

# INTEGRITY



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## Genetic Tests Module





## Genetic Tests



## Informed Consent and Genetic Databases



## Research Integrity: principles and importance



## Practical Activity



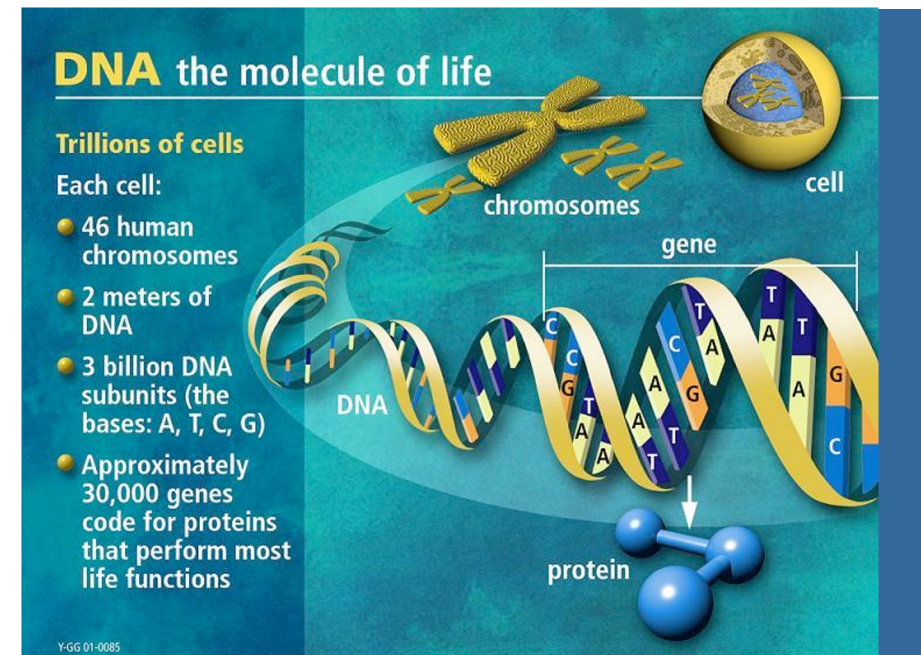
## Conclusion/Wrap-up

# What is Genetics?

Study of genes, genetic variation and heredity in organisms.

**Gene** is a sequence of DNA subunits that codes for proteins that perform key life functions

The **DNA**, the molecule of life, is responsible for the development, functioning, growth and reproduction of all known organisms and many viruses



Source: The Human Genome Project

# What are Genetic Tests?

**Genetic tests** identify changes on DNA sequences, proteins, chromosomes or genes

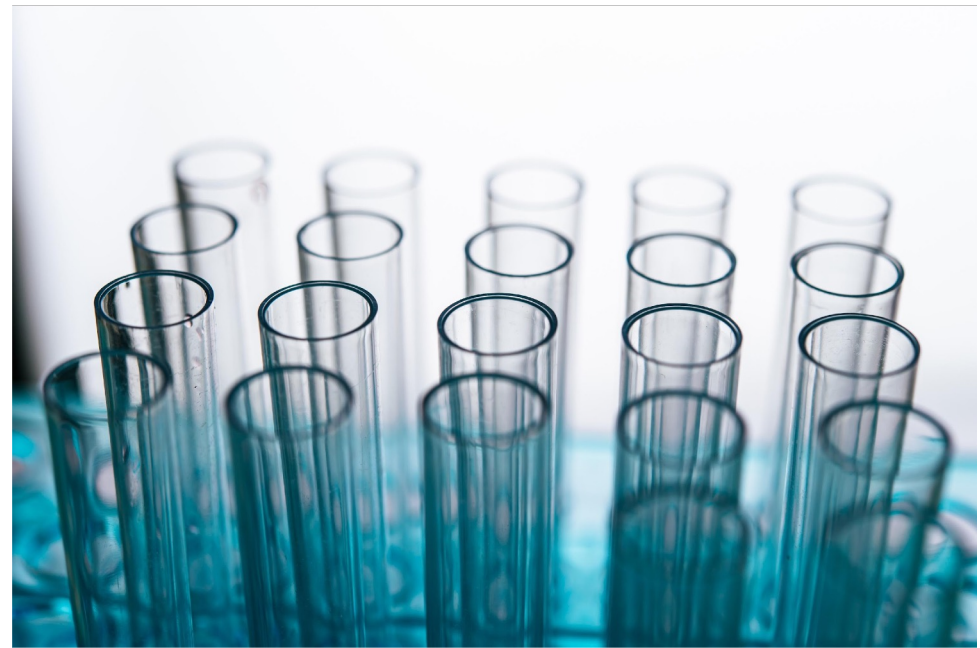
- **Where are they applied?**
  - Clinical diagnosis
  - Biomedical research studies
  - Forensics
  - Personal/Recreational use



