

# Big Data Matters Teacher Resource Pack

## Introduction

The following resource is being offered to schools to increase knowledge of health data research. Scotland's public health relies on volunteers taking part in research projects to better understand health and well-being in Scotland. We would like to support young people's understanding of health research in order to give them more confidence to engage with science. The aim is to empower young people to ask the right questions, recognize the myths and know their rights when taking part in health research.

The knowledge is transferable to the consideration or discussion of ethical practice related to data use in all areas of current society. The resource has been designed to be flexible and adaptive to the needs of the class. Each teacher knows their own class best and can decide which talking points and activities to include or not.

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## Who are we?

This resource has been created by Generation Scotland (GS) at the University of Edinburgh and the Schools Health and Wellbeing Improvement Research Network (SHINE) at the University of Glasgow.

Generation Scotland (GS) is Scotland's largest family health study. We are a collaboration between Scottish Universities and NHS Scotland. We aim to improve health and well-being through research and have contributed to studies into covid-19, cancer, depression, mental health, diabetes, cardiovascular disease and more. We have over 40,000 volunteers and would like to represent all communities in Scotland.

If you want out more about who we are and our impact, you can watch our video at:

<https://youtu.be/hPX0A1n34bY?si=oWuWHjDc3lo5YAwI> or you can visit:

<https://genscot.ed.ac.uk/>

The Schools Health and Wellbeing Improvement Research Network (SHINE) is a network of over 750 Scottish schools which are interested in keeping up-to-date with the latest health research relevant to the children and adolescents they work with. SHINE supports schools to collect and work with health data in order to better understand the health and wellbeing of the young people in their school in order to inform improvement planning. All surveys and resources created by SHINE are designed to be shared with young people, teachers and parents/carers as part of a whole-school approach to health improvement.

You can find out more about SHINE at [www.gla.ac.uk/shine](http://www.gla.ac.uk/shine)

## What are our lesson plans?

- The Big Data Matters series of lessons is called “Why big data matters” It contains three lessons covering key aspects of health research
  - What is health data research?
  - What is data linkage?
  - What is data ethics and why does it matter?
- Each 40-minute lesson covers a key concept of health research with video introductions from researchers at Generation Scotland and an activity to run in the class. Each topic can be used to generate class discussion.

## Why is it important to teach this topic in schools?

- Data literacy is an increasingly important skill for young people as data enters all aspects of our lives. We want young people to be able to understand and think critically about what health data is and how it is used in research.
- High quality data science relies on a wide variety of volunteers participating so that young people from a variety of backgrounds and experiences are represented in the data collected. We hope that by sharing knowledge about health research, young people will feel more confident and motivated to participate so that their experience is represented.

## Alignment with Curriculum for Excellence Experiences & Outcomes across the three lessons.

The three lesson plans are designed to align with the Curriculum for Excellence Experiences and Outcomes below. The sequence of lessons supports the development of data literacy skills which are increasingly required across the curriculum in various subject areas.

Generation Scotland and the Schools Health and Wellbeing Improvement Research Network (SHINE) work with population health data. The research is conducted in compliance with rigorous scientific standards and the subsequent translation of research results requires the ability to understand the health context and factors affecting health in which the data were collected.

The four experiences and outcomes below reflect the multi-disciplinary aspect of this resource which could be used as part of the science, personal and social health education, mathematics, social sciences and/or IT curriculum. As the sequence of lessons are progressive, the four e's and o's below apply to all three lesson plans.

1. I have collaborated with others to find and present information on how scientists from Scotland and beyond have contributed to innovative research and development. **SCN 3- 20a**
2. Through contributing my views, time and talents, I play a part in bringing about positive change in my school and wider community. **HWB 3-13a**
3. I can explore digital technologies and use what I learn to solve problems and share ideas and thoughts. **TCH 0-01a**
4. I have investigated factors which can influence participation in physical activity and food choices, and the impact of activity on population health in the Scottish and wider contexts. I can use this information to discuss policies and inform my own health choices. **HWB 4-28a**

