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# Genetic Testing- Issue Scan

## Teacher Guide v1.5

### Overview

There are many social, legal and ethical considerations surrounding genetic testing. This lesson plan covers a range of issues relating to the use of DNA information in healthcare. It introduces students to the principles of bioethics, which form a transferable framework for examining social, economic and cultural contexts and ethical uses of biotechnology. The activity also models the use of reasoned judgement to write evidence-based justifications and evaluations.

### Activity outcomes

Students:

- do this thing
- accomplish this outcome
- discuss and consider these topics

### Syllabus connections

This task directly addresses the “ethical understanding” and “personal and social capability” general capabilities emphasised in syllabus. It also aligns with the following outcomes:

#### **Inheritance patterns in a population**

- investigate the use of technologies to determine inheritance patterns in a population using, for example:
  - DNA sequencing and profiling

#### **Genetic Technologies**

- evaluate the benefits of using genetic technologies in agricultural, medical and industrial applications
- interpret a range of secondary sources to assess the influence of social, economic and cultural contexts on a range of biotechnologies

#### **Analysing Data and Information**

- derive trends, patterns and relationships in data and information
- assess the relevance, accuracy, validity and reliability of primary and secondary data and suggest improvements to investigations

#### **Communicating**

- construct evidence-based arguments and engage in peer feedback to evaluate an argument or conclusion

### Assumed knowledge

- Medical applications of DNA sequencing

### Materials

For the class:

- A set of 7 chat station quote sheets, folded under along dotted line (see PDF PowerPoint file associated with this activity).

For each student:

- Principles of Bioethics Handout
- Chat Stations Worksheet
- Justifying Claims worksheet (double sided)

## Activity guide

Many of the issues described in this activity are covered in the fact sheet from the Centre for Genetics Education <http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-19-ethical-issues-in-human-genetics-and-genomics>.

Sections of this lesson have been adapted with permission the Northwest Association for Biomedical Research. Their full set of six lesson plans called "Bioethics 101" can be found at <https://www.nwabr.org/teacher-center/bioethics-101>

**NB: A full teacher guide is available with suggested answers for each of the worksheets. Teachers can email [kccgeducation@garvan.org.au](mailto:kccgeducation@garvan.org.au) from a school email address to gain access.**

### Part 1- Introduction - Ethical Barometer

Ask students to take a position along the centre aisle of the classroom corresponding to the strength of their agreement or disagreement with the following statement.

*The government should pay for everyone to have their DNA sequenced at birth for better management of health*

Encourage students to take a position based on their initial reaction to the statement. A brief discussion could follow, such as asking, "what made you stand there" to a few students. The statement could then be modified with the following specifics, giving the students a chance to reposition themselves accordingly:

- a) The government should pay for everyone to have their DNA sequenced to find out about diseases that can be prevented
- b) The government should pay for everyone to find out about diseases for which they are genetic carriers
- c) The government should pay for everyone to find out about their risk of diseases that we can't currently prevent, such as Alzheimer's disease

Optional extension: Further modifications could be used illustrate how additional facts can influence decision-making:

- a) What if the government announces that, since it paid for the tests, it will own the data and use it for forensic and research purposes?
- b) What if the government had no access to the data, and it was fully controlled by the individual?
- c) What if the government made it compulsory and reduced the Medicare funding available to those who didn't participate?

### Part 2- Questioning Framework (optional)

To expand on the original question, the following writing framework could be used to prompt further discussion. This framework was developed to enhance student's argumentation skills (1).

1. What further information would help in making your decision?
2. What are the possible advantages of your decision?
3. What are the possible disadvantages of your decision?
4. If someone disagrees with you, how would you convince them that your answer is the best?
5. Has your original decision changed? In what way?

Note that this final question can be left to the end or revisited again after the other activities.

### Part 3- The Principles of Bioethics

Depending on how much previous classwork has been done on ethical issues, it may be helpful to explain that ethics is an important part of science. Ethics may not be purely objective but involves the tools of reasoned judgment. The principles of bioethics are well-recognised perspectives that can be used to structure logical evaluations of ethical questions.

