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DEFENDING HUMAN RIGHTS IN THE ERA OF DATAFICATION

Maria Normark

Department of Informatics and Media, Uppsala University, Sweden

Karin Hansson

School of Natural Science, Technology and Environmental Studies, Södertörn University, Sweden

Mattias Jacobsson

School of Natural Science, Technology and Environmental Studies, Södertörn University, Sweden

Introduction

While extant scholarship has yielded a nuanced picture of how people have used information and communication technologies (ICTs) on civic participation, less is known about why NGOs have appropriated and maneuvered some technologies but not others for communication and organization, against different contexts. Especially when it comes to the opportunity to deploying data gathering tools and engaging in public discussion, non-profit organizations (NGOs) and activist groups for example increasingly base their campaigns on data (Baack 2015; Briones Rojas 2021). A growing field of research in this area is now developing, describing the infrastructural arrangement in diverse environments, for example the Umbrella Movement in Hong Kong (Liu 2021), #blacklivesmatter in the USA (Grill 2021), and climate activists in Brazil (Skill et al. 2021a).

This paper presents findings from a study of activists and human rights defenders and how they try to manage the infrastructure of digital data (Baack 2015). In this work, data can be a resource in activism and valuable in the organization of campaigns. However, data and lack of data also mean great difficulties in everyday life for people in vulnerable positions, for example, in contact with government agencies, schools, and healthcare (Liu 2021).

Our analysis stems from interview data from four kinds of human rights activism. These include volunteers and employees from various NGOs focusing on refugees/migrants, homelessness and poverty, women's shelters, and sexual minorities. The study was

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done in Sweden, where the GDPR (General Data Protection Regulation) laws limit the handling and storage of personal data.

Social movements and human rights defenders

Previous research shows how political participation changes character through the ease with which technology can provide direct involvement in social movements (Milan 2017). Research in this area has primarily focused on the possibilities that digitalization brings with it, especially in acute crisis and disaster situations (Almohamed et al. 2022; Auferbauer and Tellioğlu 2017; Blanford et al. 2014; Haak et al. 2018; Jensen et al. 2020; Lambton-Howard et al. 2019). However, research also shows that datafication creates new sorts of risks for democratic engagement: the risk of relying on a technology that is also a means of surveillance (Liu 2021; Michaelsen 2017; Pickard and Yang 2017; Uldam 2018); the risk of relying on a crowd of participants you might never meet face to face (Klang and Madison 2016); and the risk of disinformation, especially in relation to the unreliability of user-generated data (Bradshaw and Howard 2017; Pickard and Yang 2017). The consequences are the increased threats to human rights defenders' work in many countries, which is why the actual datafication can be central to the threat against activists and the people they defend. Previous research also shows how social movements counteract the threat of surveillance, especially when it comes to activism in repressive regimes (See for example Liu 2021; Skill et al. 2021b) However, less research is done on how NGOs and activist groups handle the risks, not only of being surveilled, but also of "surveilling" their members by using more data intensive methods as part of their communication.

Human rights activists are also confronted with the problems their protégés deal with as the society becomes increasingly digital. Digitization is today a central infrastructure in society that people with protection needs need to relate to in a special way where potential risks need to be understood and managed (Clark and Albris 2020). A number of different types of everyday data transactions, in the form of documentation in registers and systems, geographical position data, digital financial transactions, to internal communications within human rights groups, can pose a risk to those in need of protection (Steinbrink et al. 2021). In addition to this, these persons have a great need for information that is reliable and accurate as well as the opportunity to communicate with loved ones (Haynes 2016). Human rights groups therefore need to consider alternative data practices to be able to support people who, for various reasons, need to avoid being exposed in digital contexts. Empirical studies of concrete digital practices in this area are scarce and few why this study can contribute with central new knowledge.

Today, we have data laws that protect the individual, rules that also have implications for how human rights organizations can operate and engage their members. While digitalization makes it easier to organize civil society, these much-needed data laws also impede organization. This dilemma between human rights in an online context and the government or state interference is currently an active research area in Europe, both in terms of applicable policies and the broader understanding (Pūraitė et al. 2020) However, empirical studies of concrete digital practices in this area are scarce why this study contributes with central new knowledge.

Based on our data we conceptualized the different types of work of volunteers and employees, using the concept of *infrastructuring human rights* to signify the creative arrangements of organizational structures and facilities needed for defending human rights in this era of datafication. Drawing attention to the opportunities and constraints that the fabric of society, the very societal infrastructures (laws, technologies, resources, etc.) provides helped us analyze the role of data and datafication in NGO's.

Based on the analysis of the data practices and arrangements surrounding data in NGO's, five major strategies surfaced.

- *Data integrity is for those who can afford it:* When people face deportation if they don't find a job, being sensitive about how one's data is shared is a less viable option (see also Steinbrink et al. 2021). Therefore, infrastructuring human rights through handling data means at least circumventing and sometimes ignoring the data laws.
- *Bridging data poverty:* This concerns groups such as undocumented immigrants without credentials and necessary data, for example social security numbers and addresses. Infrastructuring human rights means scaffolding the lack of data to avoid the effects of data poverty and invoke, for example migrants' rights.
- *Preventive data practices:* Political currents in contemporary society have rendered considerable interest in data about minoritized groups, data about who work with these groups, and who supports them (Grill, 2021; Hansson et al 2021). This attention also reflects concerns about what can and should be publicly shared on social media and how to protect people with less awareness of the potential damage sharing specific data can do.
- *Drawing attention to data:* Infrastructuring human rights through data means providing data to shed light on specific situations or developments. Data is an essential resource for affecting public opinion (Haynes, 2016).
- *Monitoring systems and data routines:* Infrastructuring human rights through handling and storage of data is affected by the affordances of the data systems. Therefore, being concerned with what is possible in the system is essential.

As a final note, the activists, and the groups that they support through their organizations, are subject to contradictory aspects of data; on the one hand, intentionally exposing data about minoritized/marginalized groups, and on the other, making sure that these groups, and the activists themselves, are not exposed. Indeed, our study indicates that the data laws and regulations are not adjusted to the most vulnerable in society, and that infrastructuring human rights in this era of datafication, therefore, requires actions of civil disobedience.

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