



## What binds biosociality? The collective effervescence of the parent-led conference



Rebecca Dimond<sup>\*</sup>, Andrew Bartlett, Jamie Lewis

Cardiff School of Social Sciences, Cardiff University, 10 Museum Place, Cardiff CF10 3BG, United Kingdom

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### ABSTRACT

Questions of community are central to many research settings in the social sciences. Rabinow argued that, in the wake of the Human Genome Project, an increasingly important form of collectivity would be *biosociality*. Biosociality recognises a central role for biomedical knowledge in constructing genetic identities and producing and reproducing social relationships. Accordingly, it is often imagined as a *new* form of social solidarity. We draw on observations of parent-led conferences to explore the way in which biosociality is expressed at events organised around a particular genetic syndrome – 22q11 deletion syndrome. The parent-led conferences took place within the United Kingdom between 2007 and 2010 and were observed as part of a multi-sited ethnographic study. By bringing together a geographically dispersed group of people together within the same physical location, conferences offer an ideal platform to empirically examine sociality. Durkheim used the term collective effervescence to describe the collective expression of heightened emotion. We suggest that in the case of the 22q11 deletion syndrome activities discussed in this paper, collective effervescence is a mechanism through which individuals become a collective. We argue that parent-led conferences gather individuals in one location on the basis of common biological factors, but it is the shared emotional experience of being together that consolidates and renews the connection between members.

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## 1. Introduction

How do people connect with one another in the 21st Century? In what ways are communities formed? These questions are central to many research settings explored in the social sciences. From research conducted on families and kinship (Featherstone et al., 2006; Young and Willmott, 1957; Willmott, 1986), to studies of work and organisations (Lave and Wenger, 1991; Salaman, 1974; Tonnies, 1957), through to more modern contemporary projects exploring the rise of the Internet and the digital age (Castells, 2009; Zhang and Watts, 2008) and studies examining biomedicine, genetics and biosociality (Rabinow, 1996; Rose and Novas, 2005), the focus of much social science has been on the new social structures that support late-modern society. Increasingly, sociologists have identified geographically dispersed communities as the source of belonging. Where once we built relationships on the basis of our immediate physical location – our neighbourhood, our workplace,

our church – the formation of 21st century collectives is less dependent on co-location. This is even more evident in the context of the digital age, which facilitates networking across national and international borders. Developments in communication technologies and greater physical mobility make it easier for individuals to seek and form relationships based on shared interests. People connect through their occupations, their cultural interests and their political and philosophical belief systems. “[I]n the ‘advanced liberal’ societies of the West, we observe new collective formations emergent everywhere” (Rabinow and Rose, 2006, p204). These are often dispersed associations of people.

Rabinow (1996) argued that, in the wake of the Human Genome Project, an increasingly important form of collectivity would be biosociality. He wrote, “it is not hard to imagine groups formed around the chromosome 17, locus 16, 256, site 654, 376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and ‘understand’ their fate” (1996, p102). The question Rabinow addressed in thinking about biosociality was ‘how had sociality changed given the rise of the new understanding of genetics?’

<sup>\*</sup> Corresponding author.

E-mail address: [DimondR1@Cardiff.ac.uk](mailto:DimondR1@Cardiff.ac.uk) (R. Dimond).

(Rabinow, 2008, p188). As Rabinow himself admits, biosociality was an under-developed concept, primarily introduced to counterbalance the dominant ideas of 'socio-biology' (Hacking, 2006; Gibbon and Novas, 2008). However, it has since been taken up enthusiastically by subsequent authors and is widely imagined as a new form of social solidarity, which can help us to understand contemporary (and possible future) societies (Rose and Novas, 2005).

Biosociality is intimately entwined with identity politics. It encapsulates a movement from patient to active citizen, facilitated by individuals subscribing to, and utilising biomedical categories (Rose and Novas, 2005) and illuminates practices of engagement and participation (Rapp et al., 2001). Indeed, the role of patient communities in civic society has been well documented in raising awareness of little known medical conditions and campaigning for access to research funding and healthcare resources (Allsop et al., 2004). In a biosocial context, patients and patient groups are recognised as pioneers and activists (Rapp et al. 2001), increasingly directing their activities towards influencing the scientific agenda in collaboration or partnership with scientists and researchers (Epstein, 1996; Landzelius, 2006; Rabeharisoa and Callon, 2004; Rapp et al., 2001). A classic example of patient groups working in partnership to extend the boundaries of science (for a broader discussion see Gibbon and Novas, 2008), is the *Association Française contre le Myopathies* (AFM) as documented by Rabeharisoa (2006), Callon and Rabeharisoa (2008) and Mayrhofer (2008). Members of the AFM have become active participants in knowledge production through the development and maintenance of biobanks and the financing of genetic research. These are understood as processes of empowerment, by using embodied knowledge as a collective force and by making the body available for 'innovative intervention' (Brown and Webster, 2004 p.80).

