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SYMPOSIUM: RISK, INNOVATION AND IGNORANCE PRODUCTION INTRODUCTION

Rethinking ignorance production in the field of reproductive biomedicine: An introduction

Biomedical innovations have radically transformed reproductive processes at every level. Although many of them have changed lives for the better, the risks and side effects – in cases such as pregnancy drugs or contraceptive pills, for example – have been insufficiently studied or even ignored, until scandals or controversies made them public. Moreover, some technologies, treatments and practices have become routine, for instance in the field of obstetrics, despite the fact that their efficiency remains unproven or unevaluated. For example, electronic monitors were introduced worldwide in maternity wards to facilitate the strict surveillance of labouring women without any clinical evidence showing that continuous surveillance improves health outcomes (Owens, 2017; Wagner, 2006). Beyond their clinical or practical impacts, innovations within fertility markets, pregnancy surveillance or reproductive care often also have ethical, legal, social, economic and even anthropological implications that are not always publicly debated. Transformations in family relationships, concepts of kinship, gender definitions, and ethical standards in medical care were observed by several scholars studying assisted reproductive technology (ART) treatments in various countries (see for example Clarke, 2009; Franklin and Ragoné, 1998; Gerrits, 2016; Strathern, 1992; Inhorn, 2012). Representations and experiences of childbirth were also deeply transformed by the tremendous technicization of the process through the massive use of epidural anaesthesia, active management of labour, induction of labour, and the increase or even 'normalisation' of Caesarean sections (Topçu, 2019; Maffi, 2016).

Bringing together reproductive studies and ignorance studies, the aim of this special issue is to analyse the dynamics of ignorance production prior to, during, but also after the rapid expansion of reproductive technologies,

innovations and products. Following its recent theorisation, ignorance refers to both strategic and systemic forms of non-knowledge, uncertainties and doubts involving iatrogenic risks, side effects or lack of efficiency of different innovations. Considering the notion of risk in its broadest sense, ignorance also implies the absence or weakness of public debate or deliberation regarding the potential destabilisations or ruptures that these innovations can provoke in ethical, social, political, economic and even existential terms. In our contemporary knowledge societies, what are the zones and frontiers of knowledge and ignorance in the field of human reproduction? Have reproductive innovations, mostly tested on female bodies, generated more risk and denial of risk than other medical or technical innovations? What are the economic, social, political or gendered prerogatives or interests that lead to the production (or not) of evidence on health externalities or to the modification of collective memory on un-medicalised ways of procreating or controlling fertility? Are there national regimes of ignorance production that persist despite the increasing importance of transnational regulatory bodies and the exceptional information flow characterising today's globalised and connected world? How are real-world or embodied experiences of women, parents, babies and patients recognised, or rather dismissed, in different political-cultural contexts?

Departing from these questions, this special issue brings together original work tackling a wide range of empirical objects from new IVF technologies and 'Fordist' birth technologies to contraceptive pills, passing through medication abortion, pregnancy drugs and female diseases. This issue also aims to contribute to an international understanding of the knowledge/ignorance regimes related to the contemporary management of the reproductive body by drawing on

case studies from four countries: France, Tunisia, Germany and Great Britain. This collective publication is the result of the international symposium 'Minimizing Risks, Selling Promises? Reproductive Health, Technoscientific Controversies and the Production of Ignorance' organised by the two guest editors at the University of Lausanne, 22–23 November, 2018.

Studying ignorance rather than knowledge: A paradox?

During the last decades, progress in reproductive biomedicine, and in science and technology more generally, has undoubtedly relied on the accumulation of a tremendous amount of new knowledge and know-how, which has paved the way for the rise of advanced knowledge economies. One can therefore ask: Is it paradoxical to focus on ignorance rather than knowledge when analysing the relations between science, medicine and human ecologies? Is it paradoxical to proceed in this manner when we consider that biomedical and scientific knowledge is – as already shown by numerous science and technology studies (STS) or feminist studies – much diffused in society (beyond laboratories or universities) (Gibbons et al., 1994) and that a vast span of alternative, amateur or lay knowledge, including that produced by patient or self-help groups (Epstein, 1998; Murphy, 2012), now offer the possibility to better regulate or govern techno-scientific or biomedical innovations, their shortages, or their risks?

