Beyond the Formal Mechanisms of Public Engagement

Communicating Biobanking Research with Other Means

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Abstract: In this contribution we explore novel, different ways of promoting public engagement in biomedical research using biobanks. Starting from a discussion about the limits of traditional formal procedures of engaging participants in biobanking activities, the contribution proposes two approaches to public involvement that use the Science Museum as an agora for communicating and representing the complex scientific, societal and ethical issues involved in contemporary biomedical research. The role of museum exhibitions, metaphors and languages of art and theater, as well as other forms of dialogues, are discussed as a way of shaping popular imaginaries about scientific research, in order to complement mechanisms of public engagement with novel forms of stimulating public understanding of scientific research using tissues and genomic data.

Keywords: science museum; art, theater; dialogues; biobanks; public engagement.

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Introduction

Lorenzo Beltrame

Issues related to participation are, likely, the most debated in STS literature on biobanking. In fact, biobanks rely on the willingness of volunteers to donate tissues and to give access to their medical, genealogical and lifestyle data. The provision of tissues and bioinformation clearly involves issues of privacy, confidentiality, informed consent, ownership, benefit-sharing and commercial exploitation (Hoeyer 2008). As noted by Tutton (2004, 19) the willingness to freely give samples and personal in-

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formation has been promoted by medical institutions by emphasizing ideals of social solidarity and personal altruism, the common purpose of improving human health through research and by resorting to powerful discourses of gift and 'gift-giving'. But, as Hoeyer (2008) remarked, the wide plethora of social and ethical issues has been dealt mainly with the same organizational solution, that is the informed consent.

Informed consent is considered a sort of technology of neoliberal governmentality, which produces the donating subject as an empowered, autonomous citizen who makes choices based on risk-benefit calculations, who is oriented to the fulfilling of her/his wellbeing and endowed with the right and duty to participate (Corrigan 2004; Hoeyer 2004; Tutton 2007). Even if it is largely still in use, however, the mechanism of informed consent is under criticism by STS and bioethics scholars.

First, its predominant focus on individual rights has been called into question. The so-called 'communitarian turn' in bioethics (Chadwick and Berg 2001; Knoppers and Chadwick 2005) has highlighted how this juridical mechanism is insufficient to deal with the collective nature of benefits and risks involved in biobanking research, by claiming the need to develop mechanisms to deal with ethical principles locating at the level of community and/or groups such as reciprocity, mutuality, equity and solidarity.

Second, the strong opposition to the Icelandic biobanking initiative – promoted by family doctors, the Icelandic Medical Association and *Mannvernd* (the Association of Icelanders for Ethics in Science and Medicine see Pálsson 2008) – showed the need to adopt more participative approaches to ethical oversight. Mechanisms of broad consent, in which participants are given information about the wide range of aims and objectives of biobanking research, have been implemented resorting to forms of public consultation through focus groups and other forms of participative ethical oversight (Corrigan and Tutton 2009).

Public engagement is thus the key word for assuring legitimacy in biobanking participation, even if the concrete strategies for enabling engagement vary a lot across different initiatives (Tupasela et al. 2015). As noted by Weldon (2004), several public engagement mechanisms are inspired by a logic of promoting scientific citizenship (Irwin 1995) by involving participants in dialogues, consultations and in participatory forums of decision-making. Indeed, a scientific citizen is not simply one fully informed, but is one who has to be made able to negotiate and influence policy decisions and research projects.

However, STS scholars are also aware of some limits of the participatory tools adopted in formal mechanisms of public engagement. McNamara and Petersen (2008), for example, have shown how these mechanisms are not neutral tools, but reflect – and work according to – assumptions about those who are to be engaged, shaping thus their participation toward forms of ethical oversight which have little substantial impact on issues of ownership, access and broad public benefit. Weldon

(2004) has discussed how public consultations are often weak in giving participants a real opportunity to influence the direction of research or to exert a true civic agency on the claimed wider societal issues (such as what counts as the common good). In fact, these mechanisms are suspected to be mainly oriented to channel participation toward a more readily provision of samples than toward an effective partnership in biobanks governance (Tutton 2007; Cañada et al. 2015).

Several researches have shown how often participants in biobanks can be uninterested in being informed and in active participation, while they donate just out of altruism through consolidated institutional practices of trusted organizations (Busby 2004; Busby and Martin 2006; Tutton 2007). Hoeyer (2004, 100-1) have brilliantly demonstrated, by interviewing biobanks participants, how uncertainties, worries and vague, inaccurate if not wrong understandings of the aims and scopes of the research outcomes characterize participants. Notwithstanding informed, participating donors appeared affected by an imaginary of cloning, eugenics, "designer babies" and genetic manipulation, largely shaped by mass media and other popular representations of science.

This has raised the main questions addressed in this contribution: how to promote effective forms of public engagement without making participants fully aware of the real aims and scope of scientific research? Is it possible to conceive forms of engagement in lack of a public understanding of what biobank research is currently doing? How to communicate the implications of biobanking research using languages more apt to the familiar popular imaginaries of science? What are the spaces, beyond the formal sites of public engagement in biobanking, to promote a public understanding of scientific research?

