

A sincere thank you to you all for your vibrant contributions to what I felt was another very successful consultation day!

It was incredibly encouraging to see such engaged conversations from both staff and Sounding Board members alike, on two very different topics, and to hear the enthusiasm in the room for working together to drive improvement.

It's important to reiterate once more that in a busy and pressured NHS, where staff are already doing their utmost to provide the best services for patients, change isn't always possible overnight, and in some instances isn't possible at all. Despite this, you provided staff with some great ideas on how to implement small, cost-efficient changes here and there that would have a big impact on the patient experience. You also provided us all with some aspirational goals – always important to consider the well versed phrase “if money was no object....”

It is with great hope and belief that I leave this group in the capable hands of the GPW team as I head off to embark on my maternity leave, and I'm confident that through working together, you'll help to ensure that the foundations set by this board will promote PPI across Genomics and beyond, over the next twelve months.

Thank you all again for helping us to make this possible – diolch yn fawr iawn.

Dr Catrin Middleton
Head of Programme, GPW



1st Consultation (AM): Website

After introductions and updates, we started on our first consultation of the day. This time we were discussing a very different topic to that of research consent – the All Wales Medical Genomics Service (AWMGS) website!

The topic was introduced by Matt Howells and Stephen Williams from the AWMGS. They started by telling us a bit about the service and what they hoped to get out of the consultation. We were also joined by Sally Spillane, Anna Barrett and Erik Waskiewicz - thank you all for your time!

We then asked you to discuss features of websites that you liked and disliked and factors that you thought would be important for the service to include in their website design.

We separated into three groups, each discussing different topics, before sharing the feedback with the rest of the group. You acknowledged that it would be difficult to design a website that would be perfect for everybody as there are a wide range of preferences; even within the Sounding board! A summary of your discussions is given on the pages that follow...

2nd Consultation (PM): Patient Journey

We were extremely grateful to Jackie Hill, Sharon Norman, and Dr Vani Jain for taking time out of their busy clinical schedules to consult with us.

The session started with an outline of the AWMGS clinical service and the current patient care pathways. Jackie, Sharon and Vani then rotated around the groups to focus discussion on specific areas of the patient journey, in order to hear your suggestions about what is important to you and how things could be improved.

The discussion was very engaging and a number of suggestions could lead to some 'quick wins'. You also shared some aspirational ideas with us, which will help us to focus on patient need when modifying parts of the service in future.

Patient-led and centred care is our number one priority so thank you all for being forthcoming with your constructive comments.

Website

The All Wales Medical Genomics Service (AWMGS) provide the NHS clinical and laboratory genetic and genomic services in Wales. Staff consulted with you about the content and functionality of their website.

Design

Preferences for design were very varied! Features such as bilingual content were seen as vital.

Navigation

You felt that the website should be easy to navigate so that diverse audiences can easily find the information they need. The consensus was that an initial holding page would be a good way of achieving this. You felt this holding page should be very simple and displayed without the need for scrolling. Pictures, with minimal text, could be used as a gateway to direct audiences - with titles such as “patients” and “professionals”. There were mixed views about whether these should have dropdown menus or short descriptions of the content...the team will decide on one approach to try, and return to you for future consultation!

Trust

What are the features that help you to trust a website? Many of you initially use a search engine and raised the importance of ensuring the website featured highly in the results. This should be achieved through the use of keywords like “genomics” and “Wales” rather than through paid advertisements. Key aspects you look for include an official URL and consistent, reputable branding.



Content

You agreed that the website should focus on the most important and unique content, signposting to other websites where relevant e.g. support groups. Material should be vetted for quality at regular intervals.

The Service

Many of you would use the website to find information about available services. You felt that no previous knowledge should be assumed about the service and recommended developing a page that explains what the service does in lay terms. This page could answer questions that might arise after referral like “what is a genetic counsellor?”, “what should I expect from an appointment?” as well as more practical concerns like car-parking. It was suggested that following the principles of “the 5 W’s” (who?, where?, what?, when?, why?) would be helpful.

Communication

You made it clear that although you didn’t expect the website to be able to answer all questions, you wanted a clear “contact us” section for those questions not answered directly on the website. Online methods of contact like email and chat boxes were seen as desirable. Telephone numbers should also be listed with relevant opening/responding times.

Features

You suggested an online appointment portal would be beneficial. The website should be formatted for all types of devices and you suggested an “AWMGS app”. You felt including patient stories on the website would humanise it.



We asked you to consider what you felt was **essential**, and what suggestions/changes you felt could improve the patient journey with both a **modest** as well as an **unlimited** budget. Your feedback is recorded below.

The key message from the discussions was the need to make the patients feel as relaxed as possible by providing welcoming surroundings and clear, relevant information

Correspondence, Communication & Information

- Letters should be tailored to the individual patient and include sufficient detail that is easy to understand with no jargon. The following should be included where applicable:
 - What to expect from an appointment e.g. blood may be taken
 - Opportunity for the patient to disclose any additional needs prior to attending the clinic e.g. behavioural, anxiety – the Service should accommodate to reduce the stress involved
 - Clear directions about where to find the clinic
 - Parking information (including park and ride arrangements where available)
- Clear signage to the clinic within main hospital buildings and in the clinic area
- Information about the role of a Genetic Counsellor in the patient care pathway
- Where genetic tests are involved, the patient should be given clear indication about how long the results will take and asked how they would like to receive their results.
- Patients should be updated regularly on waiting times or delays in test results
- Provide the ability for the patient to get in touch with the Service with any questions or request for further information (before or after their appointment) by providing a point of contact
- Where a patient is referred to other specialties, provide information about what to expect and possible waiting times

Waiting Area

- Reception staff should be available to greet patients on arrival and answer any questions
- Chairs and tables should be in a café-style layout rather than in rows
- Access to toilