Proceedings of the:

International Conference

Justice in the genomic and digital era

ICRHD & TAGC INTERNATIONAL CONFERENCE: LAW AND SCIENCE SERIES

Conference Date: 6 September 2019, Tomsk State University, Russia

Organisers*: ICRHD, ILE and TAGC. (* International Centre for Research in Human Development; Institute of Law and Ethics; The Accessible Genetics Consortium.)

Opening and welcome

By Professor Yulia Kovas

The conference was opened and chaired by Professor Kovas. Prof Kovas emphasised the importance of interdisciplinary and international work between geneticists, lawyers, and other relevant sciences from a number of countries. It was only recently when Psychology degrees in the UK did not include Behavioural Genetics modules as part of the programme. Professor Kovas described her experience of designing and implementing one of the first such programmes in the UK. Today, most psychology degrees have modules dedicated to behavioural genetics and to understanding complex interplay between genetic and environmental factors. In her view, the same should happen for law, education and other relevant degrees.

Invited talk:

Justice in the genomic and digital era

By Fatos Selita

Summary of Presentation

We live in a fast changing / 'new' world in terms of knowledge in general, and in particular knowledge on genetics and technology. To understand the implications this knowledge has for justice - including how it affects individuals' rights - we need to consider: (1) nature of genetic data and how this is related to people's rights; (2) what aspects of people's lives these advancements affect; and (3) who is (and would be) affected. We also need to assess legal protection in place in the light of these facts; as well as

consider possible solutions to minimising risks to individuals and science. For more information, see Selita, F. 2018. Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies, *Legal Issues Journal* 7(1) pp 53-95.

1. Genetic data have a number of features with serious implications for justice.

(A) From genetic data of an individual we can extract an unprecedented and growing amount of predictive information on practically all human traits (Plomin, DeFries, Knopik, & Neiderhiser, 2016). Genes account for around 50% of the individual differences on average (Polderman et al., 2015). For example, over 40 independent genetic markers have been identified for aggressive behaviour (Zhang-James et al., 2018); 187 independent genetic markers associated with intelligence, intelligence being up to 80 % heritable (Hill et al., 2018; Sniekers et al., 2017; Plomin & Deary, 2014); 17 markers for depression that are significantly associated across three types of depression (Howard et al., 2018); and carriers of the BRCA1 mutation which increases the risk of developing breast cancer to around 80 percent risk (from the average 12-18 percent) (Mavaddat et al., 2013).

(B) Anonymised genetic data can be de-anonymised using information freely available online, making it possible to re-identify an individual, despite safeguards, which is also made easier by other types of big data (e.g., Gymrek et al., 2013; Erlich and Narayanan 2014).

(C) Genetic information taken at any one point in life, has life-long and increasing value, as the DNA code does not change over an individual's life time, which means that breaches of today can be used to harm individuals during their life time. Therefore, access to an individual's DNA is unnecessary once a particular meaning has been extracted from the sequenced data. The same information can also be used to discriminate close relatives and across generations. Moreover, the risks to individuals, increase in parallel with the progress in understanding of the genomic text.

(D) We are able to edit genes in-vivo (inside the human body) - such editing first reported to have successfully removed a disease in 2017 in the US. Gene editing methods, e.g. CRISPR, no longer require cutting through the DNA – it rewrites individual genetic bases/letters (A, T, C, G) - e.g. turning a disease-causing mutation into a healthy version of the gene. A one-time procedure has potential to cure certain disorders and cancers for which currently there are no treatment options (Nordberg et al., 2018).

2. People may be negatively affected in a number of aspects of life.

(A) Access to medical care (insurance) can be determined on genetic information, making health insurance unaffordable for those with DNA predicted health risks. Polygenic scores also provide precise information on disease risk and other life outcome (Trampush et al. 2017). Access to genetic information would enable insurance corporations to assess risk significantly more precisely, allowing for tailoring premiums to risk to *DNA-based groups,* or even individuals. Insurers may have to use genetic data for commercial reasons because they rely on moneys collected from healthier people to cover costs of people with more health problems.

(B) Recruitment on genetic make-up is likely to become the main method of recruitment for larger companies, especially considering that current recruitment processes are unreliable and genetic information is highly more reliable (Oh et al., 2013; Peck and Levashina, 2017). Genetic recruitment may have advantages of placing people in employment as per make-up / propensity. However, it is also likely to disadvantage people due to the probabilistic nature of genetic information.