In our view, the reason some may consider it paradoxical or old-fashioned to study varieties of ignorance (Abbott, 2010) rather than forms of knowledge is linked to the hypothesis that science or knowledge production is necessarily a cumulative process and that each new knowledge and know-how is a further step to distance us from ignorance or from grey areas. However, if it is undeniable that science has always progressed by falsifying and correcting itself (Popper, 2002) and that different scientific paradigms have dominated our societies (Kuhn, 1970), more science or a lot of knowledge does not always mean less ignorance. On the one hand, each new knowledge is the result of a choice to invest in one field rather than another, or the effect of a specific 'epistemic form' modelling the approach to the world (Kleinman and Suryanarayanan, 2012: p.498). Vast areas of 'undone science' (Frickel et al., 2010; Hess, 2007) exist or have long remained unquestioned. The logic behind these phenomena is related to power, values, conformism, lack of social and economic interest (Council and Henry, 2016; McGoey, 2012; Tuana, 2004), or the will to avoid 'uncomfortable knowledge' (Rayner, 2012). On the other hand, as Gross and McGoey (2015) put it, new knowledge does not signify finished or complete knowledge or science. The unknown is not diminished by new discoveries; on the contrary, the territory of the unknown may even be magnified when one considers the fact that each knowledge and know-how, each innovation paves the way to new externalities, potential risks, and side effects (or possible idleness or inefficiency). This is a phenomenon that in the early 2000s some scholars designated as the symptom of 'a world that has become uncertain' (Callon et al., 2009). What is more, the follow-up of the negative externalities

of scientific and medical progress does not benefit from the same resources as those allocated to the development of a given innovation, technology or drug as several contributors to this special issue show. In this context, one can speak of a competition between progressive knowledge – the one that serves technical and medical progress – and reflexive knowledge – the one that is intended to control this progress and its effects, with the aim of 'mastering the mastering of nature', as Michel Serres puts it (see Serres, 1995). Progressive knowledge undoubtedly has more political, economic and industrial support, more means to exist and to operate a change, than reflexive knowledge which is often produced or is called to be produced at the request of or on the initiative of social movements, consumers, patients, citizens, users or victims (Council and Henry, 2016). The already mentioned concept of 'undone science', introduced by Frickel et al. (2010), insists on such imbalance, by drawing on cases such as risky chlorine chemicals, air pollution monitoring and breast cancer genetics.

The contribution of ignorance studies to the analysis of the relations between innovation, risk and health

The founding work in the field of ignorance studies focused on tobacco and its hidden carcinogenic risks (Proctor and Schiebinger, 2008; Proctor, 2011). The more than 80 million pages of archives belonging to the American tobacco industry and seized during lawsuits brought against the industry have made it possible to consider this type of imbalance between the means allocated to progressive knowledge (in the service of cigarette promotion) versus reflective knowledge. The resources available to American cancer research agencies, for example, have proven to be negligible compared to those offered by the industry. These pioneering studies have also made clear, in the case of the tobacco industry at least, the existence of an active production of ignorance, which refers to a set of strategies (of powerful actors or those oriented toward progressive knowledge) aiming at contradicting, denigrating and decredibilizing reflexive knowledge through advertising or communication campaigns, financing of contradictory studies, or even 'purchase' of certain scientific personalities (Proctor, 2011; Oreskes and Conway, 2010). This body of work revealed, in particular, how ignorance, far from being an *état de fait* with diverse causalities, can and must be approached as a form of government with its own material and theoretical equipment.

Thanks to ignorance studies, we have also been able to acknowledge the fact that not knowing can be an important resource for the success of an action. In fact, ignorance cannot be considered simply as a negative phenomenon, as a deficit model or as a deficient version of knowledge. In certain situations, it serves as capital not only for those who govern (industrialists, technocrats, innovators, scientists, or experts) but also for the governed. The fact that intersexual people can refuse to collaborate with the medical profession in its relentless efforts to define a sexual identity for them is a good example of the mobilization of ignorance ('I don't know what sex I am') to defend one's own singularity or identity. The refusal to use technologies for prenatal

diagnosis or tests revealing the predisposition to genetic diseases (Wehling, 2015), in the name of a right not to know or to ignore for moral, religious or political reasons, constitutes another example of the mobilization of ignorance by the patients or the governed. Rayna Rapp has shown that one of the concerns of black women refusing amniocentesis in the early days of the expansion of this technology was that they would not be used as guinea pigs, once again, for 'white' science (Rapp, 1998).

