

### Foreword

Welcome all to the first edition of the Sounding Board newsletter of 2021; here's wishing you all a safe and healthy New Year after such a difficult 2020. We trust that sharing your individual experiences with the group during this session, focused on Precision Medicine in Wales provided a sense of hope – knowing that you're helping to shape the future of services in Wales to improve the patient journey. Thank you very much for your invaluable contributions



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### Precision Medicine for Wales

Our first consultation of the New Year was focused on Precision Medicine in Wales. Given that Genomics is but one of four National Programmes in Wales that join under the umbrella of Precision Medicine Programmes, we were keen to extend the remit of the Genomics Patient and Public Sounding Board for the benefit of these other Programmes.

The consultation served as an early introduction to Patient and Public Involvement (PPI) for Advanced Therapies Wales, National Imaging and Pathology Programmes. The discussions were centered on the following question:

“How would you develop a PPI strategy to support the work of these Programmes; what would this include in the short, medium and long term?”

The experiences shared will help to shape the development of broader PPI strategies to support ongoing work in these areas.

### Improved Communications for GPW

The second consultation was focused on Communication and how GPW could better promote the work of the Partnership.

We discussed the GPW website, how best to structure the Patient and Public facing pages, and also how we could promote individual news stories throughout the year.

The input provided will ensure that our communications are tailored correctly and that they help to increase the awareness of genetics and genomics progress being made in Wales.

#### Genomics Showcase

2021

- Friday 14th May
- 10am - 7pm
- Free Virtual Event

To learn more or to register email:  
WalesGenePark@cardiff.ac.uk



## Meaningful PPI for Advanced Therapies Wales

There is great potential for meaningful PPI to shape the delivery of this Programme and to improve the patient experience for those receiving new treatments. Given the relatively small number of patients who would be eligible for any given treatment, the opportunity to work closely with this group to better understand their values/preferences was identified. The collective experiences of a PPI group could shape the following:

### **Communication;**

- How best to talk about advanced therapies, the choice of words and the impact these can have on patients and their families
- How to describe the process by which funding decisions are made for new treatments
- Optimised methods of communication with patients; e.g. social services now use email systems
- Age-relevant (engage with parents as appropriate) communication methods
- Patients need as much information as possible – leaflets with appointment letters, someone to talk to by phone. People worry about the logistics of having treatment; where will they stay, what the treatment will involve and financial implications of the treatment are also a worry
- Social media presence – use the experience of others e.g. Velindre, where a number of Healthcare Professionals and Patients/Public describe how the hospital is set up, videos to show what to expect from a visit, etc.
- To know which therapies are in the pipeline will inform which groups need to be involved. Initial opinions/involvement could come from people who have not had the therapies e.g. CF group

### **Staff training;**

- Working closely with service users during training will help to keeping personal stories in mind

### **Service Development;**

- Long-term data gathering opportunity from patients on advanced therapy – PPI to inform how best to ensure accurate and up to date information captured to inform future service development and changes

### **Increased Public Awareness;**

- Development of a long term group of engaged public/patients/professionals to help with future involvement

### **Approaches to Consider**

- Use experience of established networks e.g. GPW Sounding Board, Health & Care Research Wales (HCRW), Wales Cancer Research Centre (WCRC), Velindre NHS Trust, etc.
- Develop a Sounding Board of carers and patients
- Use Wales Gene Park and their engagement channels – speak at their events to raise awareness of any opportunity to get involved
- Include people with a general interest as opposed to limiting to those who have specifically received advanced therapies, e.g. patients with experiences of clinical trials

## Meaningful PPI for National Imaging Programme

Collectively, Sounding Board members have a wealth of direct or indirect experience of NHS imaging services. Although some positive experiences were discussed, overall it was felt that imaging appointments were the most impersonal aspect of the healthcare journey. The experience could be described as 'transactional', and the fact that feedback/result interpretation often takes place after the appointment and 'behind closed doors' leads to feelings of disempowerment for patients and their families.

There was passion about the role PPI could play in supporting the delivery of the Programme, and stressed that improving imaging services should be informed by good PPI, sensitive to the patient experience.

- Operating an increased number of mobile screening sites away from main hospital sites, embracing new technology and flexible approaches to resourcing, etc. were all seen as positive changes
- Improving communication prior to, and during, appointments is important and would make a big difference to the patient experience e.g. Is there a way to remind patients the day before a scan with any specific preparatory requirements (e.g. fasting)? Improved communication during the appointments themselves would help to make patients feel more acknowledged and less objectified.

- Where possible, live feedback on the results/any discussion between technicians and clinicians, was seen as important
- Current experience of imaging services can be uncomfortable. This could be improved through the creation of a suite of educational videos targeted at a lay audience describing the clinical pathway which would help to avoid feelings of alienation and ease anxiety before an appointment
- Important to be clear with any PPI group about the overall aims of the Programme as well as identifying specific areas for priority involvement e.g. targeted involvement when designing service change, or to improve sections of the patient pathway.

There were a number of options suggested for establishing PPI into the National Imaging Programme, including:

- Establishment of a Sounding Board using GPW's experience
- Development of a questionnaire to capture patient and clinician experience - true co-production
- Consider how to enable better access to imaging services from remote areas across Wales
- Consider how to improve communication from clinicians between appointments - identifying what is important to patients
- Development of audio-visual tech solutions to prepare patients and their families in advance

## Meaningful PPI for National Pathology Programme

Given the breadth of subject area, you felt that it was important to be clear with any PPI group about the overall aims of the National Pathology Programme as well as identifying specific areas for priority patient and public involvement e.g. targeted involvement when designing service change, or to improve sections of the patient pathway.

A limited understanding of pathology exists among the general population, including patient groups. It is so important to recognise that different involvement opportunities would require a different level of pre-requisite knowledge, briefing, and preparation in order to enable meaningful involvement. Given that pathology services impact on all sectors of society, you felt strongly that all PPI should be representative of our communities and encompass a range of perspectives.

‘Information overload’ should be avoided; it is better if the strategy could be broken into smaller sections to focus the involvement opportunity. It is also important to not ‘re-invent the wheel’ and, instead, learn from pre-existing networks such as GPW Sounding Board model.

The GPW Genomics Cafés were cited as a good model for involvement opportunities to be accessible to many.

In terms of improving pathology services, the emphasis should be on empowering the patient in directing their own care, with patient involvement vital as early as possible in their care pathway. It was identified that involvement in research projects with pathology components is important and suggested that Focus Groups could be effective in helping to address specific questions or project development.

It was recognised that establishing a strong PPI focus was challenging during the pandemic, with a suggestion that developing a strong online presence would help to establish an interested audience base in the first instance. Sharing messages and important updates on Facebook and Twitter should be considered (such as the Mid & West Wales Fire Service ‘Tweet and Share Volunteers’) as a good way of engaging with people and helping to create a sense of proactive support whilst people are unable to volunteer in the normal way.

Close working with the charity sector would also be an advantage when establishing an interested network.

## Improving the patient and public area on the GPW website

### **When engaging with genomic content which resources do you see patients and/or the public using (e.g. education resources, press releases, information, etc.)?**

It was felt that central to disseminating information would be to have a standardised presence across multiple social media platforms (such as Facebook, Twitter, YouTube, etc.) This is in addition to established research networks (e.g. HCRW, CRUK, Wales Gene Park, etc.) and press releases from trusted sources (for example the BBC). Posters displayed prominently at hospital waiting rooms are another way of increasing the visibility of genomics to patients.

### **How do you see patients and/or the public using our website, specifically?**

It was felt that our website should be informative and educational for patients, acting as a 'go to' place for signposting further as appropriate. Important to keep up to date with the latest information and be a conduit for two way linkages, being referred to as well as referring out. The website should therefore promote the latest advances and developments in genomics within Wales as well as include basic 'what is...' type videos.

It was also felt that the website would be useful to signpost people enquiring about a possible career within genomics.

### **What do you see, as an end user of our website, is the current draw for patients and/or the public?**

Our website was seen as a useful landing page, a place to find out about the latest news and events, with linking to and from other websites (such as AWMGS or Wales Gene Park). It is seen as a trusted source of information pertaining to genomics services within Wales, with the potential to be a place of interest.

### **What elements do you feel are missing from our website?**

Keyword identification would help to ensure that the website appears higher in the ranking when searching genomics terms on a search engine such as Google. It is important for the website to be current with old links removed regularly. Simple language must be used. Patient/public stories/testimonials would help to demystify genomics and make it more relatable. The use of videos on the website would be a versatile tool. Articles/content showcasing the difference GPW has made to a given service for patient/public benefit would demonstrate the value of partnership working.

## Improving our External Communications

### **If we are not limited by resource what sort of comms would you like to see?**

All present were very keen for GPW to develop its social media presence and coverage of achievements in both local and national press.

### **How do you normally hear about genomics in Wales? What can GPW do to increase its profile?**

Genomics-related news is primarily accessed through the following channels

- National media (e.g. newspapers, television, websites) if something important academically is published it is filtered through these channels
- Local media – newspapers, popular local bloggers/vloggers, community groups, etc.
- Regular podcasts (most commonly weekly/fortnightly)
- Patient liaison groups

The importance of maintaining a regular presence, through regular reporting of developments was stressed, especially in the fast moving national press. The strategic Comms network of GPW partners should be nurtured and expanded to ensure a maximum audience can be reached.

### **How do you envisage us communicating genomics-related news and achievements if no limit to resources?**

It is important not to forget the importance of local press publishing genomics-related stories. Additionally the use of television screens and posters in hospital waiting rooms to increase the visibility of genomics amongst patients is seen as vital, alongside a strong social media presence. GPW could utilise these channels to produce a digest of latest news and developments in an easy to understand format.

### **What would you like to see more of?**

More stories of where Wales breaks new ground and trail-blazes developments to show that Wales is competitive with the rest of the UK. Important to also build GPW links into broader research groups to demonstrate the strengths of Welsh-led research. More should be made of the role that genomics plays in preventative medicine by informing lifestyle changes to reduce risk of certain conditions developing or reducing the severity of pre-disposed conditions, such as the reduction in harm resulting from DPYD testing. Such information should be summarised to ensure it is transmitted in a way which can be easily understood and relatable.

### **Some further suggestions made included:**

- Sounding Board members can help spread the word through their respective local channels
- The Sounding Board producing a publication on a topical area (e.g. Genomics & Covid) as a collaboration with professionals
- Use of Cardiff University marketing and journalism students to take on promotion of a given topic as a project
- Integrated ethics discussions at the start of involvement, perhaps in the form of a debate-type question such as ‘how does genomics translate into care?’
- More utilisation of volunteers through digital volunteering (tweet and share), internships, marketing projects, etc.



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Partnersiaeth Geneteg Cymru  
Genomics Partnership Wales

Wales GENE PaRK  
PARC GENETEG Cymru

Ysfael Iechyd a Gofal Cymru  
Health and Care Research Wales

Aelwedd gan Lywodraeth Cymru  
Funded by Welsh Government

### • Genomics Showcase

The Genomics Showcase is an event designed to showcase the field of genomics, and its potential to improve healthcare to the people of Wales. There will be something for everyone with events for the public, patients, schools, colleges, health professionals and researchers. Attendees will have the opportunity to listen to talks from experts, take part in interactive sessions that explore the world of genomics, view stands from exhibitors and participate in many more activities

### • GPW Estates Work

Our thanks are extended to two members of this board, Harry Niece and Karen Shepherd, who attended the first Achieving Excellence Design Toolkit (AEDET) workshop. It was a useful and informative experience and has greatly influenced, along with your feedback from our Autumn Consultation, our design decisions. The project continues at pace with completion of the full business case by the end of March and further development of the building design.

### • Patient Involvement

The contribution of the Sounding Board has been noted as an example to follow, so we would like to thank all members for their involvement to date! We look forward to many more consultations to build on this strong relationship

### • Genomics Strategy Review

GPW Programme Office are currently working with all partners to review progress to date, and articulate our ambition for Wales going forward. The next consultation will ensure involvement from the SB in this process.