

**Are we ready for genomic testing in pediatric acute care? Attitudes of Australian health professionals**

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**1. Survey for intensivists**

**2. Survey for clinical geneticists**

**3. Survey for genetic counselors**

**4. Survey for laboratory genetic scientists**

# Acute Care Flagship Survey for Intensivists

## Information and consent to participate

This survey is a joint activity of the Acute Care Flagship and the Workforce Development Program of the Australian Genomics Health Alliance (*Australian Genomics*). *Australian Genomics* is a NH&MRC-funded national network working towards the development of genomic medicine within Australia. The Workforce Development Program aims to investigate current and future education and training needs of the workforce in genomic medicine.

This survey aims to:

1. To measure experience with genomic testing in clinical practice
2. To assess clinician confidence, and preferences for models of practice, with whole exome or whole genome sequencing tests
3. To examine current and future education and training needs in genomic medicine for clinicians

This information will help the Acute Care flagship with delivering a model of practice that meets clinician preferences and will inform the development of future genomic medicine education and training activities for clinicians.

The target audience for this survey is clinicians working in NICU/PICU. It doesn't matter if you feel you don't know much about genomics, or don't incorporate it into your practice at the moment; your opinions, views and experiences are valuable to us.

***Please read about the survey in the information below. You can access the survey at the bottom of this page by clicking "Yes". By clicking "Yes" you are providing consent to participate in this research study by completing the survey.***

This study has been approved by the Human Research Ethics Committee of the University of Melbourne (HREC 1646785.5).

### **What will I be asked to do?**

Should you agree to participate, you will be asked to complete a survey. The survey will take about 15 minutes to complete; you can complete it over more than one session if needed. If so, you will need to make note of your individual Return Code to ensure your answers are saved and you continue where you left off.

### **How will my confidentiality be protected?**

We will protect your anonymity and the confidentiality of your responses to the fullest possible extent, within the limits of the law. In addition, all responses are anonymous. If you choose to provide your name and contact details to participate in an interview at a later date and/or to receive a copy of the study findings, we will store these data separately from your survey responses

The information gathered in the survey will be reported in a collective way so that your individual responses cannot be identified.

Your responses will be stored on a password-protected computer at the Murdoch Childrens Research Institute in Melbourne, Australia for a minimum period of 7 years. At the end of

this storage period all the data will be disposed of by deleting all computer files and backup files.

### **What are the benefits of participating?**

You will have the knowledge that you have helped inform clinical practice around genomic. By participating in this research study, you will also be helping to shape future education programs for genetics health professionals.

### **What are the risks of participating?**

In the course of answering the questions in the survey, participants may identify gaps in either their knowledge or practice which may cause feelings of anxiety. If you do experience any of these feelings we can direct you to educational materials or you may contact one of the research team members, who will discuss your concerns with you: Professor Sylvia Metcalfe (T 03 8341 6309) or Associate Professor Clara Gaff (T 03 9345 2708).

### **Do I get a copy of the study findings?**

At the end of the study we will publish relevant findings in peer reviewed scientific journals as well as reports on the *Australian Genomics* website. At the end of the survey, you can choose to provide your details to receive a copy of the study results directly.

### **Where can I get further information?**

Should you require any further information, or have any concerns about the content of this survey, please do not hesitate to contact:

- Professor Sylvia Metcalfe, Australian Genomics Health Alliance Program 4 Co-Lead, Murdoch Childrens Research Institute (T 03 8341 6309; E [sylvia.metcalfe@mcri.edu.au](mailto:sylvia.metcalfe@mcri.edu.au)).

Should you have any concerns about the conduct of the project, you are welcome to contact the Executive Officer, Human Research Ethics, The University of Melbourne (T 03 8344 2073; F 03 9347 6739).

### **How do I agree to participate?**

By selecting the “**Yes**” checkbox below you agree to consent to completing the survey.

If you decide not to complete the survey now, we thank you for your interest in our study. You can always complete the survey at a later date.

**Note:** You can stop the survey at any time, saving your answers, by clicking ‘Return later’.

**Make sure you write down the code that will appear on your screen as each code is unique!** Use the same survey link, then click on the "Returning?" button in the top right hand corner and enter your code.

Please tick "Yes" if at least one of the following criteria apply to you.

- You gained, or are studying for, sub-specialist medical training as a NICU/PICU clinician
- You currently work in a NICU/PICU setting in Australia.
- **YES**, and I consent to participate in this research by completing this survey.
- **NO**, the inclusion criteria do not apply to me so I am ineligible to participate in this research.