## Lesson plan: 1

### Why big data matters? – what is health data research?

#### RESOURCES REQUIRED

- Accompanying PowerPoint presentation with video link
- Discussion questions

### Intended Learning Outcomes

- I understand what big data is
- I understand how health data research is used to help society
- I understand why it important for a wide variety of people to be involved in health research

### OVERVIEW OF LESSON 1 SLIDES 1 & 2 ⌚ 1MIN

- **Why big data matters – what is health data research?**
  - Learn what is big data and how is it used in research
  - Left-handedness sample size activity
  - Suggested discussion points

### WHAT IS GENERATION SCOTLAND? SLIDE 3 ⌚ 2MINS

This resource was created by Generation Scotland in partnership with the Schools Health & Wellbeing Improvement Network (SHINE). Generation Scotland is a large health study for anyone living in Scotland over the age of 12, whether they have pre-existing health conditions or are completely “healthy”. The study was set up in 2006 as a collaboration between NHS Scotland and the Universities of Aberdeen, Dundee, Edinburgh and Glasgow, and now has over 40,000 volunteers, who either join individually or with their families. The volunteers have helped scientists and researchers learn about health conditions: including COVID19, Mental Health, Cancer, Diabetes, Heart Conditions and so many more. Researchers build up a bigger picture about health through using questionnaire answers provided by volunteers and linking this data with other big datasets like NHS records.

## WHAT IS SHINE? SLIDE 4 ⌚ 2MINS

The Schools Health and Wellbeing Improvement Research Network (SHINE) is a network of over 750 Scottish schools which are interested in keeping up-to-date with the latest health research relevant to the children and adolescents they work with. SHINE is based at the University of Glasgow in the School of Health and Wellbeing. The network supports schools to understand, collect and work with health data in order to better understand the health and wellbeing of this generation's young people and how health and wellbeing has changed over time. All surveys and resources created by SHINE are designed to be shared with young people, teachers and parents/carers as part of a whole-school approach to health improvement.

Through these lesson plans we will learn more about health research, research methods and ethical considerations around the use of big data. The more people who join health studies or take part in health research, like Generation Scotland or SHINE enables better research and can lead to more future discoveries and possibly cures for conditions.

## WHAT IS BIG DATA? – VIDEO SLIDES 5&6 ⌚ 2MINS

'Data' is a word used in research for analysis. The data can be in numbers such as height or age, or in words giving an opinion. In research, it is often not enough to collect data from just a few people to come to a conclusion. We need lots and lots of data so that we can make sure the information we receive is representative of everyone we are interested in learning more about.

'Big data' refers to extremely large data sets which are analysed by computers to reveal patterns and trends that wouldn't be possible manually. In health research, it is used to look for similarities or differences between healthy people and those with medical conditions and try to understand why some people are more prone to illness than others, or who needs early intervention to protect them from future illness. This can include patient data such as, blood or tissue samples, lifestyle data, imaging data (like x-rays or brain scans), genetic data (your DNA) and data from health and fitness devices.

As an example, researchers at Generation Scotland supported The Recovery Trial, a UK-wide study to find treatments for COVID-19. One aspect of the trial compared the genetic data of COVID patients who required intensive care to the data of healthy people. The researchers identified five key genetic differences between the healthy people and the people in intensive care, which led to identifying an effective COVID-19 drug treatment. One of the differences was in a gene which reduced inflammation, and so a drug that is usually used to treat a type of arthritis was repurposed to treat severe cases of COVID-19 because of its anti-inflammatory properties. This could be used to treat people straight away because it was already known to be a safe treatment, whereas trialing new drugs can take up to 10 years.

## REFERENCES

<https://www.bbc.co.uk/news/health-60601750> <https://www.nature.com/articles/s41586-020-03065-y>

<https://www.ed.ac.uk/generation-scotland/what-have-we-found/latest-results/covid-genes>

## Left-Handedness Activity SLIDE 7 ⌚ 10MINS

The first activity will explore discussions around sample size. No materials required.