In the following interview, Lucia Martinelli explains how the science museum and the theater can be considered possible *agoras* to explore forms of public engagement with genomic research using the languages of museum exhibition, theater and art. Lucia Martinelli has been responsible of the curatorship of the 2018 temporary exhibition *'The Human Genome. What makes us unique'* at MUSE the Science Museum of Trento (Italy). As she argues, this exhibition devotes a large part to the exploration of the implications of genomic research both through direct to consumer (DTC) genetic test and through biobanking. And she illustrates how to communicate the social, cultural and ethical issues related to these technologies using metaphors and the language of art and exhibition. She has also a long experience in interacting with theatrical artists with whom she narrated the social implications of contemporary biomedical innovations. Lucia Martinelli's professional career is exemplary of the search of new ways of engaging the public, involving it and promoting public understanding of science. Formed as a biotechnologist, Martinelli progressively moved to STS, to become finally a science communicator using the science museum and the theater as means to vehiculate engagement and public understanding of lay people, by offering narratives of the complex issues rotating around current biomedicine and biotechnology that resonate with shared and familiar imaginaries. Her contribution shows how to promote a different understanding of the aims, scopes, potentialities and perils of modern biomedical research, how to conceive the museum as an important agora to involve people and, then, to complement formal mechanisms of public engagement in citizens' participation to biomedical research.

The topic of alternative spaces to enable people to explore the meaning and the implication of contemporary biomedicine is discussed also by the science historian Ilaria Ampollini. She discusses the substantial lack of public engagement mechanisms in biomedical research in the Italian context. Then, she presents the program *CLaSTer. How Science Works. Dialogues between University and the Region* (CLaSTer. Come Lavora la Scienza. Dialoghi tra Università e Territorio). It is a local project aimed at enhancing collaboration and dialogue between University and research institutes, the Province Health System, healthcare professionals and, above all, patients, patients' families and patient associations. This project is largely based on public dialogues with citizens representatives, and is hosted by the MUSE – Science Museum – complementing the exhibition on Human Genome as a way of exploring multiple languages of communication. The local setting allows, indeed, to coordinate the work of the local University Department of Biomolecular Sciences, the Department of Sociology and Social Research, the Province of Trento Health System (with its Trentino BioBank and the Clinical Service for Medical Genetics) in order to develop a wide-scope program of public engagement.

The fact that both the experiences discussed by Lucia Martinelli and Ilaria Ampollini have a local setting should not be considered a limit. On the contrary, what has been argued in this Special Issue is that participation has to be conceived and studied as the outcome of concrete practices enacted by actors involved in situated institutional settings. What these contributions add to the analyses presented in the original research articles, is the need of complementing both the interactions between actors and the formal mechanisms of engagement with novel forms of dialogue and communication, in order to promote a better understanding of the aims, scopes, implications and issues involved in biomedical research using biobanks. The experiences and examples presented by Lucia Martinelli and Ilaria Ampollini, clearly show how exploring popular imaginaries and communicating biomedical research with the languages of art, theater and museum exhibitions can play an important part in solving uncertainties and in promoting the voices of common, lay people who decide to participate in biomedical research.

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The Science Museum as an *Agora* for Public Engagement in Research Using Biobanking

Lucia Martinelli (interviewed by Lorenzo Beltrame)

Can you tell me the path that led a biotechnologist to became an STS scholar and then to move to explore new languages in communicating biomedical and genomic research?

My research activity in the field of plant biotechnology started in early 1980s with the internship for the degree thesis on genetics, when the term “biotechnology" was neither in use. Since then, for three decades, I have carried out research in industrial and public institutes in Italy and abroad. Therefore, I am a witness of the biotech development concerning both the technoscientific aspects and its growing impact on society (Martinelli et al. 2013a). If during the 1980s biotech has been regarded as a carrier of important achievements for humankind, since 2000 it has become an icon of citizens’ distrust toward science innovations. This shift had a strong impact on research and led the European Union to launch specific programs to face the gap between science and society.

I always like remembering a photograph I have personally taken in May 2000 in Genoa, during the first Italian major protest of the rising no-global community against TEBIO, an important conference on biotechnology. In this shot, a wall of armed police forces between the scientific community and the civil society portraits two conflicting visions about biotechnology whilst it seems to underline the gap between science and society. Being strongly involved in a controversial field of research, such as gene transfer (Martinelli and Mandolino 1994) and also interested in the social and political responsibilities of science, my projects started to have a multidisciplinary feature, also including humanities and social sciences in the laboratorial activity. This was the case of the OSSERVA3[1] and EcoGenEtic.Com projects (supported by Trento Autonomous Province) where forums of dialogue and tools to manage risks perception (Martinelli et al. 2006) were experimented.

