

# ROLE DESCRIPTION

## Patient and Public Sounding Board



### **Background**

**Genomics** is the study of all of a person's genes (the genome), including interactions of those genes with each other and with the person's environment. **Genetics** is the study of genes and inheritance. Both play an increasingly important role in improving personal and public health, contributing to disease diagnosis, prevention, treatment and surveillance.

In July 2017, Welsh Government launched their ambitious strategy to transform the provision of genetic testing and genomics within NHS Wales:

<https://gov.wales/sites/default/files/publications/2019-04/genomics-for-precision-medicine-strategy.pdf>

**Genomics Partnership Wales** has been established to represent a number of organisations, experts and disciplines working in the field of healthcare, who collectively aim to transform the genomic services for patient benefit in Wales.

In 2019, we established a Patient and Public Sounding Board. We recruited patients and members of the public with a broad range of experiences relating to genetic testing and genomics. This group aims to represent the citizens of Wales as we work together to improve the patient experience and ultimately, the health and well-being of our population.

Our Patient Involvement approach has been developed to:

- Demonstrate a commitment to work in an open and transparent manner with patients and the public, using their collective experiences to shape and add value to the work of Genomics Partnership Wales and future genomics services in Wales
- Use experiences of patients and the public to improve the patient care pathway, from the first interaction to the last
- Co-produce an open, transparent and publicly-agreed approach to the sharing of genomic and precision medicine data for service development, clinical care and research
- Improve the public awareness and understanding of genomics, ensuring that it becomes an accessible area of healthcare for the citizens of Wales

We recognise that the issues and factors surrounding genetics and genomics are complex. We want to work with patients and members of the public, to explain things in a clear and simple way, empowering the citizens of Wales to understand more about what genomics can mean for them.

**We would like to recruit a new cohort to join this Patient and Public Sounding Board and expand the current membership. This is your opportunity to shape the way we talk about genetics and genomics, and to improve the patient experience for all those who come into contact with our clinical genomics services in Wales. We are looking for individuals with a broad range of experiences – please see role details below.**

The current Sounding Board have been consulted on a number of topics to date including:

- Options for taking patient consent to use their genomic data / samples for research
- Designing a good website with the most suitable layout, content and functionality

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- Ways to improve clinic and waiting areas in the genomics service
- Design and access considerations from a patient and public perspective for a proposed new location for genomics services
- Content of information leaflets and other supporting material for appointments
- Specific considerations for patients when introducing some new genomics services
- How other programmes can introduce patient and public involvement in their work
- Content and approach for a large conference promoting all aspects of genomics
- Content of training courses for health professionals to ensure the needs of patients are considered
- Content of the Delivery Plan for genomics in Wales; how patient involvement should be developed, general principles that should be adhered to and communicating the Plan to a broad audience

The Sounding Board will continue to work with other members of Genomics Partnership Wales to ensure that patients and their families remain at the heart of our work.

*Since the start of the pandemic, virtual sessions have replaced face to face meetings – this arrangement will remain in place until it is deemed safe to meet in person, at which time future meeting arrangements will be discussed with the Sounding Board members.*

### **The Role**

#### **Responsibilities**

As a member of the Sounding Board you will be required to:

- Attend a face to face/virtual consultation meeting every three months
  - o Where appropriate, reading material for you to comment on and discuss during the meetings will be issued a week before each meeting
- Take part in a few email consultations throughout the year in response to ad-hoc requests that may arise in between quarterly consultations. For example, we may want to check the wording of a press release with the group before sending out
- Promote genomics work or opportunities to your contacts/networks as required (clear instruction will be provided)
- Bring your own experiences of genetic testing and genomics to the table, but also be able to represent a broader perspective

#### **Skills & Attributes**

We are looking for people (either personally or as a carer or family member) who have experience of any of the following:

- Inherited cancers such as inherited breast, prostate, bowel or ovarian cancer
- Rare diseases such as Cystic Fibrosis, Huntington's Disease, Tuberos Sclerosis, Sickle Cell Anemia
- Developmental Delay Disorders such as Autistic Spectrum Disorders, Fragile X, Down's Syndrome
- Received / been offered genetic testing for diagnosis, treatment or during pregnancy
- Participation in a precision or 'personalised' medicine trial, e.g. for cancer

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- Any interaction with the All Wales Medical Genomics Service

And:

- Are able to voice opinions in a constructive manner, in a group environment
- Can explain clearly why certain communications may generate emotions, confusion or uncertainty
- Are able to listen to other perspectives and respect other viewpoints
- Understand that Genomics Partnership Wales will use the collective insight gained to improve and shape our work but may not be able to action each individual suggestion that you put forward

You **do not** require:

- Specific scientific or research experience; recruitment will be based on personal experience, so we are not seeking professional perspectives
- Public speaking experience or media training

### Time Commitment

- **Four quarterly meetings** throughout the year –these will be held virtually (via Zoom) or face to face in Cardiff, Swansea or mid/north Wales. Meetings will last around six hours including regular breaks
- **Meeting preparation** – we will send you any documents and materials at least one week in advance so that you can read and digest them ahead of time. We do not expect preparation to take any more than two hours per meeting
- **Email consultations / specific consultations** – as required. The number and type of email consultations varies and will not require you to read a lot of material. You may also get the opportunity to attend additional meetings on specific topics
- **A one-day induction and training** session held virtually on Wednesday 6<sup>th</sup> July 2022, before the consultation meeting held virtually on Thursday 7<sup>th</sup> July 2022

### Length of Term

**Minimum of one year initially** with the view to extend to a further year based on the experience of the initial year

### Training & Support

At the beginning of your term on the Sounding Board you will receive:

- An induction and training day to cover
  - o General information about Genomics Partnership Wales and its partner organisations to provide context to your role and help you to understand where you fit in to the work of the initiative
  - o Specific information about the Sounding Board; who we are and what we do
  - o General background information about genomics and relevant tailored training where needed

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- A named contact at Genomics Partnership Wales who you can contact with any questions before, during and after an activity
- Where appropriate, exposure to different teams within the partner organisations e.g. Welsh Government, NHS Wales, Public Health Wales, communications teams

### Expenses

An honorarium payment is available to cover the time required to prepare for and attend consultation sessions. For face to face meetings, all reasonable travel, accommodation, catering and participation costs will be met by Genomics Partnership Wales as per our policy\*. Accommodation and catering will be arranged by us if required.

### Venue/base

Quarterly consultation meetings will be held virtually (via Zoom) or face to face in Cardiff, Swansea or mid/north Wales. We will provide details of meeting venues in advance – all venues will be accessible for those with additional needs such as wheelchair users, etc. For virtual meetings, connection details are provided in advance.

### Equal Opportunities

At Genomics Partnership Wales (GPW) we involve people from all backgrounds, regardless of age, sex, gender identity, race, disability, sexual orientation, religion or culture. In this role you may work with and will need to represent the views of a diverse group of people. GPW is an all-Wales initiative, and we therefore encourage applications from all parts of the country, as well as from Welsh speakers.

### Application and Selection Process

- If you are interested in applying to be a member of this Sounding Board, **please complete the associated Expression of Interest and submit to Health and Care Research Wales by 31<sup>st</sup> May 2022**
- We will shortlist applications and invite people with relevant skills and experience to an informal virtual discussion; we will contact everyone who applies by 7<sup>th</sup> June 2022 to let you know whether you have been shortlisted
- Informal virtual discussions will take place during the week beginning 13<sup>th</sup> June 2022
- **Successful candidates will be invited to a two-day virtual induction, training and consultation session on 6<sup>th</sup> and 7<sup>th</sup> July 2022. Availability for this induction and training day forms part of the selection process**

\*Our expenses policy reflects guidelines produced by Health and Care Research Wales for similar patient and public involvement activity

### Genomics Partnership Wales contact information:

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*This document is available in Welsh / Mae'r ddogfen hon ar gael yn Gymraeg*