In this article we focus on conferences organised around a particular genetic syndrome, 22q11 deletion syndrome. The conference is an under researched and under theorised space in social studies of biomedicine, particularly when compared to the hospital (Featherstone et al., 2005; Strong, 1979) and laboratory (Knorr-Cetina, 1999; Latour and Woolgar, 1979). Patient conferences have been identified as important for facilitating dialogue and engendering a sense of trust between lay and professional groups of 'experts' (Creighton et al. 2004; Huyard, 2009; Zakrzewska et al. 2009) and to advance developments in the field (Weiner, 2009). By tracking the activities of support groups, examining how rights and responsibilities are enacted, and exploring the ways in which claims to knowledge are contested, researchers have developed an empirical understanding of biosociality, expertise and participation (Rabeharisoa, 2006; Weiner, 2009). The groups and their activities observed for this study might be considered the archetypal 'collectivity' that Rabinow had predicted. The staging of large scale conferences, attracting prominent speakers and high numbers of families from across the United Kingdom (UK) is an example of professional organisation and successful collaboration. Attending such occasions demonstrates identification with the 'genetically marked category' (Rapp et al., 2001 p393) of 22q11 deletion syndrome, and enables patients and families to come into contact with each other, and with their shared 'panoply of pastoral keepers' (Rabinow, 1996). However, this paper highlights that although collectives are formed when individuals are brought together on the basis of shared biology, what binds them is not biological but social.

We argue that bonds are forged on the basis of the collective expression of emotion, facilitated by group occasions such as a conference. 'Collective effervescence' was coined by Emile Durkheim (1912) to describe the evocation of mutually shared emotional stimulation – an unusual state of shared excitement

involving exceptionally intense feelings. His analysis was based, for the most part, on the religious practices of Australian Aborigines in which he sought to discover the basic principles of religious experience (Cariton-Ford, 1992). Durkheim argued that a grounding of the religious beliefs in practical and phenomenal experience was required to create a sense of mutual community. He argued "[I]t is by shouting the same cry, saying the same words, and performing the same action in regard to the same object that [individuals] arrive at and experience agreement" (Durkheim, 1995 pp.231–232). The central feature of these gatherings is that they are *effervescent assemblies* generating intense mutual emotional connection and arousal (Pickering, 1984). As well as helping sociologists analyse religion, the concept has been used to understand the collective emotions experienced in secular contexts, such as at sporting events (Fox, 2006), nightclubs (Tutenges, 2013) and therapeutic clinics (Scott, 2011). Durkheim argued that when people express similar types of emotions, these become reinforced and develop into a collective passion (Tang, 2009). In the case of the conferences examined in this paper, members of the 22q11 deletion syndrome patient support group are brought together physically, on the basis of their shared biology. As we will illustrate, however, it is the shared emotional experience of the conference – the collective effervescence – that consolidates and renews the connection between members of the group as they engage in moments of high energy and mutual emotion. What binds individuals together is a social process, which is influenced by, but not reduced to, the nature of the 'shared allele variant' or other biological factor. This paper therefore provides further empirical evidence of the social processes that underpin biosocial collectives.

### 1.1. The research site: the 22q11 conference

We explore the role of collective effervescence in biosocialities by drawing on observations of five conferences organised around a rare genetic disease. 22q11 deletion syndrome is caused by a small deletion of genetic material on chromosome 22 and is characterised by a wide range of potential symptoms including congenital heart defects, mild to moderate learning disabilities, cleft lip and palate and immune deficiency (Shprintzen and Golding-Kushner, 2008). As Navon has noted, since its genomic designation in the early 1990's, the 22q11 deletion has mobilised activities towards a common purpose, becoming "essential to the formation of a hybrid population of patients and field of knowledge that was previously invisible to clinical research" (2012, p1639). The conference is an exemplar of these collaborative activities, and by organising, attending or presenting at these events, individuals from diverse backgrounds demonstrate identification and engagement with the biomedical category of 22q11 deletion syndrome. However, we also recognise the socially constructed nature of this diagnostic classification and the multiple contexts within which it is given meaning (Dimond, 2010). Our focus on conferences therefore extends our understanding of medicine as a local production (Bowker and Star, 2000; Mol, 2002).

The four one-day parent-led conferences were organised by UK and Ireland support groups established and led by parents of children with 22q11 deletion syndrome. These were annual meetings lasting all day with each one attended by over one hundred people, most of whom were parents and family members. They were open to the public, publicised on the support group website and took place in a range of venues including university buildings and conference facilities within a sports stadium. The three-day scientific conference was organised by an international 22q11 deletion syndrome scientific organisation, but was hosted by a parent-led support group. It was attended by over three hundred people, including a large scientific/medical contingent as well as a

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