Then, since 2011 at MUSE, my main research interest became STS. I was involved in multidisciplinary networks connecting experts in life sciences, social science, philosophy, bioethics, biolaw and art. In the COST action “Bio-objects and their boundaries”[2], for instance, the products of biology innovations were analyzed as bio-objects sharing peculiar features at the intersection of society, politics and science: they promise a better quality of human life whilst rising controversy, undermine the boundaries between living/non-living and natural/un-natural/artificial, may result as “out of place” entities and require specific regulations and communication. In particular, I focused on contested products of biobanking such as *HeLa* cells (Svalastog and Martinelli 2013), animal de-extinction (Martinelli et al 2014), gene transfer (Martinelli et al. 2013b; Pavone and Martinelli 2015), and assisted reproduction technologies such as preserved human eggs (Martinelli et al. 2015) and human embryos (Piciocchi and Martinelli 2016).

From theory to practice, in the framework of European projects, at MUSE we are developing tools for public engagement, based on the view of a more responsible research and innovation in various fields of biotechnology, such as synthetic biology (SYNENERGENE project[3]) and nanotechnology (NANO2ALL project[4]).

Usually lay people concerns are dealt with participatory decision making tools. How did you, instead, explore this issue using the language of exhibition?

Since public acceptance and legitimacy in decision-making and governance of biotechnological and biomedical innovations is a critical issue, inclusive communication is required. The metaphor of the *agora* well represents the mission of cultural institutions to act as elite forums for shared communication involving the various actors of science. Today, science museums are recognized as suitable *agoras* and “safe spaces” where science and society can meet and engage in challenging conversations (Svalastog et al. 2014). In a project concerning assisted reproduction technologies, for instance, during focus groups at MUSE[5], parents/potential parents were even surprised about their own comfortable feeling – as they never experienced before – in revealing their private experiences to the other participants.

Starting from this open concept, we designed the main 2018 MUSE temporary exhibition *‘The Human Genome. What makes us unique’*. In particular, in a core section of the exhibition, focused on genetic predispositions, we projected a scenography recreating a square where getting together the knowledge and the experiences of the main actors of the biomedical field in our society: lay people, the scientific community, medical care professionals and policy makers. During the preliminary brainstorming it was suggested to place the experts in the center of the square and, on the border, the lay people, as a metaphor for inviting exhibition visitors to approach for listening, in intimacy, those personal stories mentioned above. Finally, however, we decided to completely reverse the setting. We put lay people at the center of the scenography, to emphasize their central role and highlight their stories. We recreated a sort of "speaker corner" where private stories could become public. Video-interviews to experts, reporting on clinical experience and healthcare policies, were located at one border of the square, while the center of the agora is now for some silhouettes giving voice to “common people”. They narrate “stories-of-everyday-genetics”, inspired by cases reported in the scientific literature, mass media news and real experiences shared through the Internet or available on the websites of medical organizations and patients associations. These narratives aim to enhance the understanding of museum visitors about the impact of new genomic knowledge and applications on our lives. Moreover, at the exit of 'The Square', in an intimate room, visitors of the exhibition are invited to leave their own stories about genetic predispositions. We have already collected a great number of significant narratives about their "everyday genetics", which are still under analysis.

In some cases, current genomics is struggling with determinism, both inside the laboratory and outside in the wider society, where genetics is often perceived as an inescapable fate. How did you try to disentangle these opposed and overlapping perceptions in a Museum exhibition?

What are the reasons of our physical and psychological traits and of the talents and diseases recurring in our families? Is it a question of "destiny" marked by inherited genetic predispositions, or can personal options, responsibilities and experiences shape us? In genetic studies, the interaction between genotypes and environmental factors is a very important aspect of the phenotypic variability. The "nature versus nurture" relation to explain our traits and how we "function" has been object of countless studies, favoring alternatively one or the other component. This question also involves sensitive personal and social issues, as for instance in the case of complex traits associated with behavioral disorders related to psychic and social distress.

Already more than 2400 years ago, to explain the athletics excellence Hippocrates analyzed personal predisposition, exercise, nutrition, age, geographical origin, time of the year and also changes in wind and climate, finally considering the hereditary component as a major factor. This issue is still nowadays a hot research topic of International networks of sport medicine. The scientific literature of the last 200 years reports countless studies based on twinship aimed to associate genetic variability to specific genes or to the interactions between the same genes and different environments. One of the most original research is the recent "Twin Study" in the framework of the *NASA Human Research Program* which is analyzing the data collected from two identical twin astronauts, the one spending one year in the space and the other remaining on the Earth[6].

At the end of the 1990s, when the Human Genome project was launched, the scientific community was strongly divided: a vision considered the gene as the central matter, the other pointed out the need to explore more in depth the complex interactions between genes and the context in which they interact and express (Fox Keller 2000). Recently, this latter approach has become the subject of new attention focusing on epigenetics, that is on how experiences, choices, behaviors and many environmental factors, including nutrition habits, smoking, pollutants and stress, have an effect on our DNA through mechanisms of gene regulation. Contrary to expectations (and to opponents' concerns), the results of Human Genome project questioned the deterministic approach. The new millennium started with the recognition that we are both the result of a complex genome, mostly still to be known, and of an intricate interaction between biological events and environmental and social experiences. Moreover, contemporary genomics knowledge calls even more into question the classical definition of the gene.