(C) Surveillance of people with genetic propensity for antisocial behaviour could be deemed a justifiable crime-prevention measure, especially considering decreasing surveillance costs – digital mass surveillance now being wide-spread in developed economies. This presents significant risks for people's rights. As behaviours result from both genetic and environmental factors, genetic information will always remain probabilistic. In this context, how much genetic risk will constitute as sufficient to justify pre-emptive measures e.g. surveillance or compulsory training?

(D) Genetic information may be used to influence individuals' decisions, including their voting decisions; and consumer choices. It can also be used to inspire conflicts. Influences on personal data are already practiced. For example, it was recently reported that millions of voters have been influenced using personal data, including 198 million Americans, 93 million Mexican, 55 million Filipino, and 50 million Turkish (Freedom on the net).

(E) Children can be discriminated on genetic make-up in all these contexts Children's rights are most threatened because they lack capacity to decide whether to undergo DNA testing, but this decision has potential to change the course of their lives and the lives of their children.

(F) Consumers are and will continue to be misled to buying products which for example claim to enhance or suppress genetic expression, and which may be harmful. Unless the industry is regulated fast, and population educated where possible, direct to consumer companies will continue provide misleading information for multifactorial conditions and the number of consumers using these services is growing.

3. Virtually everyone in advanced economies will soon be affected.

(A) Millions of genomes have already been sequenced from private and State organisations, despite sequencing has been costly. In 2003 it took over 10,000 researchers in 10 countries more than 10 years and 2.7 billion USD to sequence one person's genome; and currently it can be done in less than 40 minutes and for as little as 399 USD ((Goyal et al 2017; Dante Labs, web). With sequencing costs dropping fast due to advances in technology, sequencing is likely to become common. Direct to consumer genetic testing is already a reality and growing fast; State databanks in some countries already contain genetic data of virtually entire populations (UNESCO, 2003); private data banks contain genetic data of millions of people e.g. over 2 million DNA samples (23andme.com); and over 7 million samples, AncestryDNA (ancestry.co.uk).

(B) Moreover, there is a dramatic increase in data sharing between State and private organisations . For example, the NHS in the UK shared medical data of 1.6 million patients with Google, as part of the data-sharing agreement (Independent, 2016)); there were around 3,500 organisations that were licensed in the EU (in 2013) to share data cross-continentally; and in the UK, within two years of change of processing of medical data, (by July 2014), 40 million patients had an electronic summary care record, with all doctors and nurses having access by 2018. Moreover, genomic research is becoming increasing more global (e.g. International Cancer Genome Consortium - the Pan-Cancer Analysis of Whole Genomes), with the Global Genomic Medicine Collaborative (G2MC) being formed in 2014.

(C) Advances in technology have made data sharing much faster and easier, including through use of cloud platforms such as Amazon, Google, and the European Open Science Cloud (EOSC).

(D) The large number of reported breaches (1,378,509,261 in 2016 alone) and hacking incidents (which exposed 187 million identities in 2011 alone) show that no one's data are fully protected. Children's genetic data (heel prick test) taken by hospitals at birth have also been found to be used for other reasons and given to private organisation for other studies (Arnold, 2013; Bearder v. Minnesota State 2011).

The law in place generally offers minimal protection in relation sequenced genomic data

(A) Current laws are not designed to cover information extracted from sequenced genetic data. Specific laws such as GINA 2008 in the US, and the Canadian Genetic Nondiscrimination Act 2017 – provide minimal protection to individuals (Selita 2018). Even the most advanced relevant legislation to-date in the EU, the GDPR, provides insufficient protection, for example one provision provides protection and another, counter-protection.

Why do we *NOT* sufficiently restrict use of data?

(A) Big data means 'big' progress in discoveries in medicine and other fields; and data banks are the 'new goldmines' and therefore attracts strong interest from powerful commercial players. (B) Value of data is already large: the UK's profit for 2015–2020 from big data and the Internet of Things (objects that connect and exchange data) alone, is forecasted at £322 billion; the EU data market, is valued over €285 billion in 2015, and is expected to increase to €739 billion by 2020, representing 4% of the overall EU GDP; and by 2025, Internet of Things value is expected to rise to as much as $11.1 trillion per year. (C) This high value has changed the way data are viewed - "as exploitable raw materials…" (Nuffield Foundation, 2015, para 9).

