

# “Stop Talking to People; Talk with Them”: A Qualitative Study of Information Needs and Experiences Among Genetic Research Participants in Pakistan and Denmark

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## Abstract

This article explores how research participants experienced information practices in an international genetic research collaboration involving the collection of biomaterial and clinical data in both Pakistan and Denmark. We investigated how people make sense of their research participation and the types of information they need and desire. We found great variation in what information exchange does and what participants experience as meaningful. For example, information practices could serve as a source of respect and recognition (in Denmark) or of hope, understanding or help when dealing with suffering (in Pakistan). Policies aimed at harmonizing ethics standards for international research do not encapsulate some of the most important aspects of information practices for the research participants involved. We suggest shifting the focus from standards of one-way information delivery to a more process-oriented form of research ethics, where the contextual exploration of local needs through a mutual engagement with participants gains more ground.

## Keywords

informed consent, information practices, information, feedback policies, communication in research, international research, Pakistan, Denmark

When reading the international guiding policies on harmonization of research ethics in cross-national collaborations (Council for International Organizations of Medical Sciences, 2016; Organization for Economic Co-operation and Development, 2009; World Medical Association, 2013) and current literature (Dove, Knoppers, & Zawati, 2014; Dove, Tassé, & Knoppers, 2014; Harris et al., 2012; Knoppers, Harris, Budin-Ljosne, & Dove, 2014; Mascalonzi et al., 2015), one can easily think the information needs of participants mostly revolve around (a) the participants' authorization through informed consent and (b) researchers' duty to disclose useful genetic research results. Informed consent, more than any other research ethical procedure, has become the key nexus for debates about information exchange among research participants and research institutions (Faden & Beauchamp, 1986). It is said to protect the autonomy, dignity, and safety of research participants. These principles are designed to create accountability, through universal ethical rules governing information flows across borders and between researchers and research participants (Douglas-Jones, 2015, 2017). Gradually, the emphasis in academic debates on informed consent has been supplemented with awareness of the duty to disclose research results when of use to participants (Bredenoord, Onland-Moret, & Van Delden, 2011). In this article, we aim to foreground the discrepancy

between these ideals and the actuality: the difference between policy theory and the reality of participants' information experiences and wishes—including what was variously thought of as being ‘useful’—that we observed as being at stake according to participants in a particular international genetic research project.

How do people experience information when they participate in international research where they provide their blood samples, family history, and health data? And what kind of information practices do they anticipate and desire? To answer these questions, we consider the perspective of research participants from Pakistan and Denmark contributing to the research in, and funded by, one single academic research center in Denmark. Moving beyond an understanding of information exchange as a matter of “delivery” of messages, we seek to explore what people *do* with information. We thus unpack what people *strive for* when engaging with information practices. By comparing the everyday way

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people explained their information experiences and needs across two distinctly different contexts—yet linked by providing samples and data to the same laboratory—we wish to highlight the range of stakes and concerns that people have and show that information practices involve far more than information delivery, especially in the context of global inequalities in participant recruitment. If we are to take seriously an empirically informed understanding of information practices in international collaborative research, we need to begin embracing more dialogical, that is two-way, forms of information *exchange* than is currently allowed by research policy, with regard to informed consent and feedback of results. We need to set free both our academic understanding and discussion of information practices in research from the iron cage of the informed consent paradigm. By escaping the tight grip of informed consent and its associated assumptions of “rational” agency (Kelly, 2003; Sankar, 2004), ethical analysis can better address the needs that participants themselves highlight. Studies have shown how policies seeking to regulate ethics direct attention toward certain topics while overlooking others (Kowal, Radin, & Reardon, 2013; Radin & Kowal, 2015; Reardon, 2004). To develop ethics policies that are more relevant to people’s hopes and concerns, local variations in relation to information needs and experiences should be acknowledged. As a starting point, we propose engagement in on-going dialogical forms of *information exchange*. This is instead of the current bifurcation of information provided *before* and *after* participation, hence softening the strong focus on information content. In the following section, we present our view of “information exchange” by presenting this term as a meaning-making practice.

### Information Exchange as a Meaning-Making Practice

To release the study of information from the grip of informed consent, we engage what can be termed a practice-oriented perspective on *the doing* of information (Dewey, 1947; Latour, 1993; Reckwitz, 2002). The aim is to gain insights into emotions, logics, stakes, and concerns among the research participants. Hence, our use of the term *information exchange* is not to be understood as a unidirectional *transfer* of facts. Exchanges involve the agency of more than one partner. This also means that information exchange cannot be separated from social agency which is always embedded in norms. What we *learn* relates to what *matters* to us. Our understanding of information exchange is inspired by the seminal work of American pragmatist philosopher John Dewey on how we learn (Dewey, 1947). Dewey suggested focusing on the notion of “meaning” to understand how information and knowledge are situated in specific practices where people have something at stake. He defined “meaning” as forms of knowledge people feel they can make *use* of. In line with this practice-oriented

tradition, we believe it is important to explore how research participants position themselves and how they talk about the information they receive and the origin of the information: People prefer information that is pertinent to themselves (Parkin, 2013; Whyte, 1997).

