, both parties are vulnerable if researchers are unable to reassure participants when findings generate discomfort. Researchers may lack the necessary skills, training, or information to provide support, especially in difficult cases that would require specialized clinical or psychological expertise. Deciding whether to try and give support is in itself a challenge, insofar as social science research is not usually meant to have therapeutic value.

The second case study (return of whole networks to communities) hints at dual vulnerability arising from potential misuse of research results, especially in organized settings. Local leaders may leverage these results for commercial purposes, and even use them to promote their own advantage, possibly to the detriment of weaker members. The researched community is vulnerable to the potentially destabilizing effects of such actions. Researchers are vulnerable too, insofar as they may have unwittingly contributed to developing tools for purposes that do not fit with their values.

The third case (communication of generic results to the public at large) is probably the one where the vulnerability of all parties is at its highest. Misrepresentation through highly-visible popular media may unduly stigmatize the researched population or community while also de-legitimizing researchers if they fail to strike the right balance between the complexity of the problem under study and the need to use simplified language. This is difficult to manage as researchers typically lack control over the final media product (content of the article or report) and its framing (insertion in a broader story, choice of title and accompanying images). Further, researchers are rarely prepared to handle exposure to public debates (although universities and learned societies increasingly offer training and support for press communications).

In all three cases, a reciprocation process may mitigate the emerging dual vulnerability. I argued earlier that a reciprocity obligation underlies the reporting process notably in the context of social network research. Now, it can be added that reciprocation emerges in the mirroring of reduced vulnerability as stakeholders develop trust in researchers (and *vice versa*) when communication to relevant audiences proceeds safely. The cases presented above show that when the conditions for reciprocity are met, researchers are fully able to “give back” to the communities that supported their work, while keeping vulnerability low for all parties.

Conclusions

Researchers’ presence in the field is far from neutral and naturally involves some form of feedback to those affected. In what precedes, I have argued that the act of reporting results is an important part of the ethical reflection that should permeate a research project at all stages. Some preliminary plan to share results with participants should be made at the very beginning, even though not all circumstances can be anticipated, and some adjustments will need to be made along the way.

A thorny issue is *who* to return results to. Under some conditions, research participants may expect to receive their own individual results – notably the structure and composition of their personal network, possibly though not necessarily in visual form. Using the case of a study of users of health-related websites, I highlighted some circumstances in which this is not suitable. Visuals offer an intuitive, effective means for the social network researcher to communicate, but may be misleading or unhelpful in some cases.

Whole network results may be of interest to the researched

organizations, groups or communities. Using the case of an event whose attendees I surveyed, I highlighted several ethical risks such as appropriation (and possibly, misuse) of results by stakeholders in a position of power or leadership. These influential members may sometimes raise awareness of a research in a given community, encourage participation, and provide domain-expert feedback on preliminary results. It is thus essential that researchers identify such leaders at an early stage and inform and involve them in all phases of the fieldwork. In cases in which leadership is emergent rather than determined by formal structures, social network research may detect individuals in key positions and help understand which relationships to leverage.

Generalized research results (such as the fact that people's reception of media contents is mediated by their social contacts) are also relevant for the public at large, and researchers are increasingly encouraged to communicate to the generalist press. While this serves laudable transparency and accountability purposes, the risk of misrepresentation of results is often high. As discussed above, it is wiser in some cases to renounce the visibility that media presence offers. This is by no means a call to shy away from the press: journalists can be allies who help find a larger audience for research and may be instrumental to pass the message especially when it can have policy impact. Ideally, researchers should be able to include journalists in their social networks, establishing long-term relationships that help create the conditions for "giving back" as discussed above.

These considerations prompt a reflection on *when* to return results. The Society for Neuroscience, one of the few to have released guidelines for ethical communication with the press, recommends waiting until a finding is peer-reviewed and accepted for publication before announcing it to the public at large. However in the social sciences, this should not rule out the possibility of earlier release to researched and/or affected communities, as long as the preliminary or descriptive nature of findings is clear. I construe report of findings as a cyclical process involving dynamic, mutual interchange between researchers and relevant stakeholders. I shared my preliminary OuiShare Fest findings with the organizers before showing them to academic audiences. By so doing, I both offered a reward to OuiShare and benefited my research, earning the possibility to go back to the field for a new wave of data collection, and receiving feedback that helped me refine my interpretation. Later, as peer reviews increased my confidence in the results, I communicated more broadly through the OuiShare radio and newsletter. In short, communication with field actors both preceded and followed dissemination to fellow researchers, and each step involved larger circles. While this is just one case and different sequences may be envisioned in other settings, the common challenge is to identify relevant stakeholders and decide what to share with each of them at what time.

Overall, these considerations suggest that there is insight to gain by sharing researchers' first-hand experience and the lessons learned from it. While ethical guidelines may include some general principles of how to communicate with the press, they cannot anticipate all possible issues, and some solutions are difficult to transfer beyond disciplinary boundaries. Learning from one another and working together to create the conditions for appropriate "giving back" is a form of "indirect" reciprocity that defines a more promising way forward.

We could set the example as social network scholars, while also engaging in a collective effort to rethink the way we have practiced our research and branded ourselves since the advent of ubiquitous digital technologies. Some of the difficulties I have discussed derive from an ambiguity in the way outsiders see our work. To be sure, as a group we have benefited from the increasing popularity of social media, as it has turned out very soon that we have the right analytical tools and concepts to analyse them. Our very methods – our points-and-lines graphs, our metrics, and our vocabulary – are more widely understood today than in the pre-Facebook era. And yet, we suffer from the unprecedented imbalance of economic and political power between us – a niche scientific community – and the tech giants that own online social networking sites. It is perhaps time to engage in a more upfront

discussion of the matter, to position ourselves more clearly in regard to our objects of study and our methods. It is not only a matter of identity or legitimacy toward our institutions and our funders: we also face consequences in terms of clarity of our message to the public, and capacity to illuminate broad societal issues.

Such considerations do not represent an end-point to this discussion. Our views on how to responsibly communicate our research results are bound to evolve, especially as researchers develop solutions that mitigate the forms of dual vulnerability to which they and their stakeholders are subject. It is important not to leave this to top-down regulators: we need to creatively and collectively contribute to devising an appropriate ethical framework.

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References

- Baxter, P., Jack, S., 2008. Qualitative case study methodology: study design and implementation for novice researchers. *Qual. Rep.* 13 (4), 544–559.
- Becker, H.S., 1964. Problems in the publication of field studies. In: Vidich, A.J., Bensman, J., Stein, M. (Eds.), *Reflections on Community Studies*. Wiley, pp. 267–284 reprinted in J. Bynner & K.M. Stribley (eds.), 1978, *Research Design: the Logic of Social Inquiry*, Routledge, pp. 325–340 (1964).
- Bellotti, E., 2016. Qualitative methods and visualizations in the study of friendship networks. *Sociol. Res. Online* 21 (2), 2. <https://doi.org/10.5153/sro.3936>. URL <http://www.socresonline.org.uk/21/2/2.html>.
- Borgatti, S.P., Molina, J.L., 2005. Toward ethical guidelines for network research in organizations. *Social Netw.* 27 (2), 107–117. <https://doi.org/10.1016/j.socnet.2005.01.004>.
- Borgatti, S.P., Molina, J.L., 2003. Ethical and strategic issues in organizational network analysis. *J. Appl. Behav. Sci.* 39 (3), 337–350. <https://doi.org/10.1177/0021886303258111>.
- Bourdieu, P., 1980. *Questions de sociologie* (reprinted 2015). Les Editions de Minuit (1980).
- Burawoy, M., 2004. American Sociological Association presidential address: for public sociology. *Br. J. Sociol.* 56 (2), 259–294. <https://doi.org/10.1111/j.1468-4446.2005.00059.x>.
- Burawoy, M., 2005. The critical turn to public sociology. *Crit. Sociol.* 31 (3), 313–326. <https://doi.org/10.1163/1569163053946291>.
- Cahill, C., Torre, M.E., 2007. Beyond the journal article: representations, audience, and the presentation of Participatory Action Research. In: Kindon, S., Pain, R., Kesby, M. (Eds.), *Participatory Action Research Approaches and Methods*. Routledge, pp. 196–205.
- Chardel, P.A., 2013. Réseaux numériques et pratiques de soi : le cas des communautés « Ana-mia ». Réinterroger l'articulation du droit et de l'éthique. *Éthique publique* 15 (2). <https://doi.org/10.4000/ethiquepublique.1295>. URL <http://ethiquepublique.revues.org/1295>.
- Chardel, P.A., 2012. In: Réseaux numériques et pratiques de soi. *Questions d'éthique. Présentation at the conference Comprendre le phénomène pro-ana : corps, réseaux, alimentation*. BNF, Paris, 14 December.
- Chavis, D.M., Stucky, P.E., Wandersman, A., 1983. Returning basic research to the community: a relationship between scientist and citizen. *Am. Psychol.* 38 (4), 424–434. <https://doi.org/10.1037/0003-066X.38.4.424>.
- Christakis, N.A., Fowler, J.H., 2011. *Connected: The Surprising Power of Our Social Networks and How They Shape Our Lives*. Back Bay Books.
- Chua, V., Madej, J., Wellman, B., 2011. Personal communities: the world according to me. In: Scott, J., Carrington, P.J. (Eds.), *The SAGE Handbook of Social Network Analysis*. SAGE, pp. 101–115.
- Crossley, N., 2010. The social world of the network: combining qualitative and quantitative elements in social network analysis. *Sociologica* 1. <https://doi.org/10.2383/32049>.
- Crossley, N., Edwards, G., 2016. Cases, mechanisms and the real: the theory and methodology of mixed-method social network analysis. *Sociol. Res. Online* 21 (2), 13. <https://doi.org/10.5153/sro.39>. URL <http://www.socresonline.org.uk/21/2/13.html>.
- D'Angelo, A., Ryan, L., 2019. The presentation of the networked self: ethics and epistemology in social network analysis (in press). *Social Netw.* <https://doi.org/10.1016/j.socnet.2019.06.002>. this issue.
- D'Angelo, A., Ryan, L., Tubaro, P., 2016. Visualization in mixed-methods research on

- social networks. Introduction to the special section of Sociological Research Online 21 (2). <https://doi.org/10.5153/sro.3996>. URL: <http://www.socresonline.org.uk/21/2/contents.html>.
- Dominguez, S., Hollstein, B. (Eds.), 2014. *Mixed Methods Social Networks Research*. Cambridge University Press.
- Dunbar, R.I.M., 2016. Do online social media cut through the constraints that limit the size of offline social networks? *R. Soc. Open Sci.* 3, 150292. <https://doi.org/10.1098/rsos.150292>.
- Ellis, C., 1995. Emotional and ethical quagmires in returning to the field. *J. Contemp. Ethnogr.* 24 (1), 68–98. <https://doi.org/10.1177/089124195024001003>.
- Hargittai, E., 2010. Digital na (t) ives? Variation in internet skills and uses among members of the “Net generation”. *Sociol. Inquiry* 80 (1), 92–113. <https://doi.org/10.1111/j.1475-682X.2009.00317.x>.
- Hogan, B., 2018. Social media giveth, social media taketh away: facebook, friendships, and APIs. *Int. J. Commun.* 12, 592–611.
- Hogan, B., Carrasco, J.A., Wellman, B., 2007. Visualizing personal networks: working with participant-aided sociograms. *Field Methods* 19 (2), 116–144. <https://doi.org/10.1177/1525822X06298589>.
- Iphofen, R., 2011. *Ethical Decision-Making in Social Research*. Palgrave Macmillan.
- Jeffries, V. (Ed.), 2011. *Handbook of Public Sociology*. Rowman & Littlefield Publishers.
- Kadushin, C., 2005. Who benefits from network analysis: ethics of social network research. *Social Netw.* 27 (2), 139–153. <https://doi.org/10.1016/j.socnet.2005.01.005>.
- Krackhardt, D., Hanson, J.R., 1993. Informal networks: the company behind the chart. *Harv. Bus. Rev.* 71 (4), 104–111.
- Kraut, R., Patterson, M., Lundmark, V., Kiesler, S., Mukopadhyay, T., Scherlis, W., 1998. Internet paradox. A social technology that reduces social involvement and psychological well-being? *Am. Psychol.* 53 (9), 1017–1031.
- Levine, M.P., 2012. Loneliness and eating disorders. *J. Psychol.* 146 (1–2), 243–257.
- MacKenzie, C.A., Christensen, J., Turner, S., 2015. Advocating beyond the academy: dilemmas of communicating relevant research results. *Qual. Res.* 15 (1), 105–121. <https://doi.org/10.1177/1468794113509261>.
- Mills, A.J., Durepos, G., Wiebe, E., 2010. *Encyclopedia of case study research*. SAGE. <https://doi.org/10.4135/9781412957397>.
- Molina, J.L., Borgatti, S.P., 2019. Moral bureaucracies and social network research. forthcoming. *Social Netw.* this issue.
- Molina, J.L., Maya-Jariego, I., McCarty, C., 2014. Giving meaning to social networks: methodology for conducting and analyzing interviews based on personal network visualizations. In: Dominguez, S., Hollstein, B. (Eds.), *Mixed-Methods Social Networks Research*. Cambridge University Press, pp. 305–335.
- Pallotti, F., Tubaro, P., Casilli, A.A., Valente, T.W., 2018. You see yourself like in a mirror”: the effects of internet-mediated personal networks on body image and eating disorders. *Health Commun.* 33 (9), 1166–1176.
- Parker, M., 2013. The ethics of open access publishing. *BMC Med. Ethics* 14, 16. <https://doi.org/10.1186/1472-6939-14-16>.
- Patel, K., Tchanturia, K., Harrison, A., 2016. An exploration of social functioning in young people with eating disorders: a qualitative study. *PLoS One* 11 (7), e0159910.
- Ragin, C.C., 1992. Cases of “What is a Case?” Introduction to C.C. Ragin & H.S. Becker *What is a Case? Exploring the Foundations of Social Inquiry*. Cambridge University Press, pp. 1–17.