The “Principles of Bioethics” handout outlines the bioethical principles in plain language. The principles are

- Respect for persons (Autonomy)
- Maximise good (Beneficence)
- Minimise harm (Non-maleficence)
- Justice

Advanced students may enjoy this 10min video aimed at an undergraduate audience. It uses the formal names of the principles (as well as the principle of utility) and gives examples relating to medical care.

<https://www.youtube.com/watch?v=jE3ih7dXULw>

For other students, after reading through the principles together you could check understanding by discussing an exaggerated but relatable scenario.

For example:

*“Your friend wants to read a book but it’s on the top shelf of the library and they can’t reach it. You’re pretty sure you could get it if you stepped on the shoulder of another friend who is sitting near the shelf. Would it be ethical to step up on them?”*

Working through each principle, ask how it might apply to the ethical question.

- **Respect for persons**- you must have permission before stepping on them
- **Maximise benefit**- you are trying to do someone a favour
- **Minimise harm**- it would not be ok if your weight would hurt your friend.
- **Justice**- would the book be shared? Could you spread your weight between two people?

Also note that more ethical alternatives (such as chairs) should always be sought

### Part 4- Chat Stations

Place the chat stations quote sheets at a different location around the room (such as on lab benches or stuck to the wall). Students can work in small groups, rotating around each chat station to read and discuss the quotes and fill in the “Chat Stations Worksheet”, matching the issues from the card to the related bioethical principles.

There are no definitive answers for the bioethical principles, but a suggested answer sheet is provided for teachers to prompt discussions.

### Part 5- Evidence-based argument

The “Justifying Claims” worksheet encourages students to use evidence (facts) and reference to the bioethical principles to write strong justifications for opinions about ethical questions.

There are four tasks on the worksheet:

Task 1- students distinguish between factual (objective) and opinion (subjective) statements. Review answers before proceeding to task 2.

Task 2- students find factual statements that could be used as evidence for opinion statements. To reduce the time taken for this task, students could work in pairs to work on one or two allocated opinion statements.

Task 3- Students annotate a paragraph to identify opinions, evidence and bioethical principles.

To extend students, ask them how they would counter the claim made in the paragraph.

Task 4- Students use the statements paired in task 2 to write a paragraph that supports a claim with evidence and references bioethical principles.

Students could peer-mark the paragraph by annotating it as in task 3 and/or formulating a counter-claim.

### Suggested extension activity

Students could be asked to imagine that the claim in the first exercise was posted on social media, prompting a heated exchange of opinions between their friends



Students could write a response that uses reasoned judgement, raising at least two of the issues identified in the activity and referencing the related bioethical principles.

They could also be asked to find objective evidence to support their position by performing independent research or using the Student Resource Guide associated with our depth study resource.

### References

(1) Venville, G. J., & Dawson, V. M. (2010). The impact of a classroom intervention on grade 10 students' argumentation skills, informal reasoning, and conceptual understanding of science. *Journal of Research in Science Teaching*, 47(8), 952-957. doi:10.1002/tea.20358

### Credits

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## Issues in Genetic Testing

# Principles of Bioethics

This information is an extract from the *Bioethics 101* curriculum from Northwest Association for Biomedical Research. Used with permission

### Principles

#### Respect for Persons

This principle values the inherent dignity and worth of each person, as well as respecting individuals and their **autonomy**. It means not treating people as a means to an end.

Autonomy emphasizes the right to self-determination and acknowledges a person's right to make choices, to hold views, and to take actions based on personal values and beliefs. It emphasizes the responsibility individuals have for their own lives. The rules for informed consent in medicine are derived from the principle of respect for individuals and their autonomy. In medicine, there is also a special emphasis on privacy, confidentiality, truthfulness, and protecting individuals from vulnerable populations.

#### Maximizing Benefits/Minimizing Harms

This principle stresses “doing good” and “doing no harm.” To **Maximise Benefits** one would directly help others and act in their best interests. It requires positive action.