Progressively, the pioneering work in the field of ignorance studies, which postulated the intentional and strategic character of ignorance and especially its function as a resource (or capital) for action (or inaction), were followed by others who aimed to adopt a more pragmatic, less conspiratorial approach. In the *Routledge Handbook of Ignorance Studies*, Matthias Gros and Linsey McGoey (2015) propose to approach ignorance as neither necessarily intentional nor necessarily exceptional (or accidental), but as regular, meaning that it would be an intrinsic component of the governance of technoscience. We can also call it systemic ignorance, to underline the fact that it is a durable component of the systems of knowledge, interaction and action, in the same way as one speaks for example in accidentology of systemic or 'normal' accidents: normal, not in the sense that they are socially or ethically acceptable, but in the sense that they are not or no longer forms of deviance; rather, they are part of a chain of events that are rare but certain to occur (Perrow, 1999). In short, the 'normal', regular or systemic character of ignorance is rooted in the fact that the systems of knowledge and their conditions of production are complex. They rely on diverse and varied forms of (hyper)specializations which are often disconnected from each other. They require the collection of a great variety of data on environments, bodies, milieus, and their complex interactions. Two studies—the first focusing on the intoxication of workers in the agricultural industry in France (Dedieu and Jouzel, 2015), the second on the effects of agricultural insecticides on bees in the United States (Kleinman and Suryanarayanan, 2012)—provide good examples of the sociological analysis of the production of ignorance within the domain of scientific expertise. The former shows for instance how 'the instruments that these institutions use to make visible and prevent professional intoxications linked to pesticides are indeed structurally blind to the pathogenic consequences of numerous forms of workers' exposure to these products' (Dedieu and Jouzel, 2015: 108).

Bringing together reproductive studies and ignorance studies

Ignorance studies have been partly built on the achievements of the sociology of scientific knowledge (SSK) and of STS, while also distinguishing themselves from them. While with SSK, the issue at stake has been to analyse the conditions of the production of scientific truth or knowledge by putting the winners versus the losers of history face to face, and by deciphering the reasons for the failure of the latter (Bloor, 1991), with ignorance studies, the question that outweighs rather concerns what the winner or dominant knowledge or truth does or does not allow us to know

or to see, their limited scope, their situatedness. In this respect, ignorance studies can be considered closer to feminist STS, which has insisted on 'situated knowledges' in order to better point out the subjective and partial character of knowledge production (Haraway, 1988). Such an approach has provided the opportunity to bring evidence on the ignored research areas or objects, such as the female orgasm (Tuana, 2004), the sexist production of knowledge on male and female reproductive anatomy (Martin, 1991), or the female-body oriented foundations of certain technologies (such as the contraceptive pill, see Oudshoorn, 2003) or disciplines (such as gynaecology, see Almeling, 2020).

Despite these theoretical and methodological convergences, reproductive studies and ignorance studies are two domains that have rarely been in dialogue until now. Issues of ignorance related to reproductive health were indeed theorized already in the 1980s and 90s by feminist scholars (see Susan Bell's commentary, in this issue). However, the field of ignorance studies expanded in the 2000s, mostly in an autonomous way vis-à-vis this feminist literature on the topic. Partially at least, this contributed to the underinvestment of reproductive matters as research objects in the field.

We believe that it is important, even urgent, to fill in this gap, for several reasons. One of them is related to the growing importance of risk issues in reproductive biomedicine. Over the last few decades, reproductive processes have been subject to significant biomedical manipulation and surveillance. From contraceptive pills to IVF, egg freezing, or prenatal monitoring technologies, many of them were promoted (and received) as revolutions; many of them also expanded rapidly and became routinized. However, their side or adverse effects have not always been studied extensively. This is evidenced by multiple drug scandals such as thalidomide, diethylstilbestrol (DES) and primodos/duogynon (Daemmrich, 2006; Bell, 2009; Olszynko-Gryn et al., 2018). This special issue provides fresh empirical analysis concerning two of them. Relying on extensive field research composed of sociohistorical analysis, interviews with experts and victims, and study of court archives, Fillion and Torny's article highlights the medical assumptions, the institutional settings and the patient movement's initiatives within which an intergenerational silence was established on the drug's risks and victims in the French context. Nemeč and Olszynko-Gryn's study of the hormone pregnancy test Duogynon's trajectory in West Germany also deals with an intergenerational health (non)scandal, whose management was shaped by very diverse and sometimes competing forms of ignorance production orchestrated by scientific experts, industrialists and government officials.

The medical community's indifference to the side effects of biomedical technologies has already been explained from a gender perspective, highlighting the fact that these risky innovations have often been used or tested on women's bodies, who thus became the ones to bear the 'burden' of risks and uncertainties (see for e.g. Hartmann, 1995; Van Kammen and Oudshoorn, 2002; Oudshoorn, 2003). A clear illustration of this is that sex hormones for women constitute one of the largest industrial markets in the world today. On the other end of the spectrum, ignored female diseases such as endometriosis, represent an oppo-

site movement, which can also be considered the result of gendered politics. Nicky Hudson analyses, in this special issue, the discursive, material and political mechanisms through which women's lived experience of endometriosis – a condition that in the UK affects more women than diabetes – were and still continue to be excluded from science policy making.