## Instructions

### **Thank you for taking part in this study.**

#### Navigation tips

- Click on the Next and Previous buttons at the bottom of a page to save your answers and move to the next/previous page. **Don't use the back button on your browser or keyboard as this will not save your answers.**
- If you are accessing the survey on a mobile device, the survey is best viewed in landscape (sideways) mode.
- You can complete the survey over more than one session. Click on the 'Return later' link to save your answers to date and come back later to answer. Make sure you write down the login code generated by REDCap, as you will need that code to access the survey you have already started. Use the same survey link, then click on the "Returning?" link in the top right hand corner and enter your code. (Note: you will need to type the code, not copy and paste). The survey will then open at the last page you completed. You can return as many times as you want, as long as you do not finalise the survey. Once you finalise, your unique link will not work.

If you are unsure about how to answer a question, please give the best answer you can.

Some terms are defined and these appear with an asterisk (\*) or dotted underline in the survey.

### **Your responses will be strictly confidential.**

At the end of the survey you will have the following options:

- (i) provide your contact details to receive a copy of the results directly; and/or
- (ii) provide your contact details to be contacted for telephone interview; or
- (iii) complete the survey only and not provide any contact details.

For clarification of any questions please contact Dr Belinda McClaren, Senior Project Officer, Australian Genomics Health Alliance, Murdoch Childrens Research Institute (T 03 8341 6415 or [belinda.mcclaren@mcri.edu.au](mailto:belinda.mcclaren@mcri.edu.au)).

Please note, all responses will be reported in a collective way so that specific individuals cannot be identified in any way.

Note: words with a dotted underline and asterix\* have a definition on roll-over.

**1. At which of the following sites do you have a clinical appointment? (Select as many as apply)**

- Lady Cilento Children’s Hospital, QLD
- Royal Brisbane and Women’s Hospital, QLD
- Children’s Hospital Westmead, NSW
- Westmead Hospital (adult), NSW
- Sydney Children’s Hospital Randwick, NSW
- Royal North Shore Hospital, NSW
- Royal Prince Alfred, NSW
- John Hunter Children’s Hospital, NSW
- Royal Children’s Hospital, VIC
- Monash Health, VIC
- Royal Women’s Hospital, VIC
- Women’s and Children’s Hospital, SA
- Royal Hospital for Women Randwick, NSW
- Other, please specify  
.....

**2. How many years of professional experience as a doctor do you have?**

- <10 years
- 11–15 years
- 16–20 years
- 21–25 years
- 26–30 years
- >30 years

**3. How often did you order chromosomal microarray tests in the last year?**

- Never
- Daily
- Weekly
- Monthly
- Quarterly
- Once or twice
- Don’t know

**4. Please rate the following areas of your confidence with regards to chromosomal microarray (CMA).**

\*\*\*REDCap: Participants will be asked to indicate response using a slider\*\*\*

	Very confident		Not confident at all	N/A*
Understanding indications for testing				
Discussing test with families				
Consenting families for the test				
Understanding reports				
Discussing results with families				

\*\*\*N/A definition will be provided to participants: I have not performed these tasks in my practice\*\*\*

**5. How often did you order whole exome or whole genome sequencing (WES/WGS) tests in the last year?**

- Never
- Daily
- Monthly
- Quarterly
- Once or twice
- Don’t know

**6. Please rate the following areas of your confidence with regards to whole exome or whole genome sequencing (WES/WGS) in the last year.**

\*\*\*Participants will be asked to indicate response using a slider\*\*\*

	Very confident		Not confident at all	N/A*
Understanding indications for testing				
Discussing test with families				
Consenting families for the test				
Understanding reports				
Discussing results with families				

\*\*\*N/A definition will be provided to participants: I have not performed these tasks in my practice\*\*\*

**7. Over the past year, how useful have you found the following in helping direct management of patients with suspected genetic conditions in NICU/PICU?**

	Very useful		Not useful at all	N/A*
Genetics consultation				
Metabolics consultation				
Chromosomal micro array results				
WES/WGS results				

We will offer rapid turnaround WES/WGS (<5 days) to NICU/PICU patients with suspected genetic conditions in 2018/2019 as part of a research study with Australian Genomics.

**8. In what proportion of NICU/PICU patients tested do you think the result from rapid WES/WGS will contribute to patient care?**



\*\*\*REDCap instructions: Participants will be asked to indicate response using a slider\*\*\*

**9. What is your preferred model for delivering rapid WES/WGS tests in the NICU/PICU? (Select one only)**

*You may have more than one preference; please indicate your **FIRST** preference. Other comments and preferences can be described in the Comments box.*

- 🍏 As inpatient, NICU/PICU team refers to clinical genetics team to initiate testing and discuss results with families
- 🍏 As inpatient, NICU/PICU team initiates testing and discusses results with families
- 🍏 As inpatient, NICU/PICU team initiates testing and discusses results with families, with support from clinical genetics team when needed

***If support is needed, please rank (1-5) which areas might be most helpful? Rank each item, with '1' indicating most important***

Advice on whether test is appropriate

Consent

Interpreting results

Discussing results with families

Follow-up genetic counselling of family

🍏 As outpatient following discharge, clinical genetics team initiates testing and discusses results with families

🍏 Other, please specify.....

Comment (optional) .....



**10. Have you attended any professional development education or training around genomics in the *past year*, such as lectures, seminars or workshops, either in person or online?**

- No
- Yes

If yes, was this:

- In-house (internal) program/s
- External program/s
- Online training (webinar, MOOC,\* etc.)
- Other.....

\*\*\* REDCap rollover definition: *Massive, open, online course, such as Coursera or Future Learn.* \*\*\*

**11. Which of the following do you currently access to keep up to date with, or learn new skills in, genomic medicine? *Select all that apply***

- |  |  |
|--|--|
| <input type="checkbox"/> Certification/fellowship activities                     | <input type="checkbox"/> Online webinars, courses, MOOCs, etc.                   |
| <input type="checkbox"/> CPD/CME activities                                      | <input type="checkbox"/> Reading specialty texts (journals, papers, books, etc.) |
| <input type="checkbox"/> Participating in multidisciplinary meetings             | <input type="checkbox"/> Study days at place of employment                       |
| <input type="checkbox"/> Internal specialty seminars, conferences or similar     | <input type="checkbox"/> Other.....  |
| <input type="checkbox"/> Internal genetic or genomic seminars, conferences, etc. |  |
| <input type="checkbox"/> External specialty seminars, conferences, etc.          |  |
| <input type="checkbox"/> External genetic or genomic seminars, conferences, etc. |  |

**12. Which professional development method/s do you find are most effective for you? *Select all that apply***

- |   |  |
|---|--|
| <input type="checkbox"/> Conference   | <input type="checkbox"/> Self-directed     |
| <input type="checkbox"/> Workshop   | <input type="checkbox"/> Lecture-style     |
| <input type="checkbox"/> Preparing and giving a presentation/poster/paper, etc. | <input type="checkbox"/> Hands-on learning |
| <input type="checkbox"/> Group discussion/reflection                            | <input type="checkbox"/> Online            |
| <input type="checkbox"/> One-on-one discussion/reflection                       | <input type="checkbox"/> Other.....        |

**13. We will be conducting follow-up interviews to specifically discuss education and training needs of health professionals and would like to invite you to take part in a (up to) 30 minute telephone interview. Please leave your email address below if you are willing to be contacted by one of our researchers.**

.....

**Thank you**

***You're finished the survey, thank you!  
Don't forget to click 'Submit' to complete the survey and have your say about your profession.***

**Do you have any other comments about genomic medicine in a NICU/PICU setting? .....**

**If you wish to receive a copy of the study results, please provide your name and email address below.** *Please note, if you provide your name and contact details, we will not use this information for research purposes. It will only be used to send you a copy of the results. ....*

**SUBMIT**

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# Acute Care Flagship Survey for Clinical Geneticists

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This survey aims to understand the use of genomic medicine in NICU/PICU settings. This information will help the Acute Care flagship with delivering a model of practice that meets clinician preferences and will inform the development of future genomic medicine education and training activities for clinicians.

The target audience for this survey is clinical geneticists who consult in NICU/PICU.

***Please read about the survey in the information below. You can access the survey at the bottom of this page by clicking “Yes”. By clicking “Yes” you are providing consent to participate in this research study by completing the survey.***

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- **YES**, and I consent to participate in this research by completing this survey.
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## Instructions

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- (iv) provide your contact details to receive a copy of the results directly; and/or
- (v) provide your contact details to be contacted for telephone interview; or
- (vi) complete the survey only and not provide any contact details.

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Note: words with a dotted underline and asterix\* have a definition on roll-over.

**14. At which of the following sites do you have a clinical appointment? (Select as many as apply)**

- Lady Cilento Children’s Hospital, QLD
- Royal Brisbane and Women’s Hospital, QLD
- Children’s Hospital Westmead, NSW
- Westmead Hospital (adult), NSW
- Sydney Children’s Hospital Randwick, NSW
- Royal North Shore Hospital, NSW
- Royal Prince Alfred, NSW
- John Hunter Children’s Hospital, NSW
- Royal Children’s Hospital, VIC
- Monash Health, VIC
- Royal Women’s Hospital, VIC
- Women’s and Children’s Hospital, SA
- Royal Hospital for Women Randwick, NSW
- Other, please specify  
.....

**15. How many years of professional experience as a doctor do you have?**

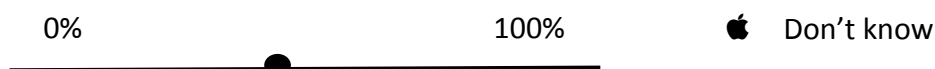
- <10 years
- 11–15 years
- 16–20 years
- 21–25 years
- 26–30 years
- >30 years

**16. Over the past year, how useful have you found the following in helping direct management of patients with suspected genetic conditions in NICU/PICU?**

	Very useful		Not useful at all	N/A*
Genetics consultation				
Metabolics consultation				
Chromosomal micro array results				
WES/WGS results				

We will offer rapid turnaround WES/WGS (<5 days) to NICU/PICU patients with suspected genetic conditions in 2018/2019 as part of a research study with Australian Genomics.

**17. In what proportion of NICU/PICU patients tested do you think the result from rapid WES/WGS will contribute to patient care?**



\*\*\*REDCap instructions: Participants will be asked to indicate response using a slider\*\*\*

**18. What is your preferred model for delivering rapid WES/WGS tests in the NICU/PICU?**

Select one only

You may have more than one preference; please indicate your **FIRST** preference. Other comments and preferences can be described in the Comments box.

- As inpatient, NICU/PICU team refers to clinical genetics team to initiate testing and discuss results with families
- As inpatient, NICU/PICU team initiates testing and discusses results with families
- As inpatient, NICU/PICU team initiates testing and discusses results with families, with support from clinical genetics team when needed

**If support is needed, please rank (1-5) which areas might be most helpful? Rank each item, with '1' indicating most important**

Advice on whether test is appropriate

Consent

Interpreting results

Discussing results with families

Follow-up genetic counselling of family

As outpatient following discharge, clinical genetics team initiates testing and discusses results with families

Other, please specify.....

Comment (optional) .....

**6. Please respond to the following questions related to the new rapid WES/WGS for NICU/PICU patients at your institution.**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. Using rapid WES/WGS fits within the processes I already use to care for NICU/PICU patients					
2. Clear goals have been established for integrating rapid WES/WGS into clinical practice					
3. Staff have enough time to facilitate the integration of rapid WES/WGS into clinical practice					
4. I can find/use reliable sources of the information I need to apply rapid WES/WGS while caring for patients					
5. Leaders have openly endorsed and supported rapid WES/WGS in visible ways					
6. The information generated by rapid WES/WGS is important for patient care					
7. I believe that rapid WES/WGS is relevant to my current clinical practice					
8. I am confident in my ability to use the results of rapid WES/WGS					

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
9. Rapid WES/WGS will be an improvement over how I currently investigate NICU/PICU patients with suspected genetic conditions					
10. Rapid WES/WGS will improve my ability to care for patients					
11. A clearly designated person or teams will lead the effort to incorporate rapid WES/WGS into clinical practice					
12. The implementation leaders/team have the necessary qualities and skills to successfully incorporate rapid WES/WGS into clinical practice					
13. A variety of strategies are being used to enable staff to use rapid WES/WGS					

\*\*\*This question has been sourced from: [https://ignite-genomics.org/wp-content/uploads/2016/03/31\\_Provider-pre-implementation-survey.pdf](https://ignite-genomics.org/wp-content/uploads/2016/03/31_Provider-pre-implementation-survey.pdf)\*\*\*

**Thank you**

***You're finished the survey, thank you!***

***Don't forget to click 'Submit' to complete the survey and have your say about your profession.***

**Do you have any other comments about genomic medicine in a NICU/PICU setting? .....**

**If you wish to receive a copy of the study results, please provide your name and email address below. Please note, if you provide your name and contact details, we will not use this information for research purposes. It will only be used to send you a copy of the results. ....**

**SUBMIT**

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# Acute Care Flagship Survey for Genetic Counsellors

## Information and consent to participate

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This survey aims to understand the use of genomic medicine in NICU/PICU settings. This information will help the Acute Care Flagship with delivering a model of practice that meets clinician preferences and will inform the development of future genomic medicine education and training activities for clinicians.

The target audience for this survey is genetic counsellors who will work in a NICU/PICU setting.

***Please read about the survey in the information below. You can access the survey at the bottom of this page by clicking "Yes". By clicking "Yes" you are providing consent to participate in this research study by completing the survey.***

This study has been approved by the Human Research Ethics Committee of the University of Melbourne (HREC 1646785.5).

### **What will I be asked to do?**

Should you agree to participate, you will be asked to complete a survey. The survey will take about 10 minutes to complete.