The literature on information practices in research has predominantly focused on informed consent. Yet while still heralded as a basic principle in research ethics, informed consent procedures have been subject to increasing criticism from scholars studying the ideals of autonomy and protection in practice. This criticism appears to follow two strands: One focuses primarily on topics related to “compliance” to the informed consent ideal due to lack of audit, assessment, and monitoring of procedures that make them culturally appropriate (Artizzu, 2008; Beskow et al., 2001; Bhutta, 2004; Burke, Evans, & Jarvik, 2014; Skovdal & Abebe, 2012; Sugarman et al., 2005); the other strand attacks the normative underpinnings of the informed consent procedures and the link established between information and consent, as it is said to silence social context known to influence choice of participation, while propagating an inadequate understanding of agency (Arnason, 2004; Brekke & Simes, 2006; Felt, Bister, Strassnig, & Wagner, 2009; Hoeyer & Hogle, 2014; Reardon, 2004). In this study, we suggest that these experiences should imply moving beyond discussions of informed consent when looking for the types of information exchanges important to research participants. When approaching information practices as matters of engaged learning, a misfit occurs between the empirical reality and two “defaults” inscribed in current policies. One default is an assumption of a *temporal bifurcation* related to the information while the other is a *substance focus* that promotes written information.

The temporal bifurcation involves a strong emphasis on what people need to know to make informed and free decisions about a potential research participation, and about which results researchers are obliged to inform participants (Fabsitz et al., 2010; Knoppers, Joly, Simard, & Durocher, 2006). Hence, efforts tend to emphasize what research participants need to know either *before* entering a research project (in relation to informed consent) or *after* conclusion of the project (in the form of feedback of results). In both cases, they focus on what researchers need to tell participants, rather than what participants might wish to tell researchers. As for the substance focus, policymakers have sought to harmonize ethics rules by developing clear specifications of content and form to ensure controllability, accountability, and efficiency. Global initiatives aimed at stimulating data sharing related to genetic research such as the Global Alliance for Genomics and Health (GA4GH; 2017) have promoted the harmonization of ethical and procedural standards for genetic research and realization of research potential across countries through specific documents and guidelines. These present informed consent as a central means of “respecting donors” by providing “relevant information” (Global Alliance for Genomics and Health [GA4GH], 2015;

H3Africa, Working Group on Ethics and Regulatory Issues for the Human Heredity and Health, 2013; Hayden, 2007; Sariyar, Schluender, Smee, & Suhr, 2015). In consequence, written information is preferred over oral, just as signed consent sheets are preferred to oral agreements.

Studies have explored how ethics fares when taking the form of formalized ethics regimes (Cooter, 2000; Eckenwiler & Cohn, 2007); others have examined research participation as a form of exchange between actors instead of autonomous decision-making (Geissler, Kelly, Imoukhuede, & Pool, 2008; Wentzell, 2016; Whyte, 2011). We now examine the forms of knowing that are most important in information exchange, rather than the harmonized policy vision of an auditable regime of information delivery operating within these constraints (Power, 1997).

## Methods and Localities

In this article, we are not seeking to compare two countries, but rather people in two distinctly different locales who participated in research conducted by one laboratory, funded by the same academic center. We do so to understand information practices operating in these entirely different locales though funded by the same academic center. The locales we compare are very different indeed: With a population approximating 200 million citizens and a size of 796,095 km<sup>2</sup>, Pakistan is about 18 times bigger with 195 million more people than Denmark, with just 5.7 million inhabitants and 43,098 km<sup>2</sup>. According to the World Bank, the gross domestic product (GDP) per capita in 2016 was US\$1,468 for Pakistan, while in Denmark it was US\$53,254. While Pakistan lacks health care infrastructure and is burdened with high rates of communicable diseases, noncommunicable diseases and humanitarian crises, along with high rates of illiteracy and poverty (World Health Organization, Regional Office for the Eastern Mediterranean, 2013a, 2013b), the Danish health care system is based on an egalitarian universal system that offers treatment and care for all (Olejaz et al., 2012), in a context of high levels of education, in a financially and politically stable nation state. These inequalities between research localities also shaped the different ways research participants were recruited in the two contexts—both by the laboratory and by us.