# Why are Genetic Tests used?

Genetic tests are **used to**:

- **confirm** or **dismiss** a genetic condition
- **predict the risk** of developing or passing on a genetic disorder
- **gain information** for medical treatments
- **gain information** for criminal investigations (e.g. identify suspects)
- **personal purpose** (e.g. ancestry search; genetic horoscope; find relatives; etc.)





# The methodologic process

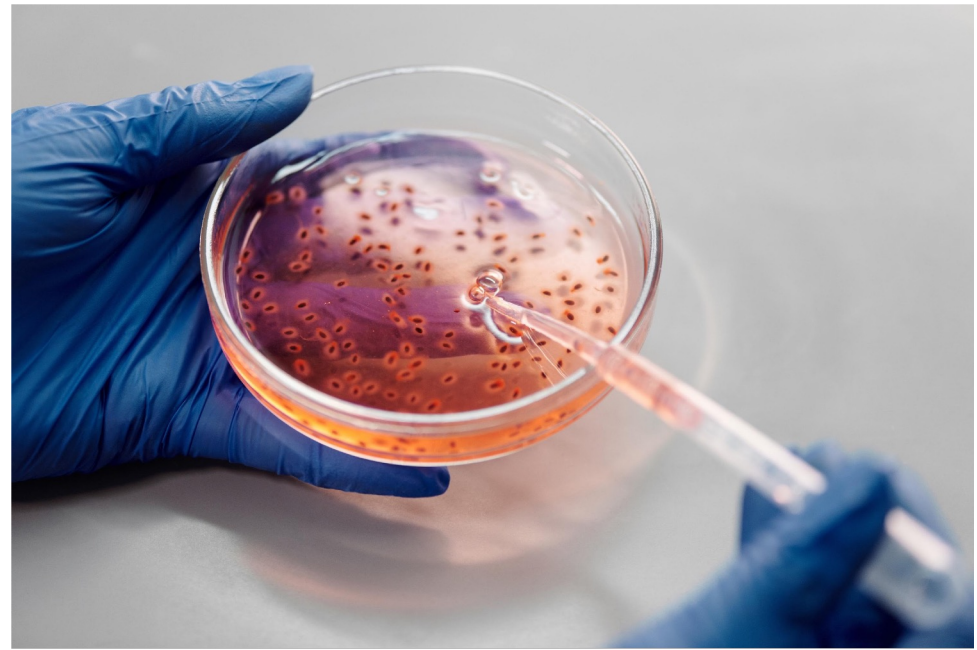
Genetic tests follow **standard** protocols:

- A **sample** is collected from blood, hair, skin, amniotic fluid or other tissues
- The sample is then **analysed** to detect specific changes or markers on DNA, chromosomes or proteins
- **Test results** are reported to the person's doctor, genetic counsellor or directly to the person (depending on the type of test)



# The impacts of genetic information

- Genetic information is **individual** and should be **private**
- The use of your genetic information has **impacts** on you, on your decisions and on your relatives' lives
- Your sample contains **information** that goes **far beyond** the purpose of the prescribed genetic test
- Your genetic information may result in **unexpected findings!**





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# What is an Informed Consent?