### **How will my confidentiality be protected?**

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In the course of answering the questions in the survey, participants may identify gaps in either their knowledge or practice, which may cause feelings of anxiety. If you do experience any of these feelings we can direct you to educational materials or you may contact one of the research team members, who will discuss your concerns with you: Associate Professor Zornitza Stark (T 03 8341 6368) or Associate Professor Clara Gaff (T 03 9345 2708).

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- Associate Professor Zornitza Stark, Australian Genomics Health Alliance Acute Care Flagship Lead, Victorian Clinical Genetics Services (T 03 8341 6368; E [zornitza.stark@vcgs.org.au](mailto:zornitza.stark@vcgs.org.au))
- Associate Professor Clara Gaff, Australian Genomics Health Alliance Program 4 Co-Lead, Murdoch Children's Research Institute (T 03 9345 2708; E [gaff.c@wehi.edu.au](mailto:gaff.c@wehi.edu.au)).

Should you have any concerns about the conduct of the project, you are welcome to contact the Executive Officer, Human Research Ethics, The University of Melbourne (T 03 8344 2073; F 03 9347 6739).

### **How do I agree to participate?**

By selecting the "Yes" checkbox below you agree to consent to completing the survey.

If you decide not to complete the survey now, we thank you for your interest in our study. You can always complete the survey at a later date.

Please tick "Yes" if **both** of the following criteria apply to you.

- You gained, or are studying for, a genetic counselling qualification
- You will be working in a NICU/PICU setting in Australia as part of the Acute Care flagship.

- 🍏 **YES**, and I consent to participate in this research by completing this survey.
- 🍏 **NO**, the inclusion criteria do not apply to me so I am ineligible to participate in this research.

## Instructions

### **Thank you for taking part in this study.**

#### Navigation tips

- Click on the Next and Previous buttons at the bottom of a page to save your answers and move to the next/previous page. **Don't use the back button on your browser or keyboard as this will not save your answers.**
- If you are accessing the survey on a mobile device, the survey is best viewed in landscape (sideways) mode.

If you are unsure about how to answer a question, please give the best answer you can.

Some terms are defined and these appear with an asterisk (\*) or dotted underline in the survey.

### **Your responses will be strictly confidential.**

At the end of the survey you will have the following options:

- (vii) provide your contact details to receive a copy of the results directly; and/or
- (viii) provide your contact details to be contacted for telephone interview; or
- (ix) complete the survey only and not provide any contact details.

For clarification of any questions please contact Dr Belinda McClaren, Senior Project Officer, Australian Genomics Health Alliance, Murdoch Children's Research Institute (T 03 8341 6415 or [belinda.mcclaren@mcri.edu.au](mailto:belinda.mcclaren@mcri.edu.au)).

Please note, all responses will be reported in a collective way so that specific individuals cannot be identified in any way.

Note: words with a dotted underline and asterix\* have a definition on roll-over.

**19. At which of the following sites do you have a clinical appointment? Select all that apply**

- Lady Cilento Children’s Hospital, QLD
- Royal Brisbane and Women’s Hospital, QLD
- Children’s Hospital Westmead, NSW
- Westmead Hospital (adult), NSW
- Sydney Children’s Hospital Randwick, NSW
- Royal North Shore Hospital, NSW
- Royal Prince Alfred, NSW
- John Hunter Children’s Hospital, NSW
- Royal Children’s Hospital, VIC
- Monash Health, VIC
- Royal Women’s Hospital, VIC
- Women’s and Children’s Hospital, SA
- Royal Hospital for Women Randwick, NSW
- Other, please specify  
.....

**20. How long have you been working in a clinical role as a genetic counsellor\*?**

*Do not include time in volunteer roles.*

*If you have had time out from your role/work (e.g., maternity leave), indicate the total time that you have been employed, not time elapsed between start and now. Part-time employment should be considered the same as full-time, e.g., 5 years of part-time employment or 5 years of full-time employment would both be considered 5 years.*

- <1 year
- 3–4 years
- 10–19 years
- 1–2 years
- 5–9 years
- ≥20 years

\* REDCap rollover definition: *This includes any clinical roles in genetics or health, including research, that you feel are related to your genetic counselling qualification*

**21. Over the past year, how useful do you think the following have been in helping direct management of patients with suspected genetic conditions in NICU/PICU?**

*Select a number to indicate how confident you feel, or tick N/A if you have not accessed these services in your practice.*

	N/A	1	2	3	4	5	6	7	8	9	10
		Not at all useful <span style="float: right;">Very</span>									
Genetics consultation	<input type="checkbox"/>										
Metabolics consultation	<input type="checkbox"/>										
Chromosomal microarray (CMA) results	<input type="checkbox"/>										
Whole exome/whole genome sequencing (WES/WGS) results	<input type="checkbox"/>										

We will offer rapid turnaround whole exome/whole genome (WES/WGS) sequencing (<5 days) to NICU/PICU patients with suspected genetic conditions in 2018/2019 as part of an Australian Genomics Health Alliance Flagship study.