We recruited research participants from each country following the practices and contacts of the respective laboratory undertaking the recruitment.<sup>1</sup> In Denmark, samples were collected by Danish researchers and in Pakistan by Pakistani researchers. In Pakistan, Sheikh participated in the fieldtrips through which material (such as blood samples, biopsies, clinical tests and personal information/family history) was collected, and conducted 36 interviews in the homes of research participants, most of whom researchers initially had established contact with through social networks (Sheikh & Hoeyer, 2018). The interviews were conducted with couples,

extended families, or individuals depending on the circumstances. Most informants were parents between 30 and 50 years old, whose children had finished the first grades or completed primary school and who were suffering from genetic disease. Oral consent was obtained before and after interview. The interviews were conducted primarily in Urdu and Punjabi, in January–December 2016 and March–April 2017 in urban and rural areas in the Punjab Province and Khyber Pakhtunkhwa Province. Three interviews were conducted over the phone. Sheikh was assisted by researchers from the laboratory through which she gained access to the families and help with translation when languages other than Urdu or Punjabi were spoken. To ensure variation, we interviewed families classified by the laboratory as belonging to 12 disease categories, including various types of skin disorders, intellectual disabilities, recurrent pregnancy loss, abnormal growth, and other diseases known or assumed to involve a genetic factor. Most families were affected by microcephaly. Pakistan is particularly interesting for international genetic research due to its high rates of autosomal recessive disorders.

In Denmark, research participants were identified by the laboratory using a public cytogenetic register. When filling in a questionnaire disseminated by the Danish genetic research laboratory (the same one also commissioning sampling in Pakistan), research participants were asked also whether they would be willing to be interviewed by Hoeyer about their experience during research participation. Hoeyer conducted 23 interviews with individual research participants in a university office, in participants' homes or by telephone, based on the research participants' preferences (see also (Hoeyer, 2016) for further explication). Six additional research participants responded by email. The interviews were conducted in Danish.

All presented quotes are translated into English by the authors, and informants are given pseudonyms. In our interviews in both Denmark and Pakistan, we had a shared set of topics for the interview guide relating to both information experiences and preferences, while some questions reflected the local context. Subsequently, we used the same coding framework and analyzed the material according to two broad questions: How do research participants experience the information exchange in the course of their research participation? What wishes and expectations do research participants have as to information practices? These two questions also provide the structure for the empirical analysis that follows.

## Results

### *Practices of Information Exchange and Research Participation*

In the following, we show how research participants in both Pakistan and Denmark used the information acquired through

their participation to make sense of personal queries. They faced various challenges, however, and therefore engaged different forms of information. Note also how participants became enrolled and learned about the research very differently in the two locales. Overall, there is a significant discrepancy between the ideals of information delivery that international ethics policies prescribe and the practices of information exchange that families talked about.

*Pakistan.* When asking research participants in Pakistan about their experience of information in relation to the genetic research project, it was striking how many were uncertain about what our question meant. “I am not sure what information you’re talking about. We just gave the samples and wanted help,” said one informant, a 65-year-old lady, living in a poor neighborhood in a small but highly populated village north of Lahore. We arrived for the interview after driving 50 miles through villages, and were met at a local market by her son, Abdullah, a 35-year-old cobbler suffering from severe achondroplasia. He and his older brother were both physically disabled, yet being the only men in the family, they were forced to work. For them, as for many others, their choice to participate had little, if anything, to do with information about the use of the sample, rather it was about reaching out for help (cf. Copeman, 2009). As we will show in the following, the ideals of being able to control and audit information propagated by harmonized ethics policies are at odds with the local reality in Pakistan. Here context and form matter more to people than does the actual content of the information, and rather than focusing on what they might be told *before* participating, they tend to focus on information exchanges *during* the course of the project.

When it came to the context and format of information delivery, families enrolled in the genetic research often could not read and therefore they rarely received written standardized information introducing the genetic research and its purpose. Instead, various forms of alternative information traveled by word of mouth: From the researchers wanting to recruit research participants, information spread to local communities who heard about it through their friends, families, doctors, teachers, or the like. When contact was made, researchers would travel for many hours or days along unmade gravel roads and through villages to reach families in remote areas. This is when many families and researchers met for the first time, and the purpose of the trip was most often to collect samples, family pedigrees, and clinical information. Therefore, in practice, participants had already agreed to participate in research before they even met any researcher or received any official information, and after the researchers had driven so far, to withdraw participation rarely appeared an option.

One example of this came across in an interview with a 55-year-old farmer, Faisal, living in a small clay house in a

village 100 miles by road from the Pakistani laboratory with his wife and two unmarried cousins in their 40s, the cousins both suffering from microcephaly and severe mental disabilities. He explained that his son’s schoolteacher had informed him about “the people coming to the village to take blood.” This schoolteacher was in fact an old friend of a genetic researcher, a PhD student working for the laboratory. This researcher had given the teacher information about the research, along with explanations of the type of phenotypic traits he was looking for. The teacher had then communicated this information with her own vocabulary and understanding to her students to identify possible research participants in the local community. When the family was identified, the information and “permission to take samples,” as Faisal formulated it, traveled through himself, his son, the teacher, and then finally to the researcher collecting samples. Previous research has shown how recruitment workers shape their own messages (Copeman, 2009; Kingori, 2013), but in our case recruitment is partly done through relatives and networks of friends, which is a common type of social organization in Pakistan (Mumtaz, Bowen, & Mumtaz, 2012). Clearly, under these circumstances the content of the information delivery is haphazard and not subject to control.