Possible solutions to protect rights and ensure fair access to benefits.

(A) Using interdisciplinary expertise, to update legislation (where possible consolidate, rather than add to the number of legislations).

(B) Train current relevant professionals such as lawyers, judges and educationalists (e.g. professional development) so that they are able to understand what they are seeking to regulate/protect or even judge, argue for, or argue against.

(C) Add genetic knowledge to education programs such as law degrees.

Keynote address:

Combatting the discriminatory use of genetic data

By Marc Willers QC

Summary of Presentation

There have been tremendous advances in genetic science that will bring enormous benefit to the human race.

But there are concerns that genetic data could also be misused as a tool to discriminate against groups, such as ethnic minorities or people with genetic dispositions to health problems. Such discrimination could occur in a variety of areas, e.g. employment, healthcare, education, the police and justice system and the provision of goods and services (such as insurance).

The concern that genetic data could be used for discriminatory purposes are borne out of bitter and painful historical experience. Crimes against humanity based upon racism litter our collective history, including: the murder of 1.5 million Armenians in the Genocide in 1915; the murder of more than 6 millions Jews and 500,000 Roma in the Holocaust during World War II (known by Roma as the 'Porajjmos').

Discrimination against Black people, people from ethnic minority groups has its roots in discredited theories about 'race' such as those advocated by the Eugenics movement in the 19th Century. Nevertheless, discriminatory practices have persisted in many States – including, e.g., the forced sterilisation of Roma women and the ethnic profiling of minority groups by the police.

In 1997 UNESCO issued the Universal Declaration on the Human Genome and Human Rights which stipulates in Article 6 that: 'No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.'

In my view there is a need to update equality and discrimination legislation in States to include a prohibition on the use of genetic data to discriminate which complies with Article 6 of the UNESCO declaration.

In the meantime there is an urgent need to educate the judiciary, lawyers and the public on the risks associated with the use of genetic data and the safeguards that need to be in place to ensure that its retention and distribution is lawful.

In the absence of up to date legislation courts can develop caselaw to protect individuals and groups from discriminatory practices using existing laws – though such developments can take time and lead to inconsistencies and anomolies. That said, decisions of supra-national courts, such as the European Court of Human Rights, could do much to advance the protection afforded to individuals and groups in a coherent and consistent way.

There is likely to be resistance to the introduction of legislative safeguards from scientists, corporations and politicians who are keen to exploit the use of genetic data to its full advantage within a relatively relaxed regulatory regime, even if that does allow for there to be some scope for it to be used to discriminate. Such resistance will need to be defeated if we are to ensure that the most vulnerable members of our societies are protected from its misuse.

Invited talk:

Public danger of misuse of human genetic data

By: Dmitriy Karelin

Summary of Presentation

The development of technologies, the consistent accumulation of empirical material on human genetic data and their potential value, will objectively expand the conditions for their legitimate and unlawful use. Therefore, the question of the protection of this data may arise in the very near future.

The protection of the object of encroachment depends on the dynamics of the social danger of the act and can be carried out by various legal means. But in any case, protection begins with the definition of social value, the importance for society of what needs to be protected, can society do without the object of encroachement?

After determining the social value of what should be protected (e.g. interest), it is important to determine - in what way can its "damage" be expressed? At the same time, such circumstances as the form and method of committing the offence, the form of guilt (intent or negligence) and other factors will also be important.

Understanding the nature and degree of public danger of the unlawful use of human genetic data does not at all mean the unconditional and immediate criminalization of these acts, i.e. their consolidation in the legislation as criminal and criminally punishable. This should be preceded by a process of assessment of: the need and expediency of such criminalization, the possibilities of the criminal justice system, the protective potential of other branches of law (civil, administrative), the possibility of using administrative prejudice and other conditions.

The choice of legal remedies and the possible criminalization of the misuse of human genetic data will also depend on the prevalence of such acts, which is an additional feature of public danger.

The effectiveness of protecting human genetic data from socially dangerous encroachments will largely depend on the development and implementation of uniform legal mechanisms, standards for their legitimate use, on the unification and universalization of the conceptual apparatus in this area. Cross-disciplinary and comparative studies will contribute to this.