22. In what proportion of NICU/PICU patients tested do you think the result from rapid WES/WGS tests will contribute to patient care? *Select one only or tick the 'don't know' box if you are unsure.*

- |                              |                              |                                     |
|------------------------------|------------------------------|-------------------------------------|
| <input type="checkbox"/> 0%  | <input type="checkbox"/> 40% | <input type="checkbox"/> 80%        |
| <input type="checkbox"/> 10% | <input type="checkbox"/> 50% | <input type="checkbox"/> 90%        |
| <input type="checkbox"/> 20% | <input type="checkbox"/> 60% | <input type="checkbox"/> 100%       |
| <input type="checkbox"/> 30% | <input type="checkbox"/> 70% | <input type="checkbox"/> Don't know |

23. What is your preferred model for delivering rapid WES/WGS tests in the NICU/PICU?

*Select one only*

*You may have more than one preference; please indicate your **FIRST** preference. Other comments and preferences can be described in the Comments box.*

- As inpatient, NICU/PICU team refers to clinical genetics team to initiate testing and discuss results with families
- As inpatient, NICU/PICU team initiates testing and discusses results with families
- As inpatient, NICU/PICU team initiates testing and discusses results with families, with support from clinical genetics team when needed

***If support is needed, please rank (1-5) which areas might be most helpful? Rank each item, with '1' indicating most important***

Advice on whether test is appropriate

Consent

Interpreting results

Discussing results with families

Follow-up genetic counselling of family

As outpatient following discharge, clinical genetics team initiates testing and discusses results with families

Other, please specify.....

Comment (optional) .....

**24. Please indicate how strongly you agree or disagree with the following statements related to the new rapid WES/WGS tests for NICU/PICU patients at your site. Select one per row**

	Strongly disagree	Dis-agree	Neither agree nor disagree	Agree	Strongly agree
1. Using rapid WES/WGS testing fits within the processes I already use to care for NICU/PICU patients					
2. Clear goals have been established for integrating rapid WES/WGS testing into clinical practice					
3. Staff have enough time to facilitate the integration of rapid WES/WGS testing into clinical practice					
4. I can find/use reliable sources of information I need to apply rapid WES/WGS testing while caring for patients					
5. Leaders have openly endorsed and supported rapid WES/WGS testing in visible ways					
6. The information generated by rapid WES/WGS testing is important for patient care					
7. I believe that rapid WES/WGS testing is relevant to my current clinical practice					
8. I am confident in my ability to use the results of rapid WES/WGS testing					
9. Rapid WES/WGS testing will improve my ability to care for patients					
10. A clearly designated person or teams will lead the effort to incorporate rapid WES/WGS testing into clinical practice					
11. The implementation leaders/team have the necessary qualities and skills to successfully incorporate rapid WES/WGS testing into clinical practice					
12. A variety of strategies are being used to enable staff to use rapid WES/WGS testing					

\*\*\* This question was sourced from: [https://ignite-genomics.org/wp-content/uploads/2016/03/31\\_Provider-pre-implementation-survey.pdf](https://ignite-genomics.org/wp-content/uploads/2016/03/31_Provider-pre-implementation-survey.pdf) \*\*\*

**Thank you**

***You're finished the survey, thank you!  
Don't forget to click 'Submit' to complete the survey and have your say about your profession.***

**Do you have any other comments about genomic medicine in a NICU/PICU setting? .....**

**If you wish to receive a copy of the study results, please provide your name and email address below. Please note, if you provide your name and contact details, we will not use this information for research purposes. It will only be used to send you a copy of the results. ....**

**SUBMIT**

*Should you require any further information, or have any concerns, please do not hesitate to contact Professor Sylvia Metcalfe (T 03 8341 6309; E [sylvia.metcalfe@mcri.edu.au](mailto:sylvia.metcalfe@mcri.edu.au)) or Associate Professor Clara Gaff (T 03 9345 27)*

# Acute Care Flagship Survey for Clinical Laboratory Scientists

## Information and consent to participate

This survey is a joint activity of the Acute Care Flagship and the Workforce Development Program of the Australian Genomics Health Alliance (*Australian Genomics*). *Australian Genomics* is a NH&MRC-funded national network working towards the development of genomic medicine within Australia. The Workforce Development Program aims to investigate current and future education and training needs of the workforce in genomic medicine.

This survey aims to:

4. To measure experience with genomic testing in clinical practice
5. To assess clinician confidence, and preferences for models of practice, with whole exome or whole genome sequencing tests
6. To examine current and future education and training needs in genomic medicine for clinicians

This information will help the Acute Care flagship with delivering a model of practice that meets clinician preferences and will inform the development of future genomic medicine education and training activities for clinicians.

The target audience for this survey is clinical laboratory scientists. It doesn't matter if you feel you don't know much about genomics, or don't incorporate it into your practice at the moment; your opinions, views and experiences are valuable to us.

***Please read about the survey in the information below. You can access the survey at the bottom of this page by clicking "Yes". By clicking "Yes" you are providing consent to participate in this research study by completing the survey.***

This study has been approved by the Human Research Ethics Committee of the University of Melbourne (HREC 1646785.5).

### **What will I be asked to do?**

Should you agree to participate, you will be asked to complete a survey. The survey will take about 15 minutes to complete; you can complete it over more than one session if needed. If so, you will need to make note of your individual Return Code to ensure your answers are saved and you continue where you left off.

### **How will my confidentiality be protected?**

We will protect your anonymity and the confidentiality of your responses to the fullest possible extent, within the limits of the law. In addition, all responses are anonymous. If you choose to provide your name and contact details to participate in an interview at a later date and/or to receive a copy of the study findings, we will store these data separately from your survey responses

The information gathered in the survey will be reported in a collective way so that your individual responses cannot be identified.

Your responses will be stored on a password-protected computer at the Murdoch Childrens Research Institute in Melbourne, Australia for a minimum period of 7 years. At the end of

this storage period all the data will be disposed of by deleting all computer files and backup files.

### **What are the benefits of participating?**

You will have the knowledge that you have helped inform clinical practice around genomic. By participating in this research study, you will also be helping to shape future education programs for genetics health professionals.

### **What are the risks of participating?**

In the course of answering the questions in the survey, participants may identify gaps in either their knowledge or practice which may cause feelings of anxiety. If you do experience any of these feelings we can direct you to educational materials or you may contact one of the research team members, who will discuss your concerns with you: Professor Sylvia Metcalfe (T 03 8341 6309) or Associate Professor Clara Gaff (T 03 9345 2708).

### **Do I get a copy of the study findings?**

At the end of the study we will publish relevant findings in peer reviewed scientific journals as well as reports on the *Australian Genomics* website. At the end of the survey, you can choose to provide your details to receive a copy of the study results directly.

### **Where can I get further information?**

Should you require any further information, or have any concerns about the content of this survey, please do not hesitate to contact:

- Professor Sylvia Metcalfe, Australian Genomics Health Alliance Program 4 Co-Lead, Murdoch Childrens Research Institute (T 03 8341 6309; E [sylvia.metcalfe@mcri.edu.au](mailto:sylvia.metcalfe@mcri.edu.au)).

Should you have any concerns about the conduct of the project, you are welcome to contact the Executive Officer, Human Research Ethics, The University of Melbourne (T 03 8344 2073; F 03 9347 6739).

### **How do I agree to participate?**

By selecting the “**Yes**” checkbox below you agree to consent to completing the survey.

If you decide not to complete the survey now, we thank you for your interest in our study. You can always complete the survey at a later date.

**Note:** You can stop the survey at any time, saving your answers, by clicking ‘Return later’.

**Make sure you write down the code that will appear on your screen as each code is unique!** Use the same survey link, then click on the "Returning?" button in the top right hand corner and enter your code.

Please tick "Yes" if at least one of the following criteria apply to you.

- You gained, or are studying for, sub-specialist medical training as a NICU/PICU clinician
- You currently work in a NICU/PICU setting in Australia.
- **YES**, and I consent to participate in this research by completing this survey.
- **NO**, the inclusion criteria do not apply to me so I am ineligible to participate in this research.





## Instructions

### **Thank you for taking part in this study.**

#### Navigation tips

- Click on the Next and Previous buttons at the bottom of a page to save your answers and move to the next/previous page. **Don't use the back button on your browser or keyboard as this will not save your answers.**
- If you are accessing the survey on a mobile device, the survey is best viewed in landscape (sideways) mode.
- You can complete the survey over more than one session. Click on the 'Return later' link to save your answers to date and come back later to answer. Make sure you write down the login code generated by REDCap, as you will need that code to access the survey you have already started. Use the same survey link, then click on the "Returning?" link in the top right hand corner and enter your code. (Note: you will need to type the code, not copy and paste). The survey will then open at the last page you completed. You can return as many times as you want, as long as you do not finalise the survey. Once you finalise, your unique link will not work.

If you are unsure about how to answer a question, please give the best answer you can.