Faisal thought the researchers had come for a “checkup” of his cousins but still agreed to participate when told about the research, as the “way they came” made the man respect them. In this country, so marked by gross inequalities, the vehicle itself served as the means of communication. Musarat, a mother to two children with microcephaly and four healthy children, explained she did not receive any “information”: “They didn’t talk to me at all. They spoke with my little brother, outside the house, and then he brought them [the researchers] inside. But it was fine, they were nice.” Note here, how both Faisal and Musarat did not object to participating in the research despite not knowing what the samples were for. Musarat had spent a lot of money traveling to shrines and offering gold and money for the rest of her children to stay healthy, and Faisal was preoccupied with his son being a good student. They had other hopes for their family members and did not place much emphasis on the donation process per se. Some families highlighted the fact that the researchers traveled far “just for them” in official vans and looked educated. Clearly many participants cared more about form than information content, or, rather, the fine van and the good manners of the researchers conveyed information about dedication, status, and competence.

Many people stated that it was only the head of the family who was able to process the complex information about the research, the only one with “*samaj*,” by which they meant “ability to comprehend.” When would later talk to the head of family, often a male figure, he would frequently express many doubts about what the research was for. One



elderly male head, Nadeem, explained, “They didn’t say anything about what the objective was. Just that they would take some samples and ask some questions and would do some search. We thought the search had something to do with treatment.” This donor had caught the phrase “search” instead of “research” in his information from the researchers. While some research participants recognized research in itself as something different than treatment, and saw it as a legitimate agenda, many did not distinguish between research and potential help and treatment, and this influenced their perception of, and expectations as to, information exchanges. Appelbaum et al., (1987) once coined such connotations of research and treatment as “therapeutic misconceptions,” but our case is closer to what Street (2014) has identified as a matter of translating a basic ambiguity involved in any communication into a window of opportunity for researchers engaging vulnerable and poor participants: The participants eagerly invested hope in researchers who in turn thrived on this investment.

Research participants talked a lot about information they had acquired or had *the impression* that they were about to acquire—about potential treatment, reports about their condition, and information about the risk related to intrafamilial marriage; all this potential information was very important for them. Many explained that they were participating so as to learn about treatment opportunities and be first in line if any cure was found. In some instances, when novel mutations were found, researchers had to visit the families a second time to conduct clinical tests or biopsies. Participating in these was seen by research participants as a step closer to getting treatment. When we asked them specifically about what information they remembered being given, mention of forthcoming “reports” on their condition was one of the most common answers. The Pakistani laboratory has established a function where they are able to send out reports to some of the participating families with information about a specific condition after genetic sequencing. With these reports, the goal is to convey genetic carrier status for family members.

Yet in practice this function has not been successful in providing these reports for all participants, as the setup required an individual effort by each researcher—not always feasible. Waiting for reports was stressful for some families: One family father, Umair, living in deep poverty in a small village in Punjab, was very worried about his daughter who was suffering from microcephaly and intellectual disability. He explained,

They said I would get some reports within one year, and that the samples were taken abroad [. . .] they told me that they have a team, they will try to find treatment for my daughter. They didn’t ask for any money or anything else. Why should I lie? They didn’t even ask for water. They only took the blood from all of us. So now we are waiting for the reports they talked about.

As described in a different paper (Sheikh & Hoeyer, 2018), the information about taking samples abroad (like the visit from the researchers in the fine van) represented a chance of getting help from imagined resourceful distant actors. Sheikh met only two families who had received a report on their condition, while 12 families shared expectations of receiving some kind of treatment, help, or report after their participation. The eager references to reports and longing for treatment also resulted in them trying to influence Sheikh to understand their cry for help and to do something about their situation. In this way, we became engaged in information exchanges ourselves. Even though the information in the reports that the families were supposed to receive would only help them if someone opted for prenatal screening, many families were upset that they had not heard from the researchers. The reports are another symbol of the investment of hope. They interpreted the word “wajah” [reason] in an action-oriented sense; when they knew the reason (i.e., the chromosomal mutation) behind the problem, they hoped they would be able to act.

These reactions show how information practices relate to much more than the consent process and interact with very intimate aspects of research participants’ lives.

*Denmark.* In Denmark, too, people talk about intimate aspects of their lives, but their hopes and concerns are inscribed in very different landscapes of opportunity. Most research participants described the information they received as sufficient and satisfactory, though actual remembrance of specific details was limited. Erik, a man in his early 60s living in a rural area far from university hospitals and researchers, had learned about his chromosomal rearrangement through having a disabled daughter. He explained how he liked the tone of the letter later inviting him to participate in research about this genetic variation: “They sent a nice letter and explained things and were very interested in having me participate (. . .) the way they sent the letter, well, I am informed.” Interestingly, Erik did not remember the content of letter and did not know the purpose of the research project, and he could not think of anything he would have wanted to know: His choice of participation was thus based more on a *feeling* of having been informed than on an actual transfer of information. Mostly, however, people had only a vague sense of how and when they became enrolled in research, and when asked how they came to participate in the research, only few thought like Erik of the letter inviting them. Instead, they began talking of events in the family that led to genetic testing in the first place.