What to do:

5. Count total individuals in the class
6. Count hands up for left-handed individuals in the class
7. Calculate the percentage of left-handed individuals
8. *Option to count the number of left-handed boys in contrast to left-handed girls, if appropriate.*

### Teacher:

- Complete the table on **slide 6 of the power point presentation** with the numbers collected from the class so that they can all see the results.
- Work out the percentage of left-handed pupils with the class

## Discussion points SLIDE 8 & 9 ⌚ 15MINS

Referring back to the numbers collected from the class about left-handedness, use the discussion points below to ask the class to consider how representative these numbers are:

- Does the data collected from the class about left-handedness represent...
  - Everyone in the school?
  - Everyone in Scotland?
  - Everyone in the world?
- If not why not? How do we make sure scientific results apply to everyone?
- Compare with statistics of left-handedness in different countries (**slide 8** on the power point presentation)

## How do we make sure scientific results apply to everyone?

### SLIDE 10 ⌚ 10MINS

In conclusion just using one school class as a sample is not enough to accurately represent a population as a whole and many sections of society are often under-represented in health research, especially young people, without whom we cannot make research relevant and meaningful to them.

**Discuss this statement:** It is important to have young people in research to make sure results are meaningful for them. Why?

**Teacher prompt for class:** Encourage the young people to think about why it is important for young people to be involved in research – *possibility to identify health concerns early, understand how health concerns develop in order to be able to prevent difficulties in adulthood, understand what is needed to help young people while they are still developing.*

*Example)* the data from HBSC about teeth brushing to see how the policy has informed practice and made improvements.

Child smile [https://www.childsmile.nhs.scot/wp-content/uploads/National-standards-for-nursery-and-school-toothbrushing-programmes-in-English\\_August-2023.pdf](https://www.childsmile.nhs.scot/wp-content/uploads/National-standards-for-nursery-and-school-toothbrushing-programmes-in-English_August-2023.pdf)

## Extension discussion points (various optional extra discussions)

The teacher can use the facts below to generate a discussion either as a whole class or in groups:

**Fact 1:** To ensure data results are as valid as possible, health researchers want to include as many people as possible to create a large data sample, but the sample should also include a variety of people.

**Teacher prompt for class:** Encourage the young people to think about the different groups of people that should be included (ages/sex/ethnicity/geography etc.)

**Discussion point 1:** Who should be included when collecting data? Can you think of different groups of people?

**Fact 2:** If we wanted to know what the average height of everyone living in a town was, but we only measured the height of the local basketball team, we might make the mistake of thinking that everyone is likely to be 6 foot 8.

**Teacher prompt for class:** Encourage the young people to think about how health researchers could get the best results for their height survey. Gathering data from large organisations might be easier eg. with young people through schools, with adults through the health service.

Encourage the young people to think about why the health researchers still might not get all the data.

**Discussion point 2:** Where could health researchers get the best results for their height survey? Could they get all the information in one place? What would the challenges be?

**Fact 3:** If we asked lots of people about their treatment for asthma but missed out a group of people with severe asthma symptoms, we would only build half a picture of what it's like to live with asthma.

**Teacher prompt for class:** Encourage the young people to think about why big data can't always reach every group and sometimes need to focus on one group (cost, time, access)

**Discussion point 3:** Is it always possible for health researchers to interview everyone who has a particular health condition such as asthma? Why/why not? What are the difficulties?

**Fact 4:** It is important when collecting data that we ensure it is representative of the people we are interested in researching.

**Teacher prompt for class:** Encourage the young people to think about what would happen if one group of people always volunteered to complete surveys and health researchers just worked with them.

**Discussion point 4:** What would happen if one group of people always volunteered to complete surveys and health researchers only worked with them? Would the data results be useful?

Why/why not? How might researchers widen participation?

## Lesson plan: 2

### Data Linkage Intended Learning Outcomes



#### RESOURCES REQUIRED

- Accompanying PowerPoint presentation with video link
- Zombie Apocalypse worksheets and datasheets
- Discussion questions

## Why big data matters? – what is data linkage?

### Learning Outcomes SLIDES 1 & 2 ⌚ 1 MIN

- I understand what data linkage is
- I understand how data linkage research is used to help society
- I understand why it important for strict data protection procedures to be used in data linkage research

## Overview of lesson 2

### Why big data matters – what is data linkage?

- Learn what is data linkage and how is it used in research
- Zombie Apocalypse activity
- Suggested discussion points

## Recap from lesson 1 NO SLIDE REQUIRED 2 MINS

Find out what the young people have remembered from what they learned in lesson one about health research, using the recap questions below:

- What is health data research?
- Why/how is health data used to help people in society?
- Why is it important for a variety of people to be involved in health research?

## Introduction to lesson 2 – what is data linkage? SLIDE 3 ⌚ 1 MIN

**Teacher** – ask the class if anyone can suggest what data linkage might be. Sometimes health researchers need to link more than one dataset to understand what is causing a particular health concern. Health researchers need to get special permission to do this.

Watch the video (**link on slide 8**) to hear what the researchers have to say about data linkage

## WHAT IS DATA LINKAGE - VIDEO SLIDE 4 ⌚ 2 MINS

Whenever you use a government or public service, such as going to see a doctor, getting a new job, paying taxes or picking up a prescription, the government makes a record of it. This is to ensure that they have accurate records of the numbers of people needing medical attention for specific illnesses, or the numbers of people who are in employment.

Researchers would like to use this routinely collected information to follow the health of the public over time. For example, researchers might investigate whether the grades you get in school can predict your mental health and wellbeing in the future. Researchers could do this by linking school records to mental health records.

At Generation Scotland, over 20,000 people have volunteered to take part in health research to help find solutions to various illnesses, giving researchers permission to access their medical records. These records can include information about when you have been admitted to hospital, health conditions you have been diagnosed with and medications you take, which can all be linked together to create a bigger and more informative dataset to use for research.

The combination of multiple data sources can be extremely useful for research. For example, research at Public Health Scotland has provided world-leading evidence for the effectiveness of the HPV vaccine using data linkage. You may know about, or have received the HPV vaccination which has been offered in schools since 2008 to prevent cervical cancer. Public Health Scotland has been able to look at people's vaccination records, whether they have attended screening, or been diagnosed with cervical cancer to show that there have been no cases of cervical cancer in girls who were vaccinated aged 12/13. This is crucial research that is needed to show whether disease treatments, or in this case vaccinations, actually work in the real world.

Data linkage can also reduce the burden on participants, meaning more people can take part in research and there is less bias in the participant data which is collected.

#### **ADDITIONAL OPTIONAL VIDEO: SHINE DATA LINKAGE DURATION 4 MINS**

<https://www.youtube.com/watch?v=z6c9nzcY6dA>

## **REFERENCES**

<https://www.bbc.co.uk/news/articles/c19132k8ke0o>

<https://pubmed.ncbi.nlm.nih.gov/38247547/>

## **Zombie apocalypse data linkage activity**

**SLIDES 5,6 & 7** 🕒 20 MINS

To understand how data linkage works, the class can complete the Zombie Apocalypse activity in groups.

#### **Resources required:**

- Print outs of the incomplete zombie apocalypse activity worksheets. Provide each group with the 4 different data sources (*1.zombie status, 2.food, 3.genetic resistance and 4. addresses*) required for the task.

#### **Organisation of the class groups:**

1. Split the class into groups of four.
2. Give each person in the group one of the four datasets so that everyone in the group has a different data source.
3. Each group member should share their dataset with the group to complete the

activity worksheet.

- Using the complete set of data sources on the completed activity worksheet, work out what the food source of the outbreak is.
- You can either run this as a timed exercise against the clock with groups competing against each other to be first to identify the source of the outbreak or allow a set time for each group to complete the exercise.

## Hints

























If groups are struggling use these hints to help

- Look to see what food and what addresses the zombies have in common – how can they have spread the disease from one person to another?
- Remember that if someone has the zombie resistant gene that they can't become a zombie, even if they have eaten the food source

## Answers

- The apples have caused the outbreak!
- Using the zombie status source and the food source, we can see that everyone who is a zombie has eaten an apple, except for Harper.
- There are two uninfected individuals who have eaten an apple but using the genetic resistance source we can see they have the zombie resistant gene which protected them from becoming zombies.
- An exception is Harper who hasn't eaten an apple but using the addresses from the location source we can see that she lives with Isabella (who is also a zombie) and so was infected by her.

## Completed zombie table SLIDE 8 ⌚ 4 MINS

Names	Zombie status	Food	Genetic Resistance	Addresses
Sam			 Normal gene	12 High Street
Lee	Uninfected		 Zombie resistant gene	56 Park Road
Angus			 Normal gene	45 Mill Lane
Isla	Uninfected		 Normal gene	34 North Road
Christos	Uninfected		 Zombie resistant gene	23 Orchard Close
Harper			 Normal gene	78 Main Street
Taylor	Uninfected		 Normal gene	13 Hope Street
Isabella			 Normal gene	78 Main Street
Zhuoni	Uninfected		 Normal gene	22 West Street
Mohammad	Uninfected		 Zombie resistant gene	71 Station Road

## Further discussion points NO SLIDE REQUIRED ⌚ 10 MINS

Referring back to the Zombie Apocalypse activity, use the discussion points below to ask the class to consider how important data linkage was to solving the zombie apocalypse challenge:

- How did data linkage help us to find out what started the zombie apocalypse?
- What would have happened if we hadn't linked the data to find out the cause?
- Can you think of any recent health crises where data linkage was important to solving the problem? (**Teacher Prompt:** COVID pandemic, vaccinations, understanding why some people got very ill and some people didn't, linked to genetic data)

## Lesson Plan 3

### Why big data matters? – what is data ethics?

#### Intended Learning Outcomes



#### RESOURCES REQUIRED

- Accompanying PowerPoint presentation with video link
- De-identification activities
- Discussion questions

## Lesson plan: 3

### Why big data matters? – what is data ethics?

#### Learning Outcomes SLIDES 1 & 2 ⌚ 1 MIN

- I understand what data ethics is
- I understand why it important for strict data ethics procedures to be used in health research
- I understand how data ethics helps researchers to make sure that health data is properly protected.

## Overview of lesson 3

- **Why big data matters – what is data ethics?**
  - Learn what is data ethics and how is it used in research
  - De-identification activity
  - Suggested discussion points

## Recap from lesson 2

Find out what the young people have remembered from what they learned in lesson two about data linkage, using the recap questions below:

- What is data linkage?
- Why/how is data linkage used to help people in society?
- Can you give any examples of how data linkage has been used to help solve health problems?

## Introduction to lesson 3 – what is data ethics? SLIDE 3 ⌚ 5 MINS

- **Teacher** – ask the class if anyone can suggest what might be a problem if lots of health data are being shared. (**Prompt** – *data protection, personal details might be made public, health records should be kept confidential*)
- Sometimes health researchers need to link more than one dataset to understand what is causing a particular health concern. Health researchers need to get special permission to do this. In this lesson we are going to learn how data ethics keep the data safe so that no-one's health data can be identified and linked back to them without permission.
- Watch the video (**link on slide 13**) to hear what the researchers have to say about data ethics

## WHAT IS DATA ETHICS (EASY DEFINITION) ⌚ 2 MINS

Data ethics is all about using information, or "data," in a fair, honest, and safe way. Imagine that you're sharing a secret with someone. You trust that they won't tell anyone else without asking you first, right? Data ethics works the same way—it makes sure that when people or companies collect information about us, they respect our privacy, keep it safe, and use it responsibly. It also means that they should be honest about what they're doing with our data, use it to help (not harm) people, and follow rules so everyone can feel safe sharing information.

In short, data ethics is about being respectful and careful with information, just like how we should be with each other!

## WHAT IS DATA ETHICS – VIDEO SLIDE 4 ⌚ 2 MINS

Data ethics also sets out guidelines for using identifiable information. Identifiable information is any data collected that can directly identify a person. We have an ethical and legal responsibility to participants to ensure that data is collected, stored and shared in a secure and confidential way.

In research, data is de-identified. This means that individuals names are kept separate from the rest of their data and would never be shared with researchers. Instead, the names are replaced with a code, such as 'participant 5' or even a string of random numbers. This means when researchers look at the data, they have no idea who it belongs to. Other potentially identifying information such as date of birth and address are also altered in such a way so as to make them less specific. A date of birth is converted to just a year of birth or an age, while a full address could be reduced to just the town or the postcode. Additionally, if data is only available for a very small number of individuals, for example if only 3 Generation Scotland participants have a rare medical condition, then this information will not be shared with researchers as the 3 participants could potentially become identifiable.

