

ROLE DESCRIPTION

Patient and Public Sounding Board

Summary

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

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.

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, to join the Sounding Board. 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.

We would like to recruit a new cohort to join this Patient and Public Sounding Board and expand the current membership. We are looking to recruit individuals with a range of experiences (either personally or indirectly as a carer or family member) including:

- Inherited cancers such as inherited breast, prostate, bowel or ovarian cancer
- Rare diseases such as Cystic Fibrosis, Huntington's Disease, Tuberous Sclerosis
- Developmental Delay Disorders such as Autistic Spectrum Disorders, Fragile X, Down's Syndrome
- Being offered genetic testing as prediction of disease, or during pregnancy
- Participation in a precision or 'personalised' medicine trial, e.g. for cancer
- Any interaction with the All Wales Medical Genomics Service

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
- 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 related programmes can introduce patient and public involvement in their work
- Content and approach for a large conference promoting all aspects of genomics

This group will continue to work with other members of Genomics Partnership Wales to:

- Help us with communication materials for patients/public
- Help us to improve patient/public awareness of genetic testing and genomics
- Help us to improve our informed consent processes and patient information sheets

- Help us to shape our approach to sample and data sharing for the benefit of research and clinical care
- Help us to shape our approach to providing genomics services to our patients
- Help ensure that patients and their families remain at the heart of our work

Background Information

In July 2017, [Welsh Government launched their ambitious strategy](#) to transform the provision of genetic testing and genomics within NHS Wales.

Genomics Partnership Wales was formed to bring together experts from across several health disciplines to ensure that ultimately, the citizens of Wales can benefit equally from the right genetic test, at the right time and in the right place.

Our Patient Involvement Strategy has been developed to:

- a. 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
- b. Use experiences of patients and the public to improve the patient care pathway, from the first interaction to the last
- c. Co-produce an open, transparent and publically-agreed approach to the sharing of genomic and precision medicine data for service development, clinical care and research
- d. Improve the public understanding of genomics, ensuring that it becomes an accessible area of healthcare for the citizens of Wales

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, both from a human and pathogen genomics perspective.

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
 - Where appropriate, reading material for you to comment on and discuss during the meetings will be issued a fortnight before each meeting
- Take part in a few email consultations throughout the year in response to any ad-hoc requests that may arise in between face to face/virtual consultations. For example, we may want to check the wording of a press release with the group before it is sent 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 who:

- Have experience of genetic testing / genomics / precision medicine / clinical trials / inherited cancer / rare diseases
- Are parents with children who have received/been offered a genetic test
- Have received/been offered a genetic test during pregnancy
- 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 lay / patient / public 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 or face to face in Cardiff, Swansea or mid/north Wales. Meetings will last around five hours including breaks for refreshments
- **Meeting preparation** – we will send you any documents and materials at least two weeks in advance so that you can read and digest them ahead of time. We do not expect preparation to take any more than three hours per meeting
- **Email consultations** – on an ad-hoc basis. The number and type of email consultations is likely to vary and there may be opportunities for this to increase. These will not require to you read a lot of material.
- **A one-day induction and training** session held virtually on Tuesday 6th July 2021, before the consultation meeting held virtually on the following day, Wednesday 7th July 2021.
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Length of Term

Minimum of one year initially with the view to extend to a further year based on the experience of Year 1.

Training & Support

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

- An induction and training day to cover
 - 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
 - Specific information about the Sounding Board; who we are and what we do
 - General background information about genomics and relevant tailored training where needed
- 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, press and 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 or face to face in Cardiff, Swansea or in mid/north Wales. We will always provide details of meeting venues in advance, as well as maps and directions. All venues will be accessible for those with additional needs such as wheelchair access, 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 Process

- If you'd be interested in applying to be a member of this Sounding Board, **please complete the associated EOI and submit to Health and Care Research Wales by 31st May 2021.**
- We will shortlist applications during the week beginning 7th June 2021 and invite people with the most relevant skills and experience to an informal telephone interview
- We will contact everyone who applies by 11th June 2021 to let you know whether you have been shortlisted for interview
- Telephone interviews will take place during the week beginning 14th June 2021
- **Successful interview candidates will be invited to a two-day virtual induction, training and consultation session on 6th and 7th July 2021. 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 PPI activity

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