- Rainie, L., Wellman, B., 2012. *Networked: The New Social Operating System*. MIT Press.
- Reyes-Garcia, V., Sunderlin, W.D., 2011. Why do field research? In: Angelsen, A., Larsen, H.O., Lund, J.F., Smith-Hall, C., Wunder, S. (Eds.), *Measuring Livelihoods and Environmental Dependence: Methods for Research and Fieldwork*. Earthscan.
- Ryan, L., D’Angelo, A., 2018. Changing times: migrants’ social network analysis and the challenges of longitudinal research. *Social Netw.* 53, 148–158. <https://doi.org/10.1016/j.socnet.2017.03.003>.
- Ryan, L., Mulholland, J., Agoston, A., 2014. Talking ties: reflecting on network visualization and qualitative interviewing. *Sociol. Res. Online* 19 (2), 16. <https://doi.org/10.5153/sro.3404>. URL: <http://www.socresonline.org.uk/19/2/16.html>.
- Schurmans, M.N., Charmillot, M., Dayer, C., 2014. Introduction du dossier « La restitution des savoirs ». *SociologieS* URL: <http://sociologies.revues.org/4713>.
- Stake, R.E., 1995. *The Art of Case Study Research*. SAGE.
- Tubaro, P., 2017. Les tensions entre sociologie et politique à l’aune d’une tentative de législation des sites web sur les troubles alimentaires. *SociologieS* URL: <http://journals.openedition.org/sociologies/6387>.
- Tubaro, P., D’Angelo, A., Ryan, L., 2016. The visual sociogram in qualitative and mixed-methods research. *Sociol. Res. Online* 21 (2), 1. <https://doi.org/10.5153/sro.3864>. URL: <http://www.socresonline.org.uk/21/2/1.html>.
- Tubaro, P., Casilli, A.A., Mounier, L., 2014a. Eliciting personal network data in web surveys through participant-generated sociograms. *Field Methods* 26 (2), 107–125. <https://doi.org/10.1177/1525822X13491861>.
- Tubaro, P., Casilli, A.A., Sarabi, Y., 2014b. *Against the Hypothesis of the “End of Privacy”. An Agent-Based Modelling Approach to Social Media*. Springer.
- Tubaro, P., Mounier, L., 2014. Sociability and support in online eating disorder communities: evidence from personal networks. *Netw. Sci.* 2 (1), 1–25. <https://doi.org/10.1017/nws.2014.6>.
- Turkle, S., 2012. *Alone Together: Why We Expect More from Technology and Less from Each Other*. Basic Books.
- Valente, T.W., 2010. *Social Networks and Health*. Oxford University Press.
- Wellman, B., Haythornthwaite, C. (Eds.), 2002. *The Internet in Everyday Life*. Wiley-Blackwell.
- Wellman, B., Carrington, P.J., Hall, A., 1988. Networks as personal communities. In: Wellman, B., Berkowitz, S.D. (Eds.), *Social Structures: A Network Analysis*. Cambridge University Press, pp. 130–184.
- Wellman, B., Gulia, M., 1999. Net surfers don’t ride alone: virtual communities as communities. In: Wellman, B. (Ed.), *Networks in the Global Village*. Westview, pp. 331–366.
- Wolf, S.M., Branum, R., Koenig, B.A., Petersen, G.M., Berry, S.A., Beskow, L.M., Daly, M.B., Fernandez, C.V., Green, R.C., LeRoy, B.S., Lindor, N.M., O’Rourke, P.P., Radecki Breitkopf, C., Rothstein, M.A., Van Ness, B., Wilfond, B.S., 2015. Returning a research participant’s genomic results to relatives: analysis and recommendations. *J. Law, Med. Ethics* 43 (3), 440–463. <https://doi.org/10.1111/jlme.12288>.
- Wong, C.A., Hernandez, A.F., Califf, R.M., 2018. Return of research results to study participants: uncharted and untested. *J. Am. Med. Assoc. (JAMA)* 320 (5), 435–436. <https://doi.org/10.1001/jama.2018.7898>.
- World Health Organization, 2007. *People-Centred Health Care: A Policy Framework*. World Health Organization, Geneva, CH.
- Yin, R.K., 2009. *Case Study Research: Design and Methods*, 4th ed. SAGE.