Bioinformatics - Biostatistics M1

Session 5 - Group B

Ethics in Bioinformatics

Poll 1

1. A hospital team is sequencing a child's DNA to explain a developmental disorder. The data also show a variant in BRCA1, a gene linked to a higher risk of breast and ovarian cancer, in the family. What should the team do? (Single choice)

- Tell the family.
- Tell the family only if they agreed in advance.
- Never look at that part of the genome.
- Not sure.

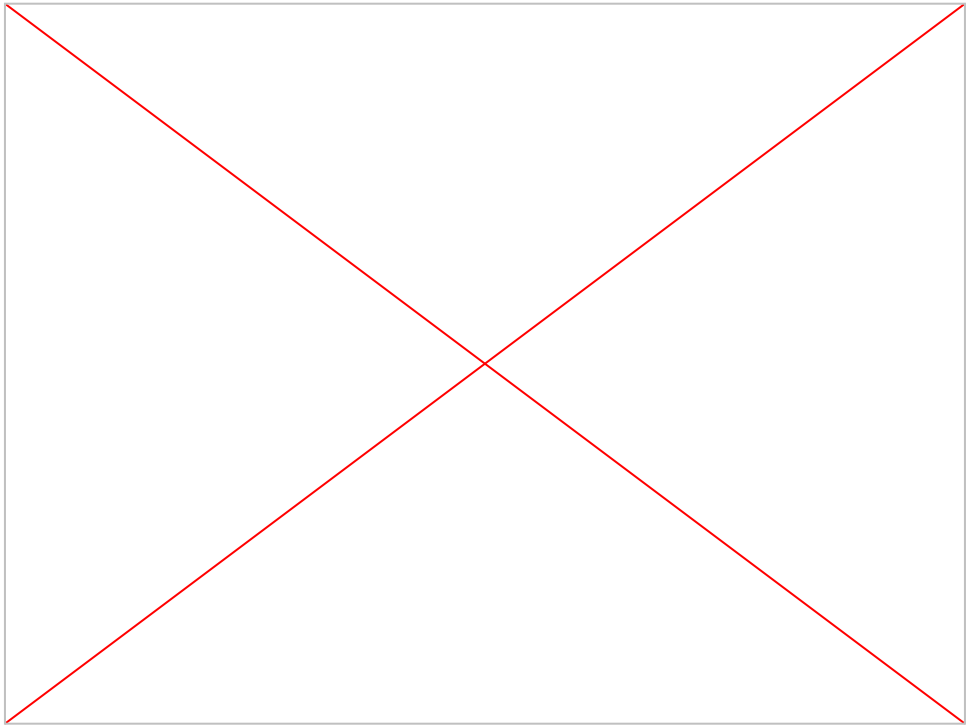
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Video 1

What are the two meanings of the noun “point”?

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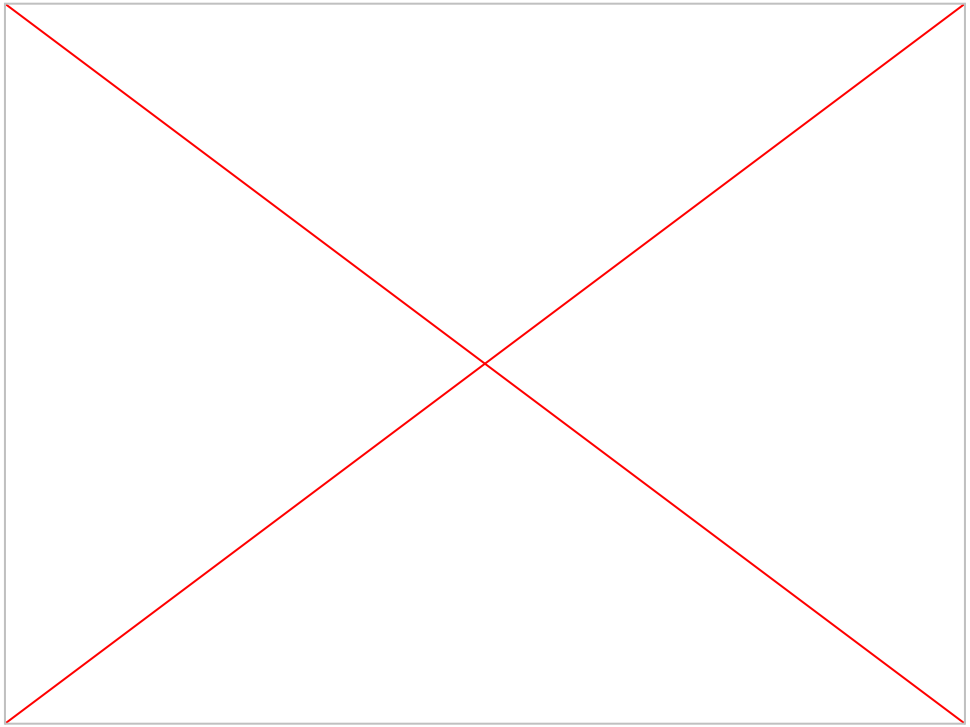


Watch and find…

3 types of data points

2 results from connecting data

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Fill in the missing words
(type your answer in the chat)

"Built on accuracy, _____ and trust."

"As the data expand, our _____ grows. We are _____ of this knowledge."