Parallel sessions

Parallel session I - Short talks:

Important issues for Russia in genomic research and the practical use of their results in light of the ECHR decisions

By: Olga Andreeva

Summary of Presentation

Scientific and technological progress, the accelerated development of biology and medicine can be both a blessing for present and subsequent generations, as well as a cause for concern, since there remains the possibility of misuse of the results of scientific achievements that jeopardize respect for human dignity.

In conditions of improving biotechnologies and the possibility of using their results in various spheres of human life, it is extremely important to examine the fundamental principles of protecting human rights and fundamental freedoms and to prevent abuse.

Since the receipt of materials for genomic research and the use of their results is associated with interference in the private life of a person, the procedure for obtaining materials, their storage and destruction needs legal regulation that takes into account the balance of both private and public interest.

In Russia, in 2008 the federal law "On State Genomic Registration in the Russian Federation" was adopted, with later development of the provisions in 2011 whereby the Government of the Russian Federation approved "The Regulation on the Procedure for Obligatory State Genomic Registration of Persons Convicted and Serving Imprisonment". This provision provides for compulsory state genomic registration of an individual convicted of a grave crime or a crime on sexual grounds.

The same regulatory legal acts were positively assessed, including by law enforcement agencies, as allowing to increase the efficiency of solving crimes, to prevent the recurrence of their commission, and to identify the persons who committed them in a timely manner. The imperfection of normative legal acts in Russia is noted, meanwhile, the development of normative legal acts regulating the issues of genomic

research and the practice of using their results, ensuring a balance of private and public interests, is fundamentally important, due to the special object of study which has no analogues.

The misuse, storage and dissemination of genetic data can harm not only individuals whose biological material was collected for genomic registration, but also their close relatives, because the genetic information contains information not only related to the person who transferred their biological material, but also to members of his family, which may entail a violation of their constitutional and civil rights, and therefore this procedure must be properly regulated taking into account the requirements of international acts.

The decisions of the ECHR, as well as the practice of the Russian courts, testify to the presence of problems in the legal regulation and in the practice of using the results, including genomic research. Disputes related to the development and use of new biomedical technologies are increasingly being addressed by national courts and the ECHR.

It is noteworthy that neither the aforementioned law nor the provision provides for the rights of persons from whom biological material is obtained for the purpose of compulsory genomic registration. The consequence of which are cases of abuse of authority by employees of correctional institutions, as evidenced by law enforcement practice.

Based on the above normative legal acts and law enforcement practice, the following problems of legal regulation of obtaining and using biological materials for the purpose of genomic assessment can be distinguished. These include:

1. The absence in the procedure for obtaining materials for genomic assessment of a mechanism that guarantees the right of the individual to be informed about the purposes of obtaining biological material, the procedure and terms for storing, transmitting, blocking, depersonalizing data, destroying biological material and excluding information from the forensic database. Meanwhile, the person subject to genomic registration should be explained the basis and procedure for the selection of biological material, and should be familiarized with the order on approval of the commission for the mandatory state genomic registration of persons convicted and serving a sentence of imprisonment.

2. A person should be entitled to favourable conditions that do not allow pain, the use of means that pose a danger to human life and health when selecting biological material from them.

3. The question remains whether the person should have access to their genomic information. According to paragraph 2 of Art. 10 of the Oviedo Convention, everyone has the right to access any information collected about their health. This is especially important if the conditions for serving a sentence, the behavior of a person in the course of serving a sentence, can aggravate their physical or mental state.

4. A mechanism has not been developed for the destruction of personal DNA data from a database in case of the individual's rehabilitation.

Thus, the legal regulation in the field of compulsory genomic registration does not solve a number of ethical issues related to the right of access to genomic information, its confidentiality during storage, transmission and destruction. It seems that despite the mandatory genomic registration, the solution of these issues should be based on the principles of processing genetic information. First, convicts should have the right to access their genetic information. Secondly, convicts, like other persons during voluntary genomic registration, must maintain freedom of choice to use their genetic information, if this is not related to the prevention, disclosure and investigation of crimes, as well as the identification of persons who committed them. Thirdly, convicts should not be deprived of the right to confidentiality of their genetic information for purposes not related to the prevention, disclosure and investigation of crimes, as well as the identification of the persons who committed them.