- **Communicating** to a person all aspects of a treatment, procedure, or care, that often results in **obtaining permission** to do it
- The person has the right to ask **and clarify any doubts** before making a decision (i.e. accepting or refusing the intervention)
- Informed consents are collected in a **form**
- By **signing** an informed consent form, the person acknowledges **to understand and to accept** the procedure to be conducted



# Details of an Informed Consent form

**Informed Consent forms** should provide the following information:

- Detailed description of the procedure, test, treatment, or care
- Purpose and methodology
- Alternatives available
- Benefits, limitations, risks, and probability of those to happen
- Types of results
- Data use and storage

# The 4 principles of an Informed Consent

There are **4 principles** in an informed consent:

01

To have the capacity to make a decision

03

To comprehend the information provided

02

To disclose all information about the treatment, test, or procedure, including the expected benefits and risks, and the probability of those to occur

04

To voluntarily grant consent

# Genetic Databases and Sample Storage

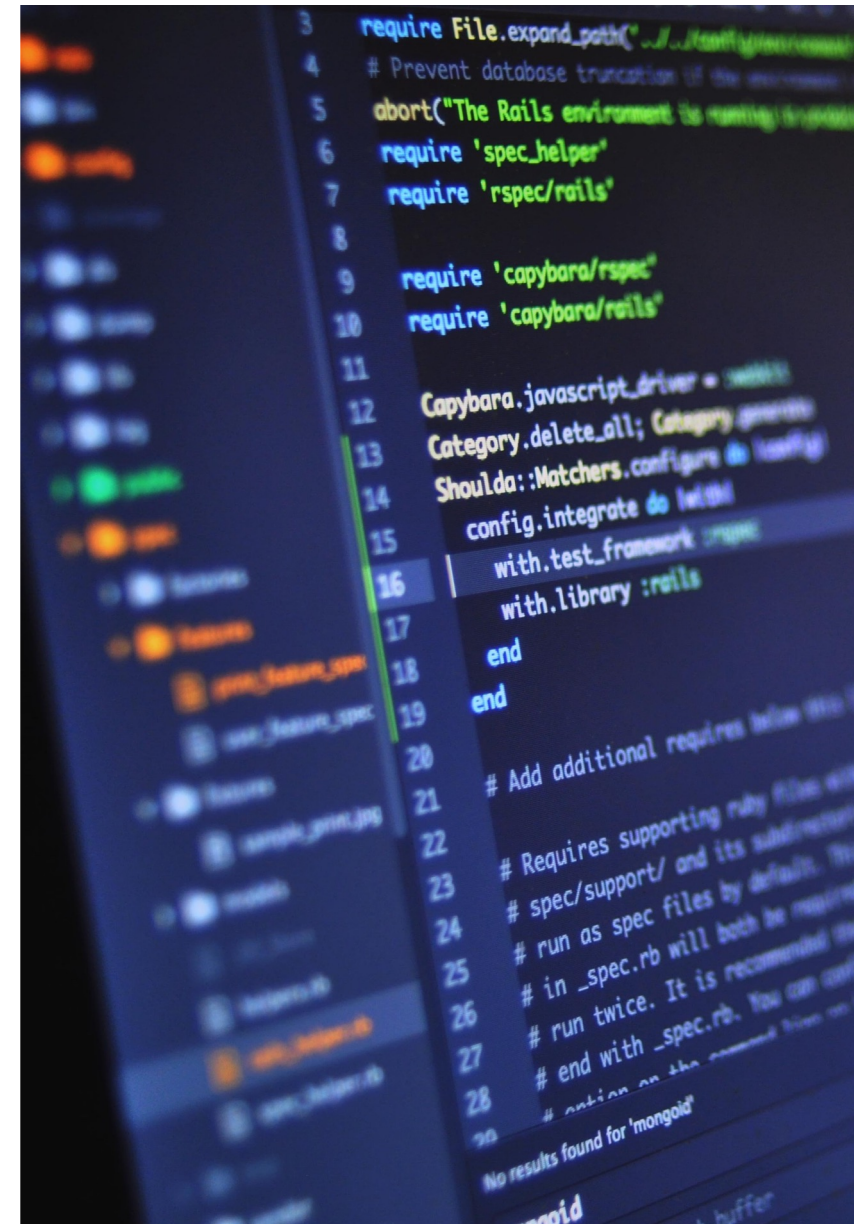
- The genetic information from individuals is stored in genetic databases or biobanks
- Genetic databases (e.g. GenBank) contain genetic data (e.g. genes, phenotypes, etc) from an individual that is stored in a computer software to enable the use of such data for clinical or research purposes
- Biobanks refer to the collection and storage of human biological samples (e.g. umbilical cord) for clinical or research purposes





# Privacy and Confidentiality in Genetic Databases

- The individual's genetic information, stored in genetic databases or biobanks, should be kept private and confidential
- Any personal data, genetic condition, etc. should only be shared between the person and their doctor, researcher or genetic counsellor
- Yet, this is not always the case (e.g. the use of genetic data from public databases for criminal investigations), which opens serious privacy, confidential and ethical discussions!





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# Research Integrity: principles and importance

**Research Integrity** means acting with **responsibility** and **honesty** in all aspects of research, so that others can trust in the findings that are reported. Relating with genetic tests, this is important for:



- Sensitivity of genetic information
- Reliable and honest data collection, analysis and reporting of test results
- Respect for people (e.g. data privacy)
- Accountability for the test results

# Research Integrity: principles and importance



## **Accountability**

Responsibility for all aspects of research;  
Answer questions



## **Respect**

People, Institution, etc.;  
Object of the research



## **Honesty**

All aspects of research;  
Fair, transparent and unbiased results



## **Reliability**

Quality of the research;  
Trust in findings

# Research Integrity: Research Misconduct

## Falsification

Manipulation of materials, data, processes and equipments

e.g. change numbers in a school work or research project

## Fabrication

Making-up data or results, and reporting them as true

e.g. reporting numbers in a school work or research project that did not resulted from any measurement or observation

## Plagiarism

Appropriation of a person's ideas, text, or data, without acknowledging such person (i.e. without mention their name)

e.g. copy a person's entire text to a school assignment or scientific article, without mentioning this person's name

# Research Integrity: Questionable Research Practices

**Authorship/Collaboration**

**Drawing from the work of others**

**Citing selectively**

**Cherry picking data**

**Omitting key results/processes**

**Mentoring issues**

- Also compromise the credibility and trust in the scientific results
- More subtle and difficult to prove an intention from the researcher doing such practices
- Could result from poor training or lack of knowledge on good (acceptable) research practices!

# Research Integrity at High School: why bother?

- Your school work should be done with responsibility and honesty, so your teacher and peers trust in your work!
- This means not plagiarize or manipulate data!
- Collaborate and contribute effectively to group work assignments!
- Respect others and your school environment!
- **Integrity at school is an important step to become a responsible person and trustful researcher!**





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# Practical Activity – 55 minutes - Structure

Activity	Description	Suggested Time
<b>Groups</b>	<ul style="list-style-type: none"><li>• 4 groups of 5-6 students</li><li>• Each group receives 1 board + 1 set of post-its (face-to-face session!)</li><li>• Watch video (find the link and QR code in the board)</li><li>• 1 spokesperson to fill in the board and represent each group</li></ul>	10 minutes
<b>Group Discussion</b>	<ul style="list-style-type: none"><li>• Discussion of the 2 dilemmas and propose solutions</li><li>• Fill in the boards using post-its or sticky notes (online session only!)</li></ul>	25 minutes
<b>Presentations</b>	<ul style="list-style-type: none"><li>• Spokespersons of each group present their boards</li></ul>	10 minutes (2-3 min/spokesperson/group)
<b>Class Discussion</b>	<ul style="list-style-type: none"><li>• Discussion of the ideas and solutions shared by the spokespersons</li></ul>	10 minutes



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What are Genetic Tests? How may your genetic information impact you?  
Why are Informed Consents and Data Protection important?



What is Research Integrity? How does it apply to your own school practices?  
Why is it important to avoid engaging in misconduct and questionable practices?

Thanks for your attention

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