



PARTICIPANT INFORMATION STATEMENT

Visions of DNA: our code up close - attendee observations

1. What is the research study about?

You are invited to take part in this research study that aims to:

- evaluate materials and resources that communicate concepts in genetic science
- to understand how individuals view and interact with the resources.

You have been invited because you expressed interest in attending the “Visions of DNA: our code up close” event.

2. Who is conducting this research?

The study is being carried out by the following researchers at the Garvan Institute of Medical Research: Dr Kate Patterson, Dr Lauren McKnight and Bronwyn Terrill.

Research Funder: This research is being funded by the Kinghorn Centre for Clinical Genomics.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Over 18 years of age

4. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

If you decide you want to take part in the research study, you will be asked to:

- Read this information carefully (and ask questions if necessary);
- Let us know that you have read the information and are happy to participate when you arrive at the event.

If you do not wish to participate, or you are under 18 years of age, you will be given a badge to wear, so that we do not include you in our observations. You may also choose not to undertake some of the activities that involve making contributions to the exhibition (written, drawn or made), as all submissions will be considered as part of the research study.

5. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, researchers may observe the ways you interact with the information and undertake activities as part of the “Visions of DNA: our code up close” event. In some locations, you may be asked if you are willing to be audiorecorded interacting with the activities or exhibits. You will remain anonymous and no photographs or video-recordings will be made as part of the study.

Researchers will observe your interactions using the following methods:

- through the use of coloured tokens that you will use to answer questions throughout the event;
- by making notes on what you do and the conversations you have during the event and any questions you may ask during specific activities;
- by audiorecording your interactions with specific exhibits or media (eg. the visualisation dome);
- by collecting your responses and contributions to creative learning activities.

Some attendees may be asked whether they would be willing to be more closely observed or audiorecorded during the event. The notes and recordings taken will relate only to experiences and activities that are part of the event. Please let us know if you would prefer not to be closely observed or recorded.

If you experience discomfort while participating in the research, you can stop participating at any time. You can also tell a member of the research team and they will provide you with assistance.



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6. What are the possible benefits to participation?

We hope to use findings from this research study to benefit people who wish to learn about DNA and genetic science. We hope to use insights from this study to develop effective and engaging information and activities for a wide variety of audiences, and to publish our findings in peer-reviewed journals so that other researchers, educators and institutes can also learn from this research.

7. What will happen to information about me?

If you indicate you are happy to participate, you consent to the research team collecting and using non-identifiable information about you for the research study. The data will be kept for five years after the project's completion. We will store this information in The Kinghorn Cancer Centre building and in a secure online Dropbox.

The data will only be used for research to evaluate the information and activities you participate in during the event and to inform the development of future materials.

8. How and when will I find out what the results of the research study are?

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you. A summary of the findings will be posted to the website of Garvan's Kinghorn Centre for Clinical Genomics (www.garvan.org.au/kccg) by the end of 2019.

9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do this by notifying any of the staff or researchers at the event, who will give you a badge and exchange your coloured tokens for nontrackable tokens. Your token identifier will be removed from the study, however some anonymous contributions you have made may not be able to be identified and removed.

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

Name	Bronwyn Terrill
Position	Manager, Education and Engagement Team, Kinghorn Centre for Clinical Genomics
Telephone	02 9355 5842
Email	b.terrill@garvan.org.au

What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC190448