Criminal justice in the post-genomic era: new challenges and searching for balance

By: Daria Matsepuro and Tatyana Trubnikova

Summary of Presentation

Nowadays we are faced with the unprecedented progress in genomic research. Genetic data banks are growing rapidly. Some countries have genetic data of almost the entire population. For example Iceland, its database contains genotypes of the entire population (about 300,000 people).

Challenges for criminal justice include: using of DNA and biological material for the identification of a criminal; and issues with aggression: genes vs. environment.

Illegal trafficking of genomic data or new types of misuse (genomic data + other big data) may also take place, and potentially these types of crime can be subjected to criminal legislation. Precedent: at the European Court of Human Rights: S. and Marper v. United Kingdom 2008, held that indiscriminate "blanket" retention of fingerprints, cellular samples and DNA profiles following acquittal is in violation of article 8. The case concerned the retention by the authorities of the applicants' fingerprints, cellular samples and DNA profiles after criminal proceedings against them were terminated by an acquittal in the case of S. and discontinued in the case of Marper.

Today, the creation of a comprehensive and consistent model of legal regulation and self-regulation of genomic research in Russia and the world is required. This model should be based on an optimal balance between various interests: state, public and private.

Genetic information in the system of civil rights

By: Maria Imekova

Summary of Presentation

In the past few decades, both at the international and domestic levels, issues related to the legal regulation of genetic research and the legal regime of genetic information obtained on their basis have become particularly relevant. However, Russia relatively recently came to the realization of the need for the relevant legislative regulation. However, a distinctive feature of such regulation was left without attention - i.e. the emphasis on public law aspects, civil aspects.

To determine the civil legal regime of genetic information, the distinction between genetic information and genetic data is of fundamental importance. Genetic information is personified genetic (genomic) information, as it is of an individual, personal nature as relating directly or indirectly to a specific or determined person. Genetic data are non-personalized (anonymized) genetic data, which are often contained in the database and, therefore, at a group level.

Genetic *information* fall under the right to a private life (right to privacy). There are no doctrinal or legislative grounds for recognizing genetic information as an independent object of civil rights. Genetic *data* are usually the result of intellectual activity, and have a form of a database. Additional legislative regulation is needed of the activity of biobanks carrying out storage of biomaterials, of genetic data is substantiated. The genetic information contained in such biobanks should be subject to the legal regime of privacy secrets.

Legal Problems of Compulsory Genomic Registration in Russia

By: Nikolai Olkhovik

Summary of Presentation

Normative legal regulation in the field of compulsory genomic registration (Federal Law "On State Genomic Registration in the Russian Federation", "Regulation on the Procedure for Compulsory State Genomic Registration of Persons Convicted and Serving Sentence of Deprivation of Liberty", approved by the Government of the Russian Federation) stipulate the mandatory State genomic registration of convicts serving a prison sentence for a serious or especially serious crime, and of crimes of sexual nature. Unfortunately, these normative legal acts do not solve a number of ethical issues related to the right of access to genomic information, its confidentiality during storage, transfer and destruction.

It seems that despite the mandatory genomic registration, the solution of these issues should be based on the principles of processing genetic information. First, convicted persons must have the right to access own genetic information processed. Secondly, convicts, like other persons during voluntary genomic registration, must maintain freedom of choice to use their genetic information, if this is not related to the prevention, disclosure and investigation of crimes, as well as the identification of the persons who committed them. Thirdly, convicts should not be deprived of the right to confidentiality of their genetic information for

purposes not related to the prevention, disclosure and investigation of crimes, as well as the identification of persons who committed them.

Confidentiality of genetic information in the Russian Federation: problems of legal regulation and law enforcement

By: Anna Semiakina

Summary of Presentation

On the issue of maintaining the confidentiality of personal and, in particular, the genetic data in the Russian Federation, there are three key considerations: legal, organizational, and technical. Currently, in the Russian Federation, there is no special law regulating the collection, storage, processing of genetic data. Liability for committing offences in this area is not sufficient. Besides, Russian laws do not always comply with the provisions of the European Convention on Human Rights. For example, adopted persons, as well as persons born with the help of assisted reproductive technologies, are not guaranteed access to information about their genetic history.