This confusion of diagnostics and treatment (in some ways similar to Pakistan) should not necessarily be seen as indicative of poor information practices, as this area of genetic counseling has long had a blurred boundary—families therefore might very well have felt little difference

between finding out about their mutation in the first place, and the specific invitation to take part in the research project we were investigating. Also, several ethnographic studies of genetic research participation in the Nordic countries have found that people do not read, remember, and use the information offered in conjunction with the informed consent process (Brekke & Sirnes, 2006; Hoeyer, 2003; Skolbekken, Ursin, Solberg, Christensen, & Ytterhus, 2005).

In fact, only a few participants talked about requesting information in relation to the informed consent process. Anette, a woman who had several impairments and who had lived a tough life with many social challenges, felt she needed to call the researchers before joining the project. She was dyslexic, but the call was not about getting information she could not read—she did not want to know anything specific; she wanted to hear the *voice* of the researcher. She had felt abused in previous research projects and wanted to “know” the person requesting her participation. We can see this as an interest in a relationship of mutual recognition, which for her was not satisfied with a formal informed consent sheet. Christian, a man of around 60 years who had kept the family chromosomal rearrangement secret and not even told his affected child, also contacted the lead researcher, more to convey his story and his choice of secrecy than to learn about the specifics of the project:

I didn't meet her, no we just exchanged emails. And this whole story that I've just told you, she got that on email. And what happened was. . . she acknowledged me. I mean, it was a matter of respect. Like that. (. . .) So I experienced her as a sympathetic person. So we called each other, spoke on the phone. A sympathetic person. Trustworthy. Calming.

Note how he did not talk about *receiving* information based on which he made a choice, but about *conveying* information to the researchers and feeling ensured that they respected his specific choices. In fact, he later commented that there were too many formalities in the information procedures. For example, he found the standard formulations about a right to withdraw “annoying.”

This does not imply that nobody emphasized the virtues of a written informed consent. Henriette, a woman in her 40s engaged in several research activities and a fierce fighter for her two disabled children, stated she would lose trust “if they did something without informing [me] about it (. . .) I want to know what I am a part of, and what I'm not a part of.” Similarly, Lisbeth also in her 40s and a researcher herself emphasized the procedural aspect of informed consent: “I would be freaking mad if they began using my stuff freely for all kinds of things!” However, neither Henriette nor Lisbeth could remember the information they had received, and in this sense, it was perhaps not so much the substance of the information as the notion of

respect associated with a *mutual* agreement that seemed to be attributed to the informed consent process.

When people did not remember the information received, could not pinpoint the specific point in time when they became enrolled, and could not easily think of information that would have influenced their choice, then this choice of participation cannot be attributed to the information content delivered in conjunction with the consent process. And when the Danish participants explained why they participated, they spoke in an altogether different register from the Pakistani participants. They talked about being citizens in a country with a “system” that cares for them, about “giving something back” to those doctors who had helped them or their children, and about ambitions of furthering knowledge and helping others. The context of the welfare state clearly mattered greatly to them. In consequence, their use of the information they acquired differed from the participants in Pakistan. For people like Lisbeth and Henriette, the consent process is clearly part of creating a trustworthy system: A written document with signatures is associated with authority, rules, and decency (Jacob, 2007; Riles, 2006). The information sheet thus operates as a symbol of auditability and control—not thanks to its inherent messages, but thanks to a more generalized impression that a written, formal agreement limits what researchers can do. Participants were not themselves controlling the researchers, but expected others—a “system”—to be doing so. Besides being derived from the wider context of the Danish welfare state, the information sheet acquired these qualities through format and genre. Erik, who could not recall the content of the information, clearly remembered the way it was given (“a nice letter”). Similarly, Anne-Sophie, who was a young academic woman, said that “information levels (. . .) have been fine. We had a long letter and a questionnaire, and it was really . . . easy to fill in. It was all very pedagogical.” In Denmark, unlike Pakistan, a letter and a questionnaire can do this kind of work for the researchers, but it reflects the interpretive context as much as any inherent properties in the consent sheet.

Even more striking, perhaps, is the fact that when talking about information, participants would associate this, like Anne-Sophie, with what they had “learned” from the questionnaire they filled in (rather than from the consent process). They did not talk about information as a matter of making decisions, but as a matter of learning about their chromosomal rearrangement. They explained how they felt that various items from the questionnaire could be used to further understand conditions they knew from their own or their relatives' lives, often taking the questionnaire as a source of information (rather than a list of questions). Several were excited about getting a glimpse into new scientific hypotheses (Hoeyer, 2016)—research participation was associated with gaining privileged access to information from the research frontier. Information was thus

discussed as a form of benefit acquired *during* the course of the project, rather than something offered *prior* to the decision to participate or after results had accumulated.