Beyond ignored female diseases, the short- and long-term effects of the technologies commonly used, for example, in hospital deliveries that generate iatrogenic risks, such as induction of labour, continuous foetal monitoring, epidural anaesthesia, or Caesarean section, have rarely been critically examined (Sarda, 2011). Epidural births for instance, studied in this issue by Sezin Topçu, have almost become the norm in France since the late 1990s, whereas the disadvantages, risks and side effects have gradually been excluded from public and medical debate. Moreover, even when there is consistent scientific evidence that an intervention is harmful, change in clinical practice is very slow (Perrenoud, 2014; Goer, 1995), as Lola Mirouse shows in her study of systematic episiotomy and its regulation in France in this volume. Through a systematic analysis of the French medical literature on episiotomy, the author proposes to understand the knowledge/ignorance production behind what appears as a paradox—that is, the fact that episiotomy became a routine practice in France in a period (1980s–90s) during which its risks and ineffectiveness engendered a scientific and medical controversy in the international arena.

Similarly, issues of risk related to ART treatments have not always been a scientific priority. The health effects of hormone treatments on women undergoing IVF, the risks of miscarriage in the case of amniocentesis, the various health disorders of 'ICSI babies' and the psychological impacts of surrogacy or egg freezing on (surrogate) mothers and babies continue to be under-investigated. Many innovations, tests, and treatments have become routine, although their effectiveness appears to be marginal, unproven, or unevaluated. This is the case for "add-ons" that are supposed to increase the success of IVF (Heneghan et al., 2016) or mitochondrial replacement therapy (MRT) aimed at preventing the transmission of mitochondrial diseases. In her contribution to this special issue, Cathy Herbrand analyses how the potential risks and inefficiency of MRT were evacuated from public and political debate in the UK thanks to reductionist institutional framings.

Beyond their clinical or practical impacts, innovations in the infertility market or those belonging to gynaecological-obstetrical care often have ethical, legal, social, economic, and even anthropological implications that are rarely publicly debated before they are introduced and even generalized. This is the case with the use of Caesarean section for breech deliveries, which in many countries became routine following the publication of a study that proved to be unfounded (Hannah et al., 2000). Hormonal replacement therapies for women suffering of symptoms related to menopause were also introduced without solid scientific evidence proving their safety, and it took a long time before studies proving their harmful effects were published and taken into consideration by the medical community and state authorities (Löwy and Gaudillère, 2006). Conversely,

the expansion of certain technologies that are considered to be feminist in some contexts may be hindered in other contexts because of conservative or religious considerations or under the influence of anti-gender or pro-life movements. Löwy and Corrêa (2020) have recently shown how policy-makers and health professionals in Brazil have strongly emphasized the risks of misoprostol use for medication abortion, in order to prevent home abortions through this method from becoming commonplace. The article by Irene Maffi in this volume examines a similar phenomenon showing how in post-revolutionary Tunisia, access to pharmacological abortion became restricted in a context of reinforced conservatism and patriarchy. Medications were made unavailable, medical knowledge about pharmacological abortion was sequestered (Heimer, 2012) and state laws were not applied thanks to the production of ignorance about them.

Following these analytical lines, this special issue – which inevitably involves a limited number of case studies – opens more research leads than it closes. Nevertheless, we are convinced that the various theoretical and methodological approaches the contributors to this volume adopt will be useful and inspiring for future research. The socio-historical approach of several articles appears to be very fruitful for the study of the production of systems of knowledge/ignorance about risk and scientific truths related to reproductive health as it offers the possibility to grasp the way they work before, during and after the generalization of a given technology, innovation or product. International comparison (Mirouse in this issue; Nemeč and Olszynko-Gryn in this issue; see also Olszynko-Gryn et al., 2018) also proves to be highly judicious for refining the analysis of forms of ignorance at stake in the field of reproductive health since it elicits a better understanding of how, on the initiative of which actors, and relying on which justifications national regimes of ignorance are established, persist and connect with pre-existing gender regimes. Thus, the comparative approach allows an exploration of how transnational mediscapes (Hörbst and Wolf, 2014) work and the processes of interaction between local and global forms of knowledge/ignorance in the domain of reproductive health. It also allows for a better understanding of the dynamics of the circulation or non-circulation of knowledge/ignorance once doubts are cast on the risks of a given technology, innovation or product. Moreover, ethnographic accounts focusing on experts' understanding of the female body – and more generally of the reproductive processes – provide important insights into the medical and institutional framings of debates over the risks and benefits of a biomedical innovation (Herbrand in this issue; Maffi in this issue). Last but not least, the study of actions carried out by feminist or patient movements against the risks and harms of an innovation (Fillion and Torny in this issue) – or sometimes their wilful ignorance of these risks for cultural or political reasons (Topçu in this issue) – as well as longitudinal approaches that tackle the experiential or embedded knowledge of women (Hudson in this issue; see also Bell, 2009) constitute a very efficient tool to complexify the study of ignorance, its producers, its recipients, and its strategic scope.

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