The task of the Russian legislator in the coming decades will be to find a balance between the constitutional rights of individuals, private interests, and the interests of society and the State. In this area, international experience in legal regulation should be considered, including the knowledge of the European Union, which adopted the General Data Protection Regulation (GDPR) in 2016.

Parallel session II - Multi-disciplinary Student Groups

Students' brief recommendations for policy makers on the use of genetic information in the Justice System

Based on the the knowledge gained during the talks, students were asked to split into groups and work in the following tasks:

They were asked to imagine that they were members of the Interdisciplinary Council on the Use of Genetic Information in the Justice System. They were asked to write a set of brief recommendations for policy makers on the use of genetic information in the Justice System, while considering the following points:

1. Single gene genotyping vs. whole genome sequencing
2. Single gene risks vs. polygenic risk scores
3. Gene-environment interplay
4. Confidentiality and anonymity
5. Use of different factors as aggravating and mitigating in sentencing
6. Genetic literacy / expertise of justice stakeholders
7. Use of genetic information in justice in the era of AI, e.g. robot judging
8. Other issues

Each group of students included students from different disciplines - law, psychology, science and linguistics faculties - as well as from a number of countries including the UK, the Russian Federation, India, Iran, Kazakstan, and Africa. After one hour of intensive discussions, students submitted orally and on paper their proposals which included:

- To establish a global organisation, that would be operated by the UN or similar organisation, for development of regulations for the use of genetic information. This independent body, should be multidisciplinary including geneticists, lawyers, policymakers etc. and should have an overarching role to decide when and how genetic data is used a by whom.
- At country level, states should establish departments that will regulate collection and use of genetic information, controlled by international law (that will need to be created).
- Non-profit organisations should be established to represent minority groups, people who do not have access to their own data - to protect these people's human and civil rights.
- Increase education and awareness for populations as how their data are being used and so that people can put pressure for appropriate laws and policy.
- Organisations who sequence DNA must have a justifiable reason for it.
- One possibility of prevention unsanctioned use is to limit the use of genomic information to state/non-commercial purposes - the use of anonymised big data should be restricted to non-commercial state run projects.
- Regarding data storage: the risk of de-anonymisation may be sequenced reduced if data from individuals were split into multiple sections and stored separately.
- In the criminal justice, in the future, genetic data e.g. polygenic scores, may be used to help with producing individualised probation and rehabilitation plans - to aim to reduce risk of reoffending.

On the issue of using AI in judging / sentencing, students suggested that:

- We need to develop algorithms that would calculate or estimate bias in the existing decisions. For a particular case, if the estimated bias exceeds a given threshold, then the case should be passed on for human judging.
- In light of gene-environment interplay, information on multiple factors (e.g. genes and environment) needs to be considered.

Other societal issues

- In education, genetic information that can be used to predict academic achievement should not be used to influence decisions in admissions into educational organisations.
- Potentially genetic information can be used by companies to select employees that are most useful/have most potential for a particular work.
- Genetic information could be used to help inform personalised learning at a school level (i.e. so teachers can identify pupils and their propensities for their learning/achievement level), but this would not be shared beyond the school and parents (i.e. should not be shared in official reporting.
- Parents should have the choice regarding whether their children's genetic data are used to inform their educational direction, but this should be done after parents have received some degree of genetic literacy.

Genetic literacy

- To begin genetic education early on so that people are familiar with principles from an early age. This will help to de-stigmatise the issue. Genetics should be introduced into the school curriculum from age 12, at an age-appropriate level.
- To include genetics in training and education of legal professional so that they are able to understand the relevant issues in order to reform laws and policy.
- To provide training for juries and judges to raise awareness of interactions between genes and environment, so that they understand the incorrectness of genetic determinism.

Acknowledgements

The conference is organised with support of InLab, ICRHD and Law Grant *RFBR 18-29-14071*.

Opportunities for students and lawyers announced at the conference

1. International Conference: 'Life in the Era of Genome, Big Data and AI: Ethical, Legal and Other Societal Issues'.

Sirius, Sochi, January 20-21, 2020.
This conference is open for applications from law students / graduates and lawyers from across the Russian Federation and international experts.

2. Winter School. 'Research and its applications in the 21st century'.

Sirius, Sochi, January 20 – Feb 3, 2020.

Applications will open soon. Places are limited and selection is on merit. More information will be available soon.

3. Contribution to ongoing projects.

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