### *Information Needs and Wishes*

Turning to the information needs and wishes articulated by the research participants, we show how research participants in both countries longed for *meaningful* information and an *ongoing dialogue* marked by mutual respect and recognition. Meaningfulness, however, depended on context. In Pakistan, people often had concrete hopes and expectations as they sought treatment or, at least, ways of aligning their suffering with meaning. In Denmark, people associated research more with curiosity. They could and did turn elsewhere when in need of help.

**Pakistan.** When Sheikh asked research participants about which types of information they would want to receive and how, all research participants immediately spoke of possibilities of treatment and cure. They did not see information as a separate issue per se; it was engrained in their quest for alleviation of suffering (Whyte, 1997). Sheikh's questions about information needs were translated into articulation of other needs. "Meaningful" information was thus when participants felt they gained information about how to obtain treatment, diagnosis, or other forms of clarification, or in some cases even financial help. Most people articulated their desperation to know if and when there was a cure for their disease, and waiting for answers constituted a source of frustration. One woman, Mahlaka, who was in her 30s, had been desperate to discover the reason for recurrent pregnancy losses. She felt very upset because she had been waiting for some type of response from the researchers:

I didn't need more information about the research. People [the researchers] came to me twice. They came after two or three miscarriages. Still they were telling the same story. That they are trying to find the cause [. . .] but I don't understand. No one should wait that long for more information. How can I wait all this time? How much longer should I wait?

While it might first sound as if she just wanted feedback from research results, her impatience indicates that she made little distinction between research (which might not have a definite result) and diagnosis and care. Like Mahlaka, others were also waiting for a diagnostic result or some explanation while making several references to the "report" they had been told about, as mentioned above. One typical answer about information wishes was expressed by Abdullah, the shoe mender from rural Punjab: "We thought that we would learn more about the condition and what's wrong with me." Later in the interview Abdullah stated

bluntly, "We don't need them to contact us and inform us about rights. We need a solution. And if they can't help us we need you to tell us." Note here, how even negative information would provide a sense of closure involving some comfort. Similarly, Farooq, a male engineer in suburban Lahore whose wife suffered from recurrent pregnancy loss, said, "I know it's difficult even to make a proper diagnosis at this point, but I wanted to know. It's like, these people's research should have an impact. Can you please tell me, whether this genetic condition can ever be solved?" The local basic need was information about their disease; results that might never come. They needed a basic health service infrastructure that could help answer their questions. To meet local needs and negotiate expectations, researchers in the field must establish a more extended form of dialogue with research participants.

If information about potential cures (or the definitive absence of cures) was central to most participants, it is important to note that some donors only expected to hear that the research would help others in their situation in their local community. One father, Josef, who was taking different jobs as a day worker to provide for his family and two paralyzed nephews, saw his participation and the research as a "great jihad" and did not aspire to anything more: "This world is not the only one I have to think about. Despite my situation I also have to think about others," he explained when asked about his information needs. When participants accepted their fate in this way, they did not want to receive more personal information but they did want recognition for their "good deed" of participation (cf. Reddy, 2007) which could also create meaning and hope. Again, to support this ambition, researchers need to engage in a dialogical, two-way, form of information exchange.

Research participants also asked questions relating not to the research, but to the daily challenges of living with their disease. In the absence of a well-functioning health care system, the researchers came to serve as sources of information for a range of issues beyond their specific area of competence. During one interview, a 17-year-old girl posed a question about her sister, a 16-year-old girl with ataxia: "Do you think someone's put a spell on her?" A little later her father asked, "Should we change her medication? Should we even be giving her medication? Will she ever get better?" This was a desperate attempt to get answers and clarification. People wanted to test the information they had from other contexts, including traditional remedies or spiritual healing and "kala jadoo" [black magic]. Participants requested information that they could use to handle the uncertainty related to their own lives (cf. Whyte, 1997).

**Denmark.** When the Danish research participants discussed information wishes, they related much like the Pakistani participants to temporality, form, and meaningfulness. The Danish participants, similarly to those in Pakistan, were

genuinely puzzled that it could take years to do research, comparing the waiting time with that of “lab results” in everyday care. They also requested opportunities for continued dialogue. Kirsten, a woman in her 40s from a rural area, wanted continued follow-up throughout the project: “Well, it could be something after a couple of months, ‘now we are doing this,’ or ‘we are working at full speed,’ and so and so. Just a debriefing. It would great for someone like me!” Likewise, Else stated, “My wish is of course to learn what’s happening. Follow what they’re doing. In relation to me, or how should I put it? The results of the project (. . .) ‘now we’re at this stage’ and so on.” The Danish participants thus conveyed an interest in a continued information process. Whether this would in reality lead to information fatigue, cannot be inferred from this study, and when we in our own research have communicated follow-up information, we have had no reactions. Nevertheless, we note how people requested information in a dialogical form that is difficult to sustain for both genetic and social science researchers within the constraints of contemporary research funding regimes.