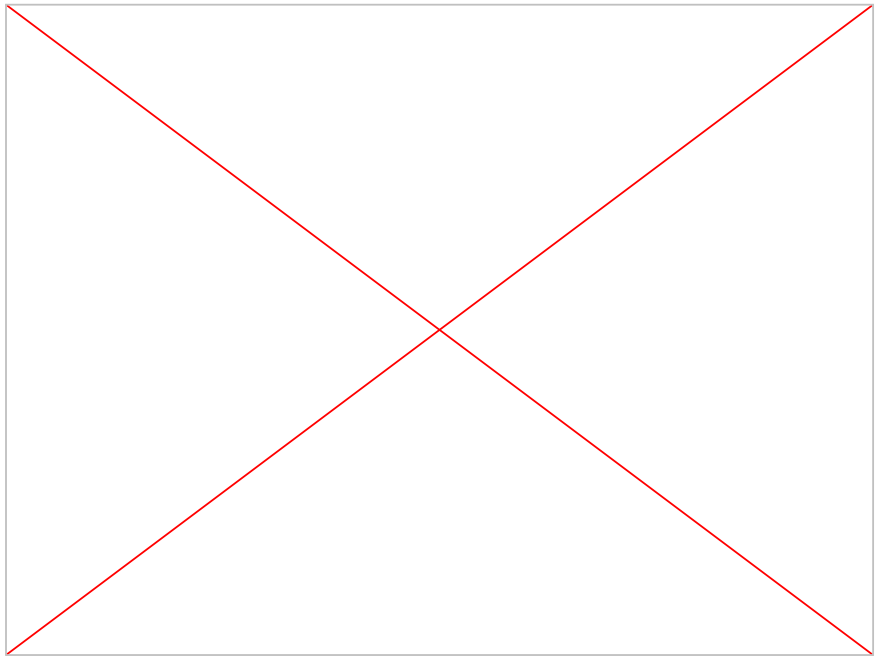
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Stewardship

A **steward** looks after something that belongs to someone else. In this video, whose knowledge is it? Who is missing from this picture of trillions of points?

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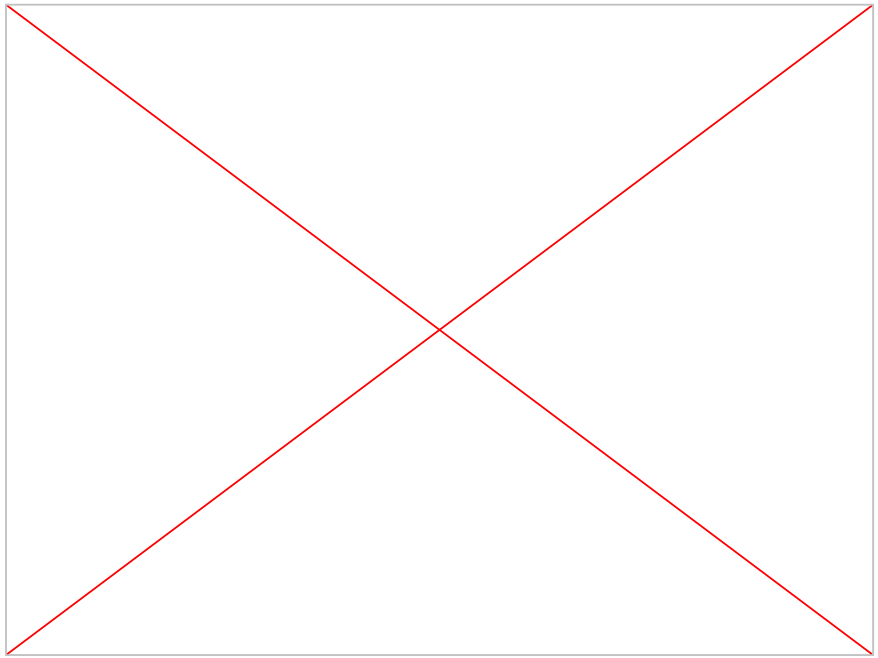


Video 2

Watch the video and answer these two questions:

1. In which two ways can incidental findings be discovered?
2. What two opposed positions do researchers take?

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Video 2

Watch the video and say if these are true/false/not given

1. Doctors have little experience of dealing with unexpected results.
2. Genomics makes incidental discoveries possible on a much larger scale than other areas of medicine.
3. The term "incidental findings" is used only for things found by accident.
4. In the speaker's project, participants know which areas of the genome are not being examined.
5. Most participants in the project asked not to hear about unrelated findings.
6. A presidential commission says researchers must look for incidental findings.

Ethics in Bioinformatics

1. "Researchers don't have to look for incidental findings."

   Rewrite with *under no obligation*.

2. "Not looking at data you already hold is unethical."

   Rewrite with *It's unethical not to ...* or *have a duty to*.

3. "Researchers may look, but only if results can be passed to clinicians."

   Rewrite with *provided that*.

> **Scenario.** A hospital research team is sequencing the genomes of children with an unexplained developmental disorder. The data also cover genes unrelated to the disorder, including BRCA1. The current consent form says nothing about unrelated findings.

Role	Position
A. Lead researcher	We should only do what participants have agreed to.
B. Clinical geneticist	If we hold the data, it is unethical not to look at it.
C. Parent	Your child is being sequenced. Say what you would want and why.
D. Ethics committee chair (4th member, optional)	Insist that any plan includes a mechanism for feeding results back and links with clinical teams.

Task. Agree a three-sentence policy for the consent form that answers: (1) Will the team look at unrelated areas? (2) Will participants be told what is found? (3) What mechanism is needed for feeding back? Use at least three expressions from Stage 5 and give one reason with *because*. Write the policy in your room's slide.