



# Building an ethical and democratic framework for genomic data governance in Can.Heal

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# Can.Heal (Cancer Healing)



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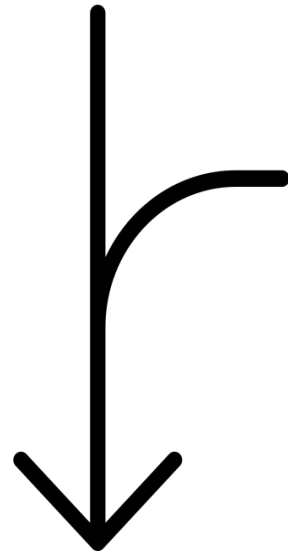
## Building the EU cancer and public health genomics platform

Unleashing the power of Public Health Genomics and Diagnostics for All: synergies between public health and genomics are possible and necessary for the optimal benefit of patients and citizens.



# WP12: Law, Ethics, Public engagement

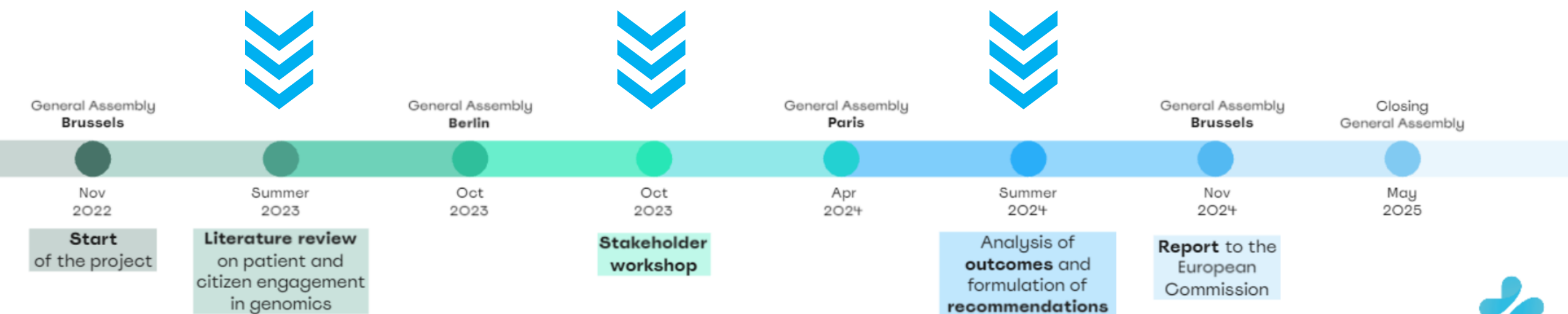
Translate the values of citizens and patients



While integrating the perspectives of  
Can.Heal stakeholders

Into an ethical framework for genomic data reuse in cancer

# WP12: Law, Ethics, Public Engagement



# Literature Review

45 citizen and patient engagement initiatives on genomics: +50,000 people

Europe  
(+ Canada, UK, USA,  
Australia, Switzerland)

Qualitative and  
quantitative  
methods

General population  
(+ ethnic minorities  
and rare disease  
patients)



# Stakeholder Workshop



**Workshop**  
**Ethical & legal issues**  
Tuesday, October 17<sup>th</sup>  
14.00-17.00

## AGENDA

- |             |  |
|-------------|--|
| 14.00-14.15 | Introduction   |
| 14.15-14.30 | Overview of ethical and legal outcomes from patient and citizen engagement initiatives     |
| 14.30-14.40 | <b>Topic 1 - Anonymization</b><br>Presentation of public engagement outcomes               |
| 14.40-15.10 | Interactive discussion   |
| 15.10-15.20 | Break  |
| 15.20-15.30 | <b>Topic 2 - Incidental findings</b><br>Presentation of public engagement outcomes         |
| 15.30-16.00 | Interactive discussion   |
| 16.00-16.10 | <b>Topic 3 - Reuse for clinical purposes</b><br>Presentation of public engagement outcomes |
| 16.10-16.40 | Interactive discussion   |
| 16.40-16.55 | Reflections by Adrian Thorogood and Pascal Borry   |
| 16.55-17.00 | Next steps   |

# 3 Topics, 3 Questions



## ISSUES RELATED TO THE IDENTIFICATION OF INDIVIDUALS

How should we balance the deidentification of data with the potential benefits of returning results to patients (and their relatives)?



## INCIDENTAL FINDINGS

Should incidental findings be limited as much as possible, or should we evolve towards a practice of secondary findings in some contexts?

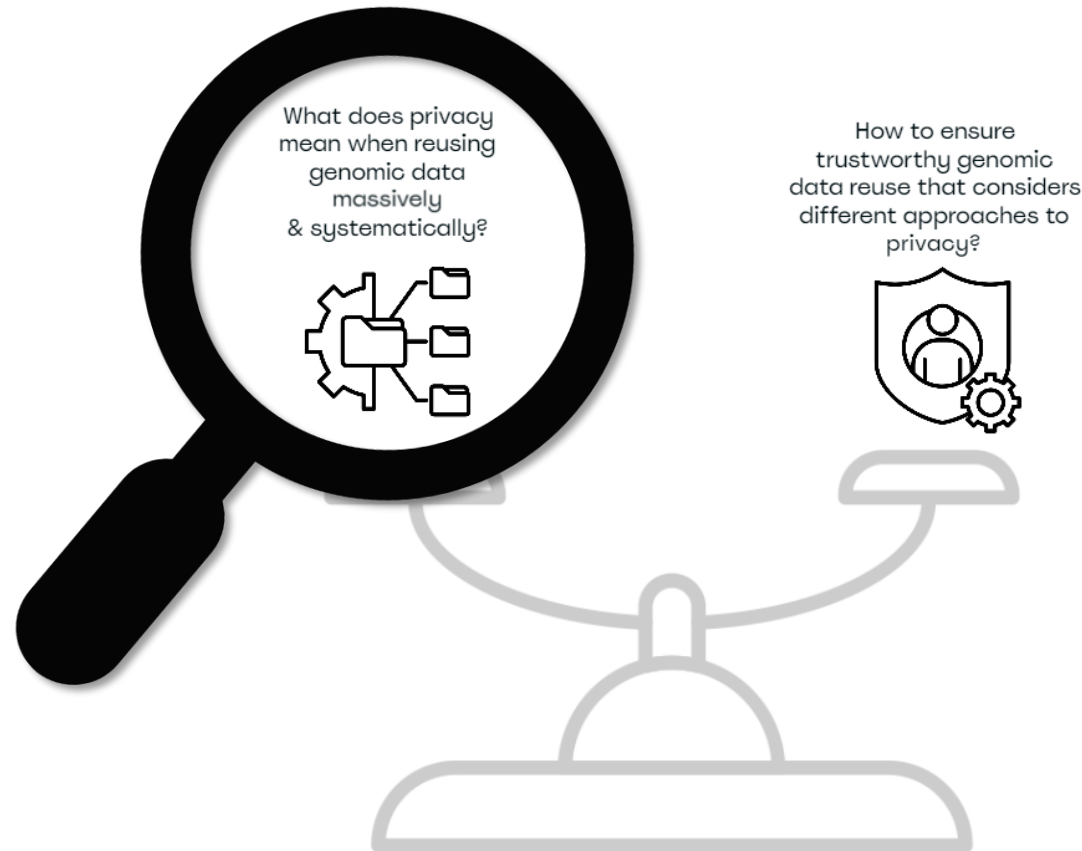


## REUSE FOR CLINICAL PURPOSES

How can we respect individual rights in data reuse (e.g. consent, right to be forgotten) without overburdening researchers or clinicians?

# Identification of Data Subjects

How to balance privacy with the benefits of returning results to individuals (and their relatives)?

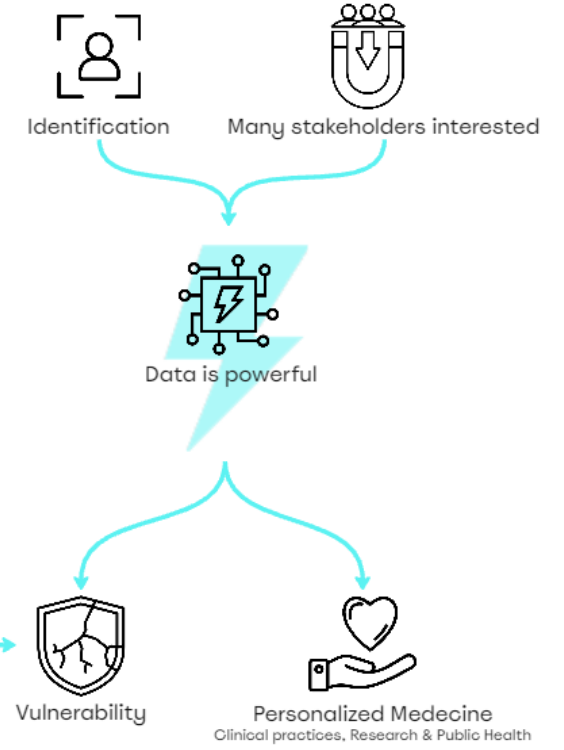
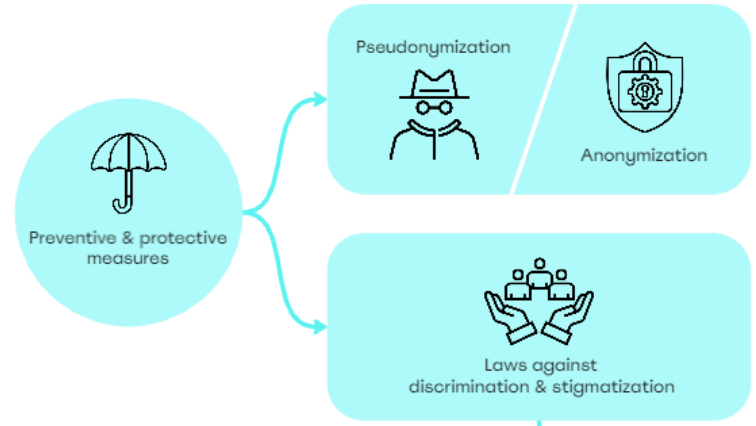
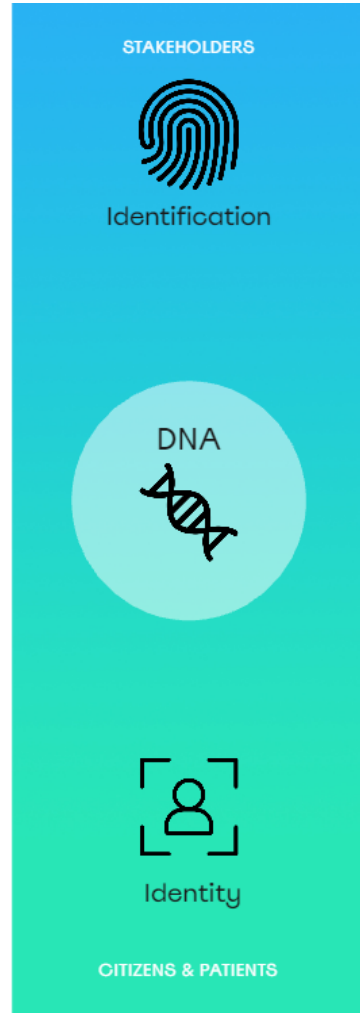




# Different Approaches to Privacy



What does privacy mean when reusing genomic data massively and systematically?



# Conclusion

Building an **ethical and democratic framework** for genomic medicine requires investigating the **shared and conflicting values** among the general public and other stakeholders in genomics.



## Contact

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