**Minimising Harms** obligates others to avoid inflicting harm intentionally. It relates to one of the most traditional medical guidelines, the Hippocratic Oath, which requires that physicians “do no harm”—even if they cannot help their patients. “Doing good” is also referred to as **Beneficence**, and “do no harm” is also referred to as **Nonmaleficence**.

#### Justice

This principle relates to “Giving to each that which is his due” (Aristotle) or **Fairness**. It dictates that persons who are equals should qualify for equal treatment, and that resources, risks, and costs should be distributed equitably.

#### Other considerations

Some ethicists also add **Care**, which focuses on the maintenance of healthy, caring relationships between individuals and within a community. The principle of care adds context to the traditional principles and can be used alongside them. Additional considerations include **Duties & Responsibilities** or taking actions that respect personal **Virtues**.

### Historical Context

The historical basis for these principles goes back thousands of years. We find references to fairness and justice in Aristotle's writings. The Hippocratic Oath entreats physicians to “First, do no harm.” The Nuremburg Code was created in response to World War II atrocities in which prisoners were used for experimentation without their consent. The Code helped to define “Respect for Persons” and created guidelines for conducting ethical human clinical trials.

The principles were further redefined in the 1970s in a document outlining guidelines for research called the Belmont Report. The advent of new life-saving technologies such as the first dialysis machines and organ transplants created a need to establish policy regarding the fair distribution of scarce resources, and to understand how to balance the benefits and burdens of this new research.



## Issues in Genetic Testing

# Justifying claims

### Facts vs Opinions

Facts can be measured or demonstrated to be true or false. They are “objective”. Opinions are “subjective”- they cannot be verified, and may be influenced by personal feelings. Opinions may involve moral statements of “right or wrong” or “should or shouldn’t”. When it comes to discussing social, ethical and legal questions, opinions have an important place. However we must be ready to back up our opinions with logic, factual evidence, and ethical principles.

**Task 1:** Below is a list of statements. Decide whether each one is stated as an opinion or a fact. (You can assume the factual statements are true.) Write an “O” or an “F” in the “opinion or fact” column.

**Task 2:** For each of the statements you marked as ‘opinion’, find a ‘fact’ statement that could be used as evidence to support the claim.

		Opinion or fact?	Evidence
1	It is morally wrong to keep your DNA results private as it slows research that could save lives.		
2	In Australia, it is legal for life insurance companies to deny coverage based on genetic test results.		
3	Decisions about DNA testing must always be made as a family		
4	In one study, 40% of online genetic test results were shown to be false positives		
5	If a parent has an autosomal dominant variant, there is a 50% chance that they will pass it to their children		
6	People should not be told genetic test results unless there is a clear medical action.		
7	Everyone should be able to get their DNA tested if they want it		
8	In a survey, 74% of respondents said yes or maybe when asked if people should make their genetic data available to benefit society.		
9	A study found that patients who were told they had high genetic risk for Alzheimer’s disease were more likely to self-diagnose cognitive decline.		
10	Widespread DNA testing would increase discrimination		

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## Issues in Genetic Testing

### Backing up a claim

Subjective claims about ethical questions can be supported with objective evidence or by making reference to established tools for ethical reasoning such as the Principles of Bioethics.

**Task 3:** Read the paragraph below and annotate it to identify

- the subjective claim being made (the opinion)
- the objective statements used as evidence (the facts)
- references to bioethical principles.

Children's DNA should not be analysed for their risk of developing diseases as adults. The principle of respect for persons requires that people can choose whether they want to know their DNA results, and NSW law states that children under 14 are too young to give their own informed consent for medical procedures.

DNA tests are not 100% predictive of disease risk, and studies have shown that results can have negative psychological impacts. Therefore to minimise harm, only relevant childhood diseases should be analysed from the DNA of children.

**Task 4:** Choose one of the opinions from the table from task 1, and write a paragraph similar to the one above to argue the position. Use the fact you identified in task 2 as evidence, and refer to at least one bioethical principle.

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