

11 October 2022

Dear Dr Henry,

We write today to share with you our recommendations around the future use of genomics in health care and health research in Ireland. Our recommendations centre around five themes – **appropriate use, national partnerships, data security, consent, and public engagement.**

We are aware of the ongoing work around this topic at the national level, and at the international level, and we hope that our recommendations are timely, useful, and thought-provoking. It is our hope that the recommendations around public engagement can ensure that opportunities like the IPPOSI Citizens' Jury are not isolated events – that the early, extensive, and diverse consultation and involvement of the public becomes a regular, valued part of the normal national policy making process.

Given the significant time and effort which each of us have dedicated to the jury process, and to gaining a better understanding of the topic and the national policy options, **we would appreciate a formal, written, public response to our recommendations.** We invite you to comment on those recommendations which resonate with you, those recommendations which are otherwise accommodated, and those recommendations which are currently not feasible. For data privacy reasons, we ask that this is delivered to the IPPOSI Citizens' Jury Coordinator ([info@ipposi.ie](mailto:info@ipposi.ie)) who will ensure that it is communicated to each of us individually.

Finally, we take this opportunity to highlight that the recommendations only share a portion of what was discussed during the jury process – the full richness of the conversations are best experienced in person. The recommendations are also a reflection of how far we were able to take the discussion during the allocated time. It is our belief that the task should now be passed on to others to delve into the detail around certain key issues – for instance, what should a national agency be responsible for and how do we operationalise it? where is a national database hosted and who is involved in its governance? what institutions can be tasked with oversight and how do we involve citizens in these structures? what does citizen access to their genomic information look like and how is it facilitated?

We look forward to your response, and we thank you in advance for your interest in our jury process.

Kind regards,

Zoha

Alan

Colm

Darragh

Rosanne

Zoë

Jim

Yvonne

Martin

Paula

Kristal

Ciarán

Elena

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Áine

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Monika

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John

## THE FUTURE USE OF GENOMICS IN IRELAND



USE | PARTNERSHIP | SECURITY | CONSENT | ENGAGEMENT