Once researchers have access to the data, there are rules that need to be followed in order to keep it safe and protected. Researchers are only allowed to collect data that is necessary for their research, they can't just ask for everything for the sake of it. Only the named researchers who requested access to the data are allowed to use it. And it must be kept on a secure server with password protections so that only specific people can access it. Researchers can also only keep the data for the duration of the research project, not forever.

## Data ethics activity 1 SLIDES 5 & 6 ⌚ 20MINS

This vaccination record is an example of the type of medical records that researchers could want access to.

Using this template, break into groups to discuss the following questions? Answers are provided in appendix A at the end of these guidelines.

Name of Patient: Archie Porteous
Date of birth: 04 Sept 2009
Ethnicity: White Scottish
Date of Vaccination: 12 <sup>th</sup> May 2012
Type of vaccine: Diphtheria/tetanus / polio
Batch number: 354783



- 1) Which information do you think is identifiable and should not be shared?
- 2) Could any of the identifiable information be altered so that it can still be used for research?
- 3) Which information do you think is acceptable to be shared?

Feedback as a class. Answers and prompt are in appendix A.

## Lesson 3: Activity 2 Data ethics: Discussion SLIDES 7 & 8 ⌚ 15 mins

Activity 2 is linked to activity 1 which the young people have just completed. The instructions below are included on the worksheet which includes activity 1 and 2 for Lesson 3: data ethics.

Instructions for pupils:

Now look at your results from activity 1. With a partner or in a group discuss the following statements. You can use the table below to make notes about the pros and cons of taking part in

- a) I think it is safe for researchers to share the de-identified information for the purposes of health research.
- b) I think there should be extra steps taken to keep the data safe – de-identification is not enough.
- c) I would be happy to participate in health research, if I knew that my personal information would be de-identified.

d)

Pros of getting involved in health research	Cons of getting involved in health research

## Lesson 3: Data ethics

### Activity 3: Debate kit

#### *Health research with young people: ethical considerations*

SLIDES 9-14 ⌚ 50 mins

#### RESOURCES REQUIRED

- Accompanying PowerPoint presentation
- Pens, paper, or mini whiteboards, or post-it notes or tablets to jot down notes
- Fact sheets
- Character cards for each debate team (both for and against)

### Introduction

The aim of this debate is to empower young people to think critically about their rights, recognize the myths and know which questions to ask if they are invited to provide personal data, such as their name or Scottish Candidate Number, as part of health research.

This resource focuses specifically on the ethical considerations associated with providing personal data.

This activity is a structured debate on a current topic, as the collection of personal data affects many aspects of our society today. The information provided in the debate pack will help young people to think critically through the different issues associated with the topic. Data facts from health research in Scotland are provided to help young people back up their opinions and consider the perspectives of other characters.

This activity could be used in a wide variety of curriculum areas:

- English to practise listening and expressing opinions as part of a debate or discussion.
- Social sciences and/or science to practise using data to draw conclusions and consider the societal aspects of scientific evidence.
- Religious, Moral and Philosophical Studies to consider ethical issues and consider different points of view.
- Personal and Social Health Education to support young people to make an informed choice as to whether they would like to take part in health and wellbeing surveys or health research.

Provided below there is a core version of this debate which can be used as a role play exercise to support young people who have limited experience of debating. The core version allows young people to learn how debates are structured as well as considering the debate topic in a support manner. Throughout this pack, there are also extension resources which could be used as stand-alone preparatory activities or provided to pupils with more experience of debating.

## Debate Motion:

*It is ethical for young people to be asked to provide personal data (eg, name or Scottish Candidate Number) in health and wellbeing surveys at school.*

## Characters

Ten characters are provided in the pack. You can use all 10 characters if you want to.

The minimum number for a group debate is four characters, two who believe that young people should be asked to provide personal identifiers (eg. name or Scottish Candidate Numbers) in school health and wellbeing surveys and two who don't.