Some terms are defined and these appear with an asterisk (\*) or dotted underline in the survey.

### **Your responses will be strictly confidential.**

At the end of the survey you will have the following options:

- (x) provide your contact details to receive a copy of the results directly; and/or
- (xi) provide your contact details to be contacted for telephone interview; or
- (xii) complete the survey only and not provide any contact details.

For clarification of any questions please contact Dr Belinda McClaren, Senior Project Officer, Australian Genomics Health Alliance, Murdoch Childrens Research Institute (T 03 8341 6415 or [belinda.mcclaren@mcri.edu.au](mailto:belinda.mcclaren@mcri.edu.au)).

Please note, all responses will be reported in a collective way so that specific individuals cannot be identified in any way.

Note: words with a dotted underline and asterix\* have a definition on roll-over.

**25. Please describe your current professional role (e.g. bioinformatician)**

.....  
 .....  
 .....

**26. How many years of professional experience in a clinical lab do you have?**

- <1 year
- 3–5 years
- 11–20 years
- 1–2 years
- 6–10 years
- >20 years

Your laboratory will offer rapid turnaround WES/WGS (<5 days) to NICU and PICU patients with suspected genetic conditions in 2018/19 as part of a research study

**27. In what proportion of NICU/PICU patients tested do you think the result from rapid WES/WGS will contribute to patient care?**



\*\*\*REDCap instructions: Participants will be asked to indicate response using a slider\*\*\*

**28. Please respond to the following questions related to the new rapid WES/WGS service.**

	Disagree (1)	Somewhat Disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Agree (5)
1. People who work here feel confident that the organization can get people invested in implementing this change.					
2. People who work here are committed to implementing this change.					
3. People who work here feel confident that they can keep track of progress in implementing this change.					
4. People who work here will do whatever it takes to implement this change.					
5. People who work here feel confident that the organization can support people as they adjust to this change.					
6. People who work here want to implement this change.					
7. People who work here feel confident that they can keep the momentum going in implementing this change.					
8. People who work here feel confident that they can handle the challenges that might arise in implementing this change.					
9. People who work here are determined to implement this change.					
10. People who work here feel confident that they can coordinate tasks so that implementation goes smoothly.					

	Disagree (1)	Somewhat Disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Agree (5)
11. People who work here are motivated to implement this change.					
12. People who work here feel confident that they can manage the politics of implementing this change.					

\*\*\*This tool is the Organizational Readiness for Implementing Change (ORIC)\*\*\*

**29. Have you attended any professional development education or training around genomics in the *past year*, such as lectures, seminars or workshops, either in person or online?**

No

Yes

If yes, was this:

In-house (internal) program/s

External program/s

Online training (webinar, MOOC,\* etc.)

Other.....

\*\*\* REDCap rollover definition: *Massive, open, online course, such as Coursera or Future Learn.* \*\*\*

**30. Which of the following do you currently access to keep up to date with, or learn new skills in, genomic medicine? (Select all that apply)**

Certification/fellowship activities

Online webinars, courses, MOOCs, etc.

CPD/CME activities

Reading specialty texts (journals, papers, books, etc.

Participating in multidisciplinary meetings

Study days at place of employment

Internal specialty seminars, conferences or similar

Other.....

Internal genetic or genomic seminars, conferences, etc.

External specialty seminars, conferences, etc.

External genetic or genomic seminars, conferences, etc.

**31. Which professional development method/s do you find are most effective for you?**

(Select all that apply)

Conference

Self-directed

Workshop

Lecture-style

Preparing and giving a presentation/poster/paper, etc.

Hands-on learning

Group discussion/reflection

Online

One-on-one discussion/reflection

Other.....

**32. We will be conducting follow-up interviews to specifically discuss education and training needs of health professionals and would like to invite you to take part in a (up**

to) 30 minute telephone interview. Please leave your email address below if you are willing to be contacted by one of our researchers.

.....

Thank you

*You're finished the survey, thank you!*

*Don't forget to click 'Submit' to complete the survey and have your say about your profession.*

Do you have any other comments about genomic medicine in a NICU/PICU setting? .....

If you wish to receive a copy of the study results, please provide your name and email address below. Please note, if you provide your name and contact details, we will not use this information for research purposes. It will only be used to send you a copy of the results. ....

**SUBMIT**

*Should you require any further information, or have any concerns, please do not hesitate to contact Professor Sylvia Metcalfe (T 03 8341 6309; E [sylvia.metcalfe@mcri.edu.au](mailto:sylvia.metcalfe@mcri.edu.au)) or Associate Professor Clara Gaff (T 03 9345 2708; E [gaff.c@wehi.edu.au](mailto:gaff.c@wehi.edu.au)).*