This debate is quite fascinating and is also a remarkable example of how scientific knowledge is more a source of uncertainty than of certainty. This is one of the most difficult aspects to be communicated to the general public. However, the growing knowledge about the human genome already applied in several fields, including healthcare. Easily accessible information about our genome, and the availability of markers for genes involved in important diseases diffuse the awareness of predispositions that may lead citizens to undertake a deterministic approach toward their biology. Moreover, results of genetic analyses, in particular concerning health, may be difficult to manage from a psychological point of view, being linked to mere probabilities (will a predisposition to develop a disease turn into a disease?), to events related to the future (when will the "predicted" disease occur?) or to anxiety (how to face diseases without therapies?). For these peculiarity of genetic analysis, it has been established the "right not to know", to make people able to choose not to know certain information. On the other hand, according to analysis of patients' narratives, the awareness of carrying a genetic predisposition to a certain disease may produce, in different people, different impacts. Besides anxiety and distress, a feeling of relief from a sense of guilt has also been noted when the cause of an illness can be assigned to a "sculptured fate" (of which one is not guilty) rather than to a lifestyle (of which one is responsible).

In this framework, in line with a non-deterministic view, the narratives of texts, multimedia and exhibits of *The Human Genome* exhibition at MUSE are meant to stimulate reflections and questions about contemporary genomic knowledge and, moreover, about the knowledge still to be achieved, rather than feeding visitors with notions and dogmas. Worth mentioning some examples. Genetic predispositions are constantly proposed as a probability, rather than a fate, to be translated into traits. The metaphor of the human language, with its "cultural" and "structural" variability, as well as its unknown aspects, is always constant in the various sections of the exhibition. The four letters of DNA – the chemical bases of the genetic code – fluctuate in combinations, of which some have meaning, some not, almost like an ancient language whose alphabet has been decoded, but whose meaning is still little understood. Similarly to a puzzle game, genetic mutations are proposed in an interactive game, where reversing, deleting and duplicating letters and words in a text are used for producing new meanings or non-senses, signifying genetic mutations. The slogan "it's not just a matter of genes", repeated like a mantra in different languages, is the crucial and final message left to visitors. Finally, epigenetics is central, also proposed through an impacting sculpture, which immerses visitors in emotions to feel the interaction between some environmental and psychological situations and the DNA.

One of the main issues in biobanking is trust. How did you communicate about the issues of confidentiality and the commercial use of personal and genetic data?

In genetic analysis, biobanking regards the storage of both the biological samples to extract DNA and data and information generated from the analysis. These latter are the most intimate part of a person and, what is specific for the genetic information, even of his/her family and relatives. This practice may produce the risks of violations of privacy and confidentiality, it could lead to possible discriminations and involves issues of property rights and of informed consent, concerning bioethics and regulation. A renewed example of privacy violation, faced by a symbolic agreement between the U.S National Institutes of Health and Lacks Family[7], was the publication of the genome sequencing of two cell lines deriving from *HeLa* cells (Adey et al. 2013; Landry et al. 2013), which could reveal some hereditary biological information about Henrietta Lacks' offspring.

Population genomics studies require a huge collection of phenotypic trait data on health, lifestyles and behaviors and genomic data to study genetic variability and interaction between genes and environment. Consequently, population databases are indispensable infrastructures for research in the biomedical field, which requires a large number of samples to process data and obtain statistically significant results. Some populations, because of their geographical, historical and social isolation, are precious "genomic blocks" for accomplishing these studies. In the Sardinian Ogliastra region, for instance, the close collaboration between the local communities and the researchers during the whole *SardiNIA project*, as well as a careful design of informed consent, was considered a virtuous example of wise involvement of volunteers (surpassing 80% of the population) for sample collection, which resulted in the production of a huge genetic biobank with samples from 11,700 individuals (Piciocchi et al. 2018).

Trust in institutions managing such precious and sensitive data is, therefore, a main issue. If direct contact with the institutions managing the biobanks seems to be an important aspect of trust, it is reasonable to wonder why people turn to the genetic testing offered by private companies on the Internet. Direct To Consumers (DTC) genetic testing is a multifaceted product of genomic research intended to extremely varied applications, from medical to leisure purposes, and bearer of a series of personal and social meanings. The wide range of tests available includes diagnostic tests and tests for predisposition to certain diseases, pharmacogenetic tests for responses to pharmacological treatments, nutritional tests focused on diets and obesity, and tests variously oriented to the search for personal characteristics and talents that go beyond the medical field. These include tests for origins, paternity, athletic talent, affective/amorous compatibility and even sentimental betrayals and responses to beauty treatments.

In literature, DTC genetic testing has been discussed as a symbol of people empowerment, a means of emancipation from a top-down health care system, a potential road toward democratization of medicine and care, but also as a source of concern, complacency or fatalism, a support of narcissistic approaches to manage (personal) genetic data, an incentive to misleading use and consume of scientific and medical information, and finally as a form of lucrative use of a technology (Turrini and Prainsack 2016).

For these features, in our exhibition on human genome at MUSE, we regarded DTC genetic tests as an excellent topic to be (re)presented, to stimulate reflections about crucial questions arising from genomics applications where scientific, economic, personal, social and legal aspects are intertwined (see Martinelli and Tomasi 2018). In 'The genetic test supermarket' exhibit, we recreated a consumerist setting where visitors can virtually buy the four DTC genetic tests we consider exemplary for this purpose. They are: PATOGEN ("A test to discover your genetic predispositions to oncological, cardiovascular and neurodegenerative diseases"), PATERSCREEN ("A reliable test to know who your father is, reunite relatives or determine rights of inheritance"), GENEOTEST ("A test to discover your roots and reveal the origin and native land of your ancestors") and GEN&AMOR ("Find your soul mate through modern genomic analysis"). Prices of tests and narratives to describe and advertise them were *ad hoc* studied to resemble the real products sold by the various genetic companies through the Internet.

The core part of this exhibit is based on two self-checkout machines, with a video-talked interactive multimedia questionnaire for museum visitors, proposed by two animated talking cartoons. The former is the "salesman", representing the interests of the biotech companies, and the latter is the "scholar", representing the bioethics and bio-law expert. Developed thanks to a cooperation with the BioLaw Project of the Department of Law of the University of Trento (Marta Tomasi), the questionnaire is intended to make museum visitors aware about the main issues concerning DTC genetic testing, i.e. intended use, reliability and accuracy of the analysis, comprehensibility and competency in interpreting results, impact of the results in people's understandings, and privacy and regulatory frameworks (Martinelli and Tomasi 2018).

In biobanking are involved questions of individual, collective and populations' identities. People can develop biosociality and sense of belonging and, in some cases, forms of collective action. How to deal with these issues in an exhibition?

The knowledge of our own genome seems to deeply involve identity. In the case of the DTC genome testing, for instance, the analyses are generally proposed by companies as tools "to know yourself better" (in a sort of modern, technological “γνῶθι σεαυτόν” exhortation) and “to build your own identity”. On the other hand, what do motivate people to undergo a genetic test? According to the few studies investigating on this question (Harris et al, 2014), motivations are to know health status, to trace origins, curiosity about a new technology, the desire to be innovative in experimenting a new technology or in participating in the scientific progress, and just pure leisure. Narcissistic motivations are clear when tests’ results are shared through social media and YouTube, from sample collection to result reading and sharing through the web, with videos and “genetic narratives” full of emotions and expectations. In the narratives of tests aimed at tracing origins, curiosity, joy and wonder are shown as people discover a sense of belonging to a group in a new form of “biosociality” where the genetic information becomes at the same time a personal and social issue. These tests, in fact, have a big social component, requiring to be shared through specific Internet sites.

The perception of belonging to a group is quite important in the cases of genetic diagnosis for major and rare diseases, which lead patients to participate (increasingly often through social networks) in disease-specific mutual-help groups to exchange information and suggestions on treatments, as well as feelings, fears and psychological support to face their state. In the cases of hereditary pathologies, involving relatives with various degree of kinship, there are also involved some ethical issues that can give rise even to pressing individual and family conflicts, concerning for instance sense of responsibility/guilt to likely transmitting a disease, privacy issues and the right to know/not know. This is quite clear when analyzing the confidences in reliable web sites of patient organizations of woman carrying the genetic mutations BRCA (Breast Related Cancer Antigens), related to breast and ovarian cancer in the female population and to prostate and breast cancer in the male population. In addition, a sense of “genetic identity” is quite clear since these patients introduce and refer themselves as “mutated”, in a sort of identification with their genetic mutation rather than with a person affected by a disease. Here, the description of their self is mostly based on their own biological data. To represent these issues, in the exhibition on human genome, in the above mentioned “square” section, among the personal stories of “common people” we imagined the story of a young woman and future mother, about to take the decision to undergo the genetic test for the BRCA mutation, a test requiring responsibility for herself and for the child she is waiting for. She is represented right in the moment she knows from a close member of her family, who already resulted positive to the test, about this family predisposition and has to face the difficult choice to know/not know about the chance to carry - or not - this hereditary genetic mutation. Her narrative is meant to give voice to a deep personal conflict as well as to an advice to prevent/manage the disease thanks to the knowledge about the (eventual) genetic predisposition.

Commercial exploitation is another big issue in biobanking. People freely give tissue samples and information as a gift, that could be turned into a commodity. How to communicate this complex question?

The biological materials stored in the repositories – as well as the information processed from them – are goods donated by patients. Being these essential to the progress of medical research, patients' trust is fundamental to implement biobanking. Commercial exploitation of samples would certainly undermine their trust not only in biobanking but also in the general accountability of biotechnological and biomedical innovations. Therefore, as already pointed out (Piciocchi et al. 2018) biobanking is an interesting example of controversial relationship between research institutions and civil society, which requires transparency and legal regulation. Here, public trust and civic engagement are particularly important features.

