

STUDY INFORMATION SHEET

Evaluation of nursing and midwifery capacity to deliver genomic healthcare in Wales

You are invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Take time to decide whether or not to take part. If having read the information, you would like more information before taking part, contact details for the research team are provided at the end.

The field of genomics is offering better diagnoses for patients; improved and safer treatments; opportunities for screening; and possibilities for disease prevention. Genomics Partnership Wales has been established to ensure a united approach to genomics in Wales and to deliver a programme of work that will enable the ambition and commitment laid out in the Welsh Government's Genomics for Precision Medicine Strategy to be realised.

For more information on the Genomics for Precision Medicine Strategy, please visit: <https://gov.wales/sites/default/files/publications/2019-04/genomics-for-precision-medicine-strategy.pdf>

What is the purpose of the study?

Genomics Partnership Wales (GPW) is working with the University of South Wales in this study to gather some initial data on the current capacity of nurses and midwives working in Wales to deliver genomic healthcare. Data will inform future education and training initiatives provided through GPW.

Why have I been invited to take part in this study?

All nurses and midwives currently working within health boards and trusts across Wales are eligible to take part. You may have found out about this study via email, posters, social media or word-of-mouth.

We know that some nurses and midwives will already be involved in talking to individuals and families about screening, testing and/or treatment options that involve genomics, and/or are providing care to individuals with either a genetic diagnosis or increased risk for an inherited condition. However, we also recognise that many nurses and midwives will not be doing this yet and may be unfamiliar with how genomics is likely to be incorporated within their area of practice. We hope a cross-section of the nursing and midwifery workforce will take part in this study in order that we can capture some of this variation.

Do I have to take part?

It is up to you to decide and participation in the survey is entirely voluntary. If you are willing to take part, completion of the online survey will be viewed as you giving your consent.

What happens next?

Once you have finished reading this information you can move directly onto the survey. We will ask you questions on your awareness and views of genomics; your current practice; continuing professional development (CPD) opportunities and workplace environment, and learning preferences. Most of the questions are either a yes/no/don't know question format or 'select one answer from a range' question (e.g. strongly agree ←→ strongly disagree). We anticipate that it will take 10-15minutes to complete the survey.

You will not receive any incentive or payment for taking part.

What are the possible disadvantages and risks of taking part?

The questions that we ask are unlikely to cause you any harm. If, as a result of completing the survey, you identify a gap in your knowledge or skills around genomics that you are concerned about then please speak with your line manager as you would for any other professional training need that you identify.

What are the possible benefits of taking part?

This study has not been designed to directly benefit those taking part, although some participants may become more aware of genomics and the Welsh Government's strategy as a result.

The information that we get from this study will be used to inform future education and training initiatives provided through Genomics Partnership Wales (GPW) for nurses, midwives and potentially the wider health workforce in Wales. Participants will be given the option at the end of the survey to provide a contact email that will only be used by GPW to share information on GPW activities and events (including education and training).

What if there is a problem?

If you have a complaint about the research study or you experience in taking part please contact the chief investigator Dr. Emma Tonkin (details at the end of this information) in the first instance, who will do her best to resolve the problem.

If you wish to complain formally you can do this by contacting Genomics Partnership Wales or the University of South Wales Research Governance Officer (details for both are provided at the end of this information).

Will my taking part in the study be kept confidential?

Data collected in this survey is entirely anonymous unless you choose to provide you name and contact details at the end of the survey (for the purposes of receiving notifications from Genomics Partnership Wales, GPW). If you do provide a name and email, this information will be handled in accordance with GDPR guidance. Your name and email will be separated from your survey responses before your responses are

analysed, and passed electronically to GPW. GPW will only use your details to contact you about their events and activities, and will not pass your information onto a third party. The research team at the University of South Wales (USW) will not keep or use your contact details.

Electronic data (your survey answers) will be stored on a password protected computer and the data will be used only for this study. This de-identified (anonymised data) will be accessible to authorised users only (the research team at USW and specific staff at GPW). If in the future we wish to use the data as part of a different study we will seek new ethics approval from the university before going ahead.

The data will be kept for 5 years in accordance with NHS and UK Research Integrity Office guidelines

What will happen if I do not carry on with the study?

You are free to withdraw at any time during the survey. Once the survey has been completed you will only be able to withdraw and destroy your data if you have 1) provided your name (optional) so that your specific data can be identified and 2) contacted the project team immediately after the survey closes and before names are separated from the responses to anonymise the data. After this anonymisation process it will not be possible to identify your specific responses and so we will not be able to remove and destroy them.

What will happen to the results of the research study?

It is anticipated that results of this study will be published in peer-reviewed journals and presented at conferences as spoken and/or poster presentations. A summary of the findings will be shared by Genomics Partnership Wales (GPW) via their various networks (e.g. report(s) to government and/or health boards; public website [when launched] and other social media channels). Participants in this study may receive information on the findings only if they have signed up to receive notifications from GPW (optional).

Who is organising or sponsoring the research?

The research project has been organised by Genomics Partnership Wales in collaboration with the University of South Wales (USW) and is sponsored by USW because Dr. Emma Tonkin (chief investigator) is a member of staff.

Contact details:

Chief investigator: Dr. Emma Tonkin, Genomics Policy Unit GTAB031, Faculty of Life Sciences & Education, University of South Wales, Pontypridd CF37 1DL

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University of South Wales Research Governance Officer: Mr. Jonathan Sinfield, Research and Business Engagement, 8 Forrest Grove, University of South Wales, Pontypridd CF37 1DL.

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