***Jury to Shine a Light on Genomic Research…***

**Public Invited to Become Members of Citizens’ Jury to
Deliver Verdict on Future of Genomics in Ireland**

**Date of issue: February 28 2022**It is one of the defining medical ethical issues of our time. The exploration of the human genome has the potential to improve and save countless human lives. But it’s a project that doesn’t come without risk.

The role genomics can play in our lives, the opportunities and the challenges, is the subject of a forthcoming Citizens’ Jury in which members of the public are being invited to hear the arguments for and against, and to deliver their judgement.

A jury of 25 people broadly representative of the Irish population is now being sought to deliberate on this topic and to deliver a verdict that will be presented to Government and policy makers to help shape future regulation in the area.

Organised by IPPOSI, the Irish Platform for Patients’ Organisations, Science & Industry, in collaboration with the RCSI Public Patient Involvement Office, the jury will be guided by an independent Oversight Panel made up of representatives from Rare Diseases Ireland, Health Research Charities Ireland and the RCSI University of Medical and Health Sciences.

During the month of June 2022, jury members will meet for a number of sittings chaired by an independent facilitator. They will have the opportunity to hear testimony and to cross-examine witnesses who are expert not only in the field of genomics, but also in the related areas of medical care, ethics and law.

The jury will examine how genomic information can improve our health as individuals and as a society. It will also probe to what extent we should support the increased use of genomics in our health care and health research, the challenges and opportunities that arise from doing so, and the safeguards that need to be put in place to maximise progress while containing the risks.

The jury verdict, once announced, will be discussed in depth via a series of follow-on Deliberative Dialogue workshops with diverse population-based groups organised by the RCSI University’s Public Patient Involvement (PPI) Office, in September 2022.

*To be a member of the Citizens’ Jury, people must be aged 18 years and above, and resident in the Republic of Ireland. The successful applicants will be randomly selected through an independent process overseen by an academic expert in data protection, informatics and ethics, to ensure representation from a cross-section of the Irish population on the final jury. Jurors will receive a gratuity as a token of appreciation for their time. For full information and to make application, visit* [*www.ipposi.ie*](http://www.ipposi.ie) *before the closing date of Wednesday March 23, 2022.*

**Blueprint for our Bodies
Welcoming the initiative as an opportunity to seek the views of the public on an area that urgently needs robust oversight, IPPOSI board member, Prof. Orla Hardiman, comments:**“Genomics. Not exactly a word that trips off the tongue or that we’re hugely familiar with. However, we wouldn’t exist without it. The human genome is the blueprint for our bodies. Made up of DNA, no human genome is the same, and tiny glitches in that DNA can give rise to serious illness and disability. Developing genomic medicine that is specific to a person’s DNA, can have a transformative effect on their lives and future health and well-being, as well as for wider society. However, we do need to take steps to maximise the societal benefits, and to also minimise the risks that come with genomic research in Ireland and to ensure that the appropriate structures and guidelines are in place so that everything we do benefits us collectively as a society.

“As a doctor and a scientist, I have seen the benefits of genomic research. But at the moment, as a society, we need to understand what the best approaches are that will allow us to conduct meaningful research that benefits everybody. It’s important that we hear from the Irish people about what they are comfortable with when it comes to giving consent for genetic research, and the types of information that is needed to understand how their genetic data will be used. You don’t have to have a science or medical background or know anything about genomics to join the jury. We want you to come with an open mind and lots of questions.”

**Social & Ethical Challenges
For Derick Mitchell, CEO of IPPOSI, genomic research is a double-edged sword and it is important that Government and policy-makers listen to the views of the public:**“There are many challenges around genomics. Notwithstanding these, many of IPPOSI’s members living with chronic and rare diseases believe that if we get it right, it offers the potential for scientific and medical breakthroughs that will enable patients receive a quicker diagnosis and a treatment plan that is personalised to them.

“However, it is also the case that genomics can potentially be used for other less altruistic purposes. Conceivably, employers, banks, insurance companies and businesses could use this information to discriminate against one person over another in the provision of services.

“With this Citizens’ Jury, we want to explore public opinion around the opportunities presented by genomics, as well as the challenges that may arise from a social, ethical, legal, and practice point of view. What rules do we need to have in place around how genetic information is stored, who can access it, whether the information can be deleted on request, and safeguards to protect it from getting into the wrong hands?”

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| **YOUR QUESTIONS ANSWERED**1. **What is a genome?**

We all have something called a ‘genome’. And, no, we’re not taking about the little man with the funny hat who lives in gardens. Our genome acts like an instruction manual for our bodies controlling how they work.1. **What is in the genome?**

The genome is made up of all the DNA in our bodies. If you stretched the DNA in one cell all the way out, it would be about two metres’ long and all the DNA in all your cells put together would be about twice the diameter of the solar system.1. **Is everyone’s genome the same?**

No. Everyone’s genome is slightly different. Small differences in DNA can determine minor things, like how we respond to caffeine or alcohol, to relatively big things, like how likely we are to develop a serious illness like cancer or diabetes. 1. **What does genomic research do?**

If we look at a person’s genome in detail, also known as genetic or genomic research, we can learn a lot about someone’s DNA and what makes a person “tick”. This work can be quite specific, such as genomic testing of an individual to provide a diagnosis for a particular condition. Equally it can have much wider application by providing more general insights into how our genome works. For example, by determining if messages being sent out to different parts of the body by our DNA are not working correctly, we can look at ways to disrupt, or possibly even prevent, the messages being sent in the first place, preventing potential disease. 1. **So how could genomic research impact the development of medical treatments?**

Armed with genomic information, doctors will be able to go to their computer, pull up the person’s genome profile and see straight away the differences in an individual’s DNA which may be causing one or more symptoms. They may also be able to determine particular conditions, for example, some rare and inherited health conditions and some cancers. Scientists could then develop future genomic treatments specific to particular patients, resulting in faster, more effective, care.It also means that we can take pre-emptive action too and that if we know what diseases we are at risk of developing, we can take steps to reduce our chances of these negative DNA processes being activated, by changing how we live our lives or by taking a particular treatment. This is already the case with some childhood cancers.1. **Are there other ways in which genomic research may change how we live our lives?**

Although research in this area is very much in its infancy, it is thought that our genome may impact not only our health but also determine aspects of our behaviour and how we respond to external stimuli. For example, it may impact how we learn, how we cope with risky situations, or how we react to potentially addictive substances. This, in turn, may predict how well we are likely to do at school or be in a car accident or have potential addiction issues. This clearly raises ethical questions for our society, but by exploring these now we will be able to fully consider and widely engage so as to make informed decisions. |

**ENDS**

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**About IPPOSI**

IPPOSI – The Irish Platform for Patient Organisations, Science and Industry – is a patient-led, non-profit alliance of 105 patient organisations, 250-plus scientists and 23 companies that work together to improve the lives of people living with a chronic and/or rare disease in Ireland.

IPPOSI connects patients and patient groups with the multiple and diverse stakeholders in health, thus strengthening the patient voice by shaping health research, policies and services in Ireland and in Europe.

IPPOSI membership is open to all groups with an interest in healthcare and research and development, patient representatives, academics, scientists and the healthcare industry.