Blank character cards have been included in case young people want to create their own characters, facts and issues.

**For** young people being asked to provide personal identifiers (eg.name or Scottish Candidate Number) in health and wellbeing surveys in school

Jake O'Reilly – S5 pupil at High School

Dr Chris Taylor - Parent & Laboratory technician

Elodie Delaney – Guidance teacher

Avrind Dhillon – Director of Education

Professor Anna Chi – Health researcher

**Against** young people being asked to provide personal identifiers (eg.name or Scottish Candidate Number) in health and wellbeing surveys in school

Suzie Cheng – S4 pupil at High School

Sam Murray - Parent & manager

Toni Wade – Art teacher

Iain Naldoni – Local Councillor

Dr Ben Wallis: Lecturer in Education

## Debate set-up

- **Set up the debate groups** ⌚ 10 MINUTES
  - Display Slide 11 from the Lesson 3 power point on the whiteboard
  - Split the class into groups (minimum 4 pupils in each group)
  - Each group should divide into 2 teams: one team “for” the motion and one team “against” the motion
  - Hand out the fact sheets physically or make them accessible in a virtual classroom
  - Hand out the character cards to each group or make them accessible in a virtual classroom

- **Optional vote to start** ⌚ 5 MINUTES

Show slide 9 with the debate motion “*It is ethical for young people be asked to provide personal data ( eg. name or Scottish Candidate Number) in health and wellbeing surveys at school?*” Ask the young people to vote yes or no (raise hands/ move to different sides of the classroom etc). Record the results to compare with the result after the debate.

- **Optional Starter questions** ⌚ 10 MINUTES

Show slide 10 with the icebreaker questions. Ask each group to jot down answers to each question, then pick one group in turn to offer an answer to one of the questions so that all are covered

- What is a health and wellbeing survey?
- What kind of questions do you think might be included in a health survey?
- Why do schools ask young people to complete health and wellbeing surveys?
- What happens to the data that are collected?

If the group doesn’t know the answer to any of the questions, they should simply note down “don’t know”. If none of the young people know the answers to particular questions, the teacher can prompt some answers using the guide below:

<p>What is a health and wellbeing survey?</p>	<p><i>Questions about young people’s health and wellbeing – health behaviour and habits or how they feel. Can be physical and/or mental health and wellbeing</i></p>
<p>What kind of questions do you think might be included in a health survey?</p>	<p><i>Diet, physical activity, screen time, substance use, sexual health, relationships, social support, confidence, loneliness, gambling, mood, anxiety, sleep</i></p>

<p>Why do schools ask young people to complete health and wellbeing surveys?</p>	<p><i>To gather an overall view of the health and wellbeing context in the school to support improvement planning, to identify health priorities, to identify gaps in resources, to identify young people who might need additional support</i></p>
<p>What happens to the data that are collected?</p>	<p><i>It depends who is conducting the survey and if it is online or on paper. If the school or Local Authority is conducting the survey, the data might be stored in the school, on a school computer, on Local Authority servers or on an external survey platform. If the survey is conducted by a university research team, the data will be deidentified and stored on university secure servers with access limited to a small number of researchers.</i></p>

### Debate preparation SLIDE 11 ⌚ 10 MINUTES

- The debate teams can study the fact sheets to gather facts and take notes to back up their opinions.(5 to 10 minutes)

### Debate role-play SLIDE 12 ⌚ 25 MINUTES

- Using a role-play approach, Speaker 1 in the team **for the motion** should state their opinion and any supporting facts, followed by Speaker 1 **against the motion**, followed by Speaker 2 **for the motion**, then Speaker 2 **against** and so on until all the members of the group have been heard. Each speaker can speak for up to 1 minute.
- Once all speakers have been heard, the teams can decide if they wish to either add one further piece of information to back up their argument or ask one question to the opposing team (5 minutes)

### Conclusion of the debate SLIDE 13 ⌚ 5 MINUTES

- A final vote can then take place in each debate group to establish the group's real views on whether they are **for** or **against** the motion . Count up how many groups are for or against the motion to see if the motion was successful or not.