Interestingly, several of the Danish participants emphasized face-to-face meetings as their preferred format for this continued dialogue. The emphasis in the policy papers on controllable, auditable, written communication is strangely at odds with this longing for real-life encounters. Anette, who could not read, obviously preferred oral information, but also others like Anne-Sophie said that in a “perfect world” she would have liked an opportunity to meet the researchers: “If you could say, this and this day, we’ll talk about the project, an hour, half an hour, whatever.” While the Danish participants (except Anette) could easily read information, the physical encounter seemed to offer them something more. When Hoeyer explained how thousands of people around the entire country would need to be gathered, Anette and Anne-Sophie quickly asserted that their idea would be inapplicable—but it is important to remember how the oral face-to-face format was seen as delivering something they did not get from consent sheets. Nicklas, a young man with a history of psychiatric disorders, explained how he wished that not just researchers, but doctors too would “stop talking *to* people; talk *with* them. There are many doctors who are. . . socially impaired so to speak, they don’t know how to talk to people (. . .) it’s all about reaching people eye-to-eye.” For Nicklas, information practices should be about expressing mutual respect and interest.

What did the research participants in Denmark want to talk about? They wanted “meaningful” information, they typically said. “Meaningful” referred not to formally assessed levels of comprehensibility (as often discussed regarding information sheets), but to what made sense in the contexts of participants’ personal lives. As Dewey (1947) remarks, “meaning” relates to forms of knowledge people feel they can use. Anne-Sophie knew of a particular

disease running in the family and thought, “It might have something to do with this [chromosomal rearrangement], and it might *not* . . . but I think this is the type of thing I need to know.” Later she continued that it “could also just be for the sake of curiosity. It’s not like I expect a manual of how to live the rest of my life.” Unlike the Pakistani participants, the Danes did not invest the same desperate hopes in the research activities. They invested curiosity. What became meaningful for them reflected their personal histories. But mostly the Danes relied on the health services and social services of the welfare state for many facilities for which in Pakistan participants turned to researchers in the hope of receiving. Importantly, however, in both countries donors expressed wishes for further information about entirely different areas beyond the methodology and content emphasized by the ethics policies. Participants wanted information addressing their personal curiosities, preferably through dialogical forms of communication.

## Discussion and Conclusion

With this study, we have sought to separate debates regarding information from traditional discussions about informed consent and feedback of genetic research results. With these findings, we cannot generalize on information needs across countries or types of research; what we show instead is that significant variation is possible even when the same laboratory collects samples and data in two different locales, and that even in these two very distinct locales, participants from both had information needs that were not captured with the current focus on informed consent and feedback of results. We therefore think that there are reasons to explore, also in other settings, which types of information people remember, use, and prefer—and in which formats and when.

We have compared research participants in a high-income welfare state, Denmark, with people from Pakistan, a low-income country fraught by political unrest and health care failure. These participants agreed to take part in the research undertaken by one and the same laboratory, but they came to do so through very different information practices. Nevertheless, we found both similarities and differences as summarized in Table 1. Research participants in both Denmark and Pakistan wanted *meaningful* information, and in both countries participants actively sought to *make* information meaningful in light of their own situations. However, the socioeconomic, cultural, and political contexts differ so radically between the two settings that the same pieces of information, provided in the same manner, could never fulfill the same objective: They could not address the hopes and concerns of those people giving genetic samples and personal illness narratives to the international research endeavor.



**Table 1.** Similarities and Differences in Experiences with, and Wishes for, Information Among Research Participants in Pakistan and Denmark.

|  | Pakistan   | Denmark   |
|--|--|---|
| How do research participants describe their experience with information? | <p>They use the information acquired through participation to make sense of personal queries. They focus less on content, and more on form, and praise the form when it provides a sense of respect.</p> <p>Generally they do not seem to remember, use or recall specific information given in conjunction with the consent process: Their choice of participation does not build on the information provided.</p>            |   |
|  | <p>Information comes through multiple oral sources and its content is haphazard. The meaning of the information is mediated by the networks providing it. People use information to learn about and negotiate the meaning of family disease. Information serves as a source of hope, for example, they remember samples being sent abroad. Few people articulate an understanding that they have participated in research.</p> | <p>Official information is mostly written and documentable, but people do not remember the specific content. The meaning of the letter is mediated by awareness of social institutions. People use information to make sense of family challenges and personal queries. Information serves as a source of respect/ recognition, for example, they notice that consent puts limits on researchers' freedom. Everybody articulates the understanding that they have participated in research.</p> |
| What kind of information do they wish to receive?                        | <p>People express interest in ongoing dialogical forms of information exchange. People emphasize forms that involve respect and mutual understanding, and they like oral communication. People request information that is meaningful for their lives.</p>   |   |
|  | <p>Information is meaningful when it allows people to act, or which aligns suffering with meaning. Many have concrete expectations of feedback and are disappointed when timelines are not kept.</p>   | <p>Information is meaningful when it relates to interpretations of personal queries and doubts, or stimulates the sense of curiosity. People have few concrete expectations and can go to other sources for help when they need it.</p>   |

Note. The table lists what is partly shared across contexts and what differs between them.

Harmonized global ethics policies are meant to address exactly this type of research endeavor operating across global inequalities and cross-national regimes of formalized ethics. However, the policies have come to focus on information delivered *before* or *after* research participation, either in relation to informed consent procedures or feedback policies, and thereby they have come to tie our understanding of information needs to these organizational procedures. The temporal bifurcation, the division into “before” and “after,” poorly matched the experiences and preferences of the participants in both contexts (Pakistan and Denmark). Most participants sought to engage an ongoing dialogue. In some cases, informed consent is not about giving information, but a form of power-sharing that can instigate a dialogue. What we propose, however, is a simpler way of initiating power-sharing: to ask research participants questions about their hopes and concerns and to do so independently of (and in addition to) the informed consent process. Information can serve as a source of respect and recognition (in Denmark), or a source of hope, understanding, or help when dealing with suffering (in Pakistan). The comparison between Pakistan and Denmark thus allows us to see the limits to harmonization or, at least, how harmonization might in some cases be at odds with the interests articulated by the participants.

We believe that the ambition of harmonization should not become a barrier to seeking to understand the people whom we engage in research in all their potential diversity and that empirical ethical analysis plays a special role in stimulating these types of reflections. When accountability regimes have resulted in systems that do not seem to work in practice, it is dangerous if ethical analysis is swallowed up by compliance debates. We believe it is important for medical ethics and social studies of science to articulate the interests of those who rarely gain a voice in research policies, and for ethics policies to work toward an organization of research that responds to these voices. There should be a special role for empirical ethics in making outreach respond to real local needs (Jeffery & Jeffery, 2010).

Finally, it is worth contemplating briefly how the findings presented here relate to the emerging trend in international research collaborations toward conceptualizing information exchange as a matter of giving individuals control of the exchange of their own health data. This trend is sustained by the European Data Regulation (2016): a legal framework that installs a data portability principle giving individuals the right to sell or donate their data to vaults managed by either companies (e.g., Blockstack<sup>2</sup>) or nonprofit trusts (e.g., Sage Bionetworks<sup>3</sup> or My Data<sup>4</sup>). This movement might be seen as

making research participants into exchange partners and thus providing some of the features we have found missing in existing debates about international collaboration. There still remains the same division of researcher obligations toward information into a “before” and “after” the project; however, participants are now being acknowledged as sources of information in the period in between. Yet this does not necessarily speak to the interpersonal desires for mutual recognition that we found participants longing for, nor does it guarantee the care that participants, in particular in Pakistan, request. Furthermore, the people who are most destitute are inadequately equipped to strike a balanced deal when they agree to take part as donors (Orth & Schicktanz, 2017). We therefore wish to emphasize how no legal “quick-fix” can create the contextually dependent forms of mutual respect and recognition that participants request. We need to embrace the very ethos of research and bring the stories of the data sources into researchers’ conversations to allow the researchers to contemplate the situation(s) of the participants. This article attempts to do that.

## Best Practices

Most donors request an ongoing dialogical form of communication. This implies focusing not merely on what researchers convey to participants but also on what participants do with the information offered and on the hopes and concerns that participants want to convey to researchers. To soften the global inequalities in research recruitment, there is a need not for further harmonization but for new forms of stratified demands: The threshold for acceptable information exchange cannot continue to be the same for countries like Denmark and Pakistan, and different funding standards are needed for bringing them into balance when health care systems are unable to support families with their queries.

## Research Agenda

It is important to begin exploring information practices in research participation independently of informed consent and feedback rules, to better understand what people want, what they remember, and what they see as information gained, as well as what they use, and for what purposes. In particular, there is a need for more qualitative investigations of information experiences and practices related to data collection in low-income countries. This is especially important as the international urge to collect data for health research purposes across regions grows, along with the distance between collection sites and research funding agencies.

## Educational Implications

Researcher training should work on the *ethos* of researchers and not just the formalized ethics procedures surrounding

research projects. Understanding the current divides between policy and experience and learning not only to *respond* to but also to *ask* questions could improve the probity of the research and help researchers to better handle information exchanges. Asking questions will limit the influence of the researchers’ own assumptions and give voice to concerns that research participants might have.

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## Notes

1. We have followed the rules set by the Danish Data Protection Agency and a Research Ethics Committee in Pakistan. Qualitative research is not subject to research ethics committee approval in Denmark.
2. <https://venturebeat.com/2017/12/04/blockstack-raises-52-million-to-build-a-parallel-Internet-where-you-own-all-your-data/>
3. <http://sagebase.org/>
4. <http://mydata2016.org/>

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