At MUSE, to deploy suitable communication strategies for science communication on topics with relevant bioethical and biosocial implications, we adopted a new format, a kind of science theatre named "science lecture-performance", where a science expert and an actor/actress dialogue on the stage without losing their specific features and roles. *'ETERNeETÀ – la vecchiaia può attendere'* ['ETERNeETÀ - aging can wait'] was the result of a fertile interaction between the sensitivity of a director (Elena Marino) and an actress (Silvia Furlan) of the company *Teatrincorso* and myself[8]. Scientific and theatrical texts and artistic representations, including projections, multimedia and music, were the tools to deliver concepts and new insights by reaching the public's emotions.

Among the various bio-objects, the case of the immortal *HeLa* cells has been an amazing "good story" to be represented, in particular because of its biosocial implications and symbolic meanings, as previously discussed (Svalastog and Martinelli 2013). They are emotionally impacting, being invasive and frightening, immortal and of extraordinary value for science and humanity[9], but also an example of fraud and abuse of a woman of marginalized origins[10]. Therefore, these cells are suitable to both deliver knowledge and to engage debates specifically on the topic of biobanking and in general on the impact of biomedical innovation, also by reaching the public's emotions. This latter is an important aspect of communication. For instance, a very inspiring moment of the performance 'ETERNeETÀ was when the actress rolled up herself in plastic wrap to be kept in a freezer, in an attempt to "aging without aging" and to last forever, with an emotional metaphor of her dramatic wish to escape the inexorable fate of biological decay and death. I believe that this was an interesting example of a successful integration between scientific concepts and theatrical performance.

With the same company, we staged the performance *'Vite sintetiche'* ['Synthetic lives'], a monologue performed by the actress and inspired by synthetic biology[11]. Topics were the controversies (opportunities and risks, promises for a best life quality and a sense of disorientation) produced in the every-day life of a family by various bio-objects, including – reference to biobanks – the tissues of extinct animals preserved for de-extinction experiments. In this case, in the refrigerator of a housewife it was stored a piece of bone of a dinosaur stolen from a science museum (MUSE) by the youngest son.

Why did you feel the need of using the language of theater and art to communicate, and how did you interact with artists?

There are numerous successful experiences in scientific communication based on art. Art and science show many points of contact. Both are based on creativity, innovation and a rigorous attitude. Science offers interesting topics to art and results in a fertile source of ideas and metaphors. On the other hand, by eliciting emotions, art induces curiosity and passion.

As for the scientific theatre, in general, the texts are written by the artistic counterpart, whilst scientists inspire the topics and validate the accuracy of scientific information. In our intense relation with the company *Teatrincorso*, on the contrary, a high interdisciplinary attitude was essential during the creative brainstorming, text writing and even the participation on stage in the case of 'ETERNeETÀ'. Motivation leading scientists and artists to cooperate has been analyzed (Dowell and Weitkamp 2011). On the basis of my personal experience, I agree that, in this challenging relation, the "scientist" should be a person quite motivated to exploit public engagement, curious about the new experiences that the theater can offer and open to new forms of communication; the "artist" should be a person very interested in science and in new ideas and incline to engage with challenging topics. Finally, a science performance would result successful when it is not distinguishable whether it is science that offers art subjects to perform or whether art is a vehicle for communicating scientific concepts and opportunities for reflection to the publics.

Another challenging experience of science-art communication was the collaboration with Claud Hesse, a visual arts practitioner, known as the "DNA artist". For the section focusing on epigenetics of the exhibition on human genome at MUSE, she specially created 'DNA EPIGEN', an interactive sculpture involving visitors to discover epigenetic concepts. By causing changes on cubes interacting with a large double helix of DNA, visitors are invited to experience some epigenetic imprints produced by the interactions between the genome and the environment (including life style and stress such as light, darkness, peace, violence, abundance and famine). In this case, the production of the artwork involved various subjects with specific multidisciplinary skills: the artists, the curators and the architect of the exhibition, the epigeneticists, the manufacturers and the experts in information and communication technologies and technical assistance. I believe that the most critical aspect of this science-art experience was the need to suitably balance the correct scientific presentation of a complex concept - as epigenetics - with the artist's creative action for freely interpreting the topic, to generate a piece of art and not (just) a scientific model.

What people learn from an exhibition on human genome? And why do you think is important communicating genomic research and biobanking activities with other means?

Genomic research and biobanking, because of their importance in the current science landscape and of their significance on society, are suitable topics to engage people in reflections about scientific culture. Scientific exhibitions are particularly suitable sites where presenting hot topics of science nowadays and reaching different publics of various ages and backgrounds. In the case of our exhibition on human genome, and in particular for the hot topic of DTC genetic testing, for instance, we can evaluate its effectiveness in engaging a great number of citizens. During nine months (February 26th – November 27th, 2018) 16,086 people completed the food-for-thought questionnaire offered in 'The genetic test supermarket' exhibit above described. Visitors involvement, moreover, can be analyzed in the many "stories of everyday-genetics" they are leaving in the "memory book" in the intimate room –mentioned above – at the exit of 'The square' section. According to a preliminary analysis, we can conclude that the various inputs we offered resulted in effective stimuli for reflections on important issues of genomic knowledge, concerning personality, traits and disease. It has emerged, for instance, the desire – never felt before – of visitors who were adopted at an early age to start investigating about their biological and geographical origins.