Motion: ***It is ethical to ask young people to provide personal data (ie. name or Scottish Candidate Number) in health and wellbeing surveys at school.***

- **Plenary SLIDE 14** ⌚ 5 MINUTES

- Ask the class to look at slide 14 and vote for the factor that was the most important for them when voting.
- If relevant, the teacher can recheck the young people's understanding and knowledge in relation to the starter questions

## Homework or extension exercises

### Research activity

- Read the HBSC 2022 research briefing on [Trends in young people's substance use in Scotland](#) and then answer the following questions:
  - What changes since 1990 do the HBSC 2022 data show in relation to young people smoking cigarettes?
  - In 1998, the HBSC survey showed that 34% of 15 yr old girls and 26% of 15 yr old boys said they smoked cigarettes. The legal age to smoke was 16 years old. What changes to the law did the Scottish government make to reduce smoking in society.
  - In the 2018 HBSC survey, a new question about vaping was added to the questions about young people drinking alcohol and smoking cigarettes.
    - What did the survey reveal about vaping in 2022?
    - What laws did the Scottish government introduce in 2017 for vaping?
    - Why have the Scottish Government banned single use vapes?
  - Do you think the results from health and wellbeing surveys conducted in schools should be shared with the Scottish Government? Why / why not?

### Poster

- Make a poster showing the benefits and challenges of young people participating in health and wellbeing surveys in schools. Show how you think this kind of data should be used? E.g. who should it be shared with? What difference should it make?

### Blog/Magazine article

- Using the facts from the debate as presented by the different characters, write an article for the school magazine or a blog about the benefits and challenges of young people participating in health and wellbeing surveys in schools.

## Summary

We hope that this resource has been beneficial in providing additional information about Big Health Data. Participants will hopefully have achieved the following learning outcomes.

## Learning Outcomes

- I understand what big data is
- I understand how health data research is used to help society
- I understand why it important for a wide variety of people to be involved in health research
- I understand what data linkage is
- I understand how data linkage research is used to help society
- I understand why it important for strict data protection procedures to be used in data linkage research
- I understand what data ethics are
- I understand why it important for strict data ethics procedures to be used in health research
- I understand how data ethics helps researchers to make sure that health data is properly protected.

## Next Steps

Generation Scotland and SHINE are keen to continue collaborating with schools across Scotland to improve young people's knowledge of health research.

If you are interested in partnership opportunities or developing additional health research resources we would be really keen to hear from you. Please email [gen.scot@ed.ac.uk](mailto:gen.scot@ed.ac.uk)



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Helen Cameron (English teacher) for feedback on the debate kit

## APPENDIX A Data Ethics Activity answers

Discussion question	Answer
1. Which information do you think is identifiable and should not be shared?	<ul style="list-style-type: none"> <li>- Name</li> <li>- Date of birth</li> </ul>
2. Could any of the identifiable information be altered so that it can still be used for research?	<ul style="list-style-type: none"> <li>- Name                             <ul style="list-style-type: none"> <li>o Would be removed and an id number used instead</li> <li>o An individual's name is never shared out to researchers as it identifies them straight away</li> </ul> </li> <li>- Date of birth                             <ul style="list-style-type: none"> <li>o Changed to just year of birth or age</li> <li>o Date of birth is usually changed to just year of birth or age to make the information less specific and cover a larger number of potential individuals</li> </ul> </li> <li>- Date of vaccination                             <ul style="list-style-type: none"> <li>o Changed to just month and year for same reason as date of birth – less specific</li> </ul> </li> </ul>
3. Which information do you think is acceptable to be shared?	<p>Information that can be shared unaltered</p> <ul style="list-style-type: none"> <li>- Ethnicity, Batch number and NHS health board                             <ul style="list-style-type: none"> <li>o These pieces of information cover a large number of individuals and so are unlikely to be able to identify someone</li> </ul> </li> <li>- Type of vaccine                             <ul style="list-style-type: none"> <li>o This will also cover a large number of individuals</li> <li>o Would also would not be removed as the vaccination is the required information that someone would be looking for in the vaccination records</li> </ul> </li> </ul>

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