Finally, aiming at promoting reflections and new questions about science rather than offering certainties, in the concluding section of the exhibition we proposed a series of questions about genome – without giving answers – collected during focus groups with citizens to investigate about their interests in the topic. Questions as: "Is there is a DNA test to know the length of someone's life?", "Can human genes be put on sale?", "Do criminals have a particular 'killer gene'?", "Is happiness linked to our DNA?", "Are people born gay or do they become so?". If they might at a glance appear naïve, conversely they point out important issues about genome knowledge still waiting for (conclusive) answers.

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Communicating Genomics Research. Participative Models in a Local Context

Ilaria Ampollini

The active involvement of citizens is today at the core of many international initiatives where an effective cooperation between scientific research and society is needed. This is particularly true when it comes to biomedical research, which increasingly addresses to patients, patients' relatives or patient associations: during the last years, in fact, growing prominence has been given to patient engagement in the developments of therapeutic solutions or in designing new research projects. Although these elements precisely meet the EU objectives and requirements established by the *Science with and for Society programme – Horizon 2020 for the Public Engagement and a Responsible Research and Innovation*, different pathways and answers have been put in place by European countries.

As it is well known, one of the most innovative approach has being experienced by the UK. The England National Health System (NHS) has a wide range of policies for the enhancing of patient participation. The involvement of patients and citizens includes not only *ad hoc* social media or standard surveys, but, more importantly, online forums, focus groups and deliberative events. For instance, in case of proposals of policies for new therapies, open consultations are launched and people can express their own views. Most notably, the UK National Institute for Health Research (NIHR) supports the *INVOLVE programme*: established in 1996, it encourages "active public involvement in NHS, public health and social care research". Another example is that of the *Patient Led Research Hub* (PLRH), founded in 2015 by Cambridge University Hospitals, NHS Foundation Trust and the Cambridge Clinical Trials Unit from the University of Cambridge. Interestingly, the assumption at the basis of PLRH project is that the other initiatives do not actually take into account patients priorities in setting the research agenda. This is why PLRH aims at collecting and supporting research ideas coming from patient organizations.

Another almost unique scenario is offered by the French context. Here, the involvement is more generally addressed to all citizens, through the *États Généraux de la Bioéthique*. According to the French system, laws regulating bioethical issues are subjected to revision every seven years (as minimum requirement). On the occasion of revision, citizens committees are summoned and asked to express their own opinion, via web or during dedicated meetings, on the main bioethical concerns. Committees' final reports are then presented to the French Parliament, which is expected to take them into account when assessing the new regulatory acts. Last revision took place in the first half of 2018. Among the revised Articles, many obviously concern biomedical issues, such as cloning, assisted reproduction techniques, organs transplantations, DNA tests and genetic medicine.

Italian context is quite different both from the UK and France contexts. We do not have a National Health System which directly promotes the involvement of patients neither do we submit bioethical dispositions to citizens' revision. Since the involvement of citizens and more specifically of patients is not officially promoted by state bodies, the importance accorded to patient participation is left to the responsiveness and the responsibility of hospitals, research groups, actors of the pharmaceutical industry or patient associations. Moreover, one must consider that the initiatives of science communication in Italy still show a clear predominance of a top-down approach as well as an unjustified, and often unaware, commitment to deficit model's practices.

These two elements – on the one hand the absence of centralized actions aimed at patient and public involvement, on the other hand the limited use of participative models by people engaged in science communication – obviously do not foster an effective engagement of citizens when it comes to matters related to medicine and health issues.

However, during the last years a good number of projects was born: at least a couple of them deserve to be mentioned. The first one is the *Research Lab for Citizens' Involvement in Healthcare System* (Laboratorio Ricerca per il Coinvolgimento dei Cittadini in Sanità), promoted by the Mario Negri Institute in Milan. The Lab includes a remarkable number of initiatives, such as projects about informed consent and aware decisions – it is quite common that the concept of patient participation is merely intended as a proactive choice of treatments and therapies. Nevertheless, the Mario Negri Institute also promotes a series of Citizens Committees (Giurie dei cittadini), which are expected to evaluate the necessity of screening programmes for cystic fibrosis and prostate cancer. The project is a pilot one and it is currently run in the Verona area.

Another example is the European project EUPATI, started in Italy in 2013, which aims at creating a collaborative consortium involving and connecting pharmaceutical industry, academia, non-profit organizations and patient associations. EUPATI partners provide information and training courses to patients willing to know more about the processes behind medicine development and clinical trials, thus becoming "expert patients". As part of the project, in 2014 the Patients' Academy was founded in Italy, as well as in other European countries – France, England, Germany for instance. There is also an Italian Stakeholders Board, which includes prominent stakeholders, such as AIFA (Italian Medicine Agency), Farmindustria (Association of pharmaceutical industries) and the Ministry of Health.

It is within this framework that in Trento, during the exhibit *The Human Genome. What makes us unique* at MUSE, an initiative to involve patients, patients' families, patient associations and more in general citizens was designed . It is obvious that, compared to the projects listed above, we are talking about a small initiative at local level. However, it shows some points of interest on which it is worth to focus on. The two-days meeting is part of a wider project, called *CLaSTer. How Science Works. Dialogues between University and the Region* (CLaSTer. Come Lavora la Scienza. Dialoghi tra Università e Territorio), a three-years project funded by the Autonomous Province of Trento and hosted at the Department of Sociology and Social Research at the University of Trento. The main goal of CLaSTer is to draw attention to scientific research and the ways it works, through two combined approaches: the use of history of science and the recourse to participative models. In cooperation with CIBIO, the Department of Biomolecular Sciences of the University of Trento and MUSE itself, we decided to organize two days of consensus conferences on the topics of genomic and precision medicine.

The reason of the initiative relies on the awareness that it is essential, generally speaking, and even more within a small local context such as Trento, to enhance and enforce effective and long-term collaborations between research institutes, the Province Health System, the doctors and the healthcare professionals working at the public hospital, and the patients, patients' families and patient associations. It is clear that a strong partnership where each of these actors can bring their own experience and where clinical practice can constantly benefit from working closely with academic research, while patients can express their needs and priorities, would not only certainly boost local scientific research, but also help increasing citizens trust in researchers and healthcare.

Notwithstanding all this, we must point out that in Trento no participative models have been put in place to build and strengthen this stakeholders' network, partly because the communication of science in the Province is still mostly constituted by top-down models, and partly because the development of partnership between academia, healthcare system and patients usually goes through different channels. The exhibit GENOME at MUSE offered the right occasion to experience new pathways, especially considering that the themes addressed are strongly linked to the research being done at CIBIO (which in fact has collaborated in designing the exhibit's contents), as well as to the directions in which the Province Health System is today working – for instance the Trentino BioBank, which collects samples of tissues and blood, or the Clinical Service for Medical Genetics.

The initiative, named *From Genome to Precision Medicine. Discussion groups between Citizens and Scientific Research*, was planned to be developed through two days. During the first day, four roundtables, constituted by two experts and five citizens each, took place: each table was asked to discuss a specific issue linked to genomics and precision medicine, that is to say risks and benefits, ethical issues, bio-law and economic sustainability. The aim of this first day was to collect concerns, opinions and priorities emerging from citizens and to draw special recommendations based on them. During the second day, yet to take place, the results from the first day will be displayed by citizens representatives (one per table) to doctors, policy makers and researchers.

Since the initiative is still ongoing, it is too early to outline a proper research paper on it, or even to draw any kind of conclusions. However, there is at least one element which has already come up during the first date and which is worth to be reported. It especially concerns the phase of the recruitment of participants, during which we tried to reach those citizens potentially interested in the themes of the Consensus conference through the various associations actively working in the Trento area. We are of course referring to those associations promoting research funding and citizens' awareness on a wide range of diseases, that is to say, for instance, different forms of cancer, neurodegenerative illnesses, such as Huntington's, diabetes or cystic fibrosis. Moreover, there are also other associations whose focus is on active citizenship and therefore deliberative democracy. We also contacted teachers and members of the association Friends of MUSE, a group of citizens who support MUSE activities.

While teachers and Friends of MUSE members easily accepted to take part to the experience – and, by the way, also the doctors and the researchers we contacted in preparation of the second appointment did so – the response from the majority of patient associations was far lower than we expected. The reasons can be of course numerous – and we can not provide an in-depth analysis here – and one of the reasons, beyond the organizational details that can be always improved, may be that people, and especially patients, are not familiar with this kind of initiatives in the Trento area.

This is exactly why it will be even more important for the University and its research groups to create a stronger link with the territory and not to stop proposing similar projects in order to make them more familiar to citizens and, at the same time, make citizens more willing to participate. Obviously, it will also be necessary to demonstrate that this first initiative has been effective and will have some concrete and positive impacts on all the actors involved.

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[1] https://www.youtube.com/watch?v=ymN6sZf9mmM

[2] https://www.univie.ac.at/bio-objects/index.htm

[3] https://www.synenergene.eu/

[4] http://www.nano2all.eu/

[5] https://www.youtube.com/watch?v=ds0gSoAs7Bg

[6] https://www.nasa.gov/twins-study/about

[7] https://www.nih.gov/news-events/news-releases/nih-lacks-family-reach-understanding-share-genomic-data-hela-cells

[8] The trailer is available at https://www.youtube.com/watch?v=FvxFcFJ0BNY

[9] *HeLa* was the first immortalized cell line, established in the late 1950s from Henrietta Lacks' rare cervix adenocarcinoma, an aggressive lethal cancer, and its descended lines are still used in the laboratories all over the world. These cells have been the basis of thousands of scientific publications and important biomedical innovations, some of them also awarded with Nobel prizes.

[10] Henrietta Lacks, a poor, black woman, has been never informed about her cells' use whilst they became economically valuable for the biotech industries.

[11] https://www.spazio14.it/vite-sintetiche-al-muse-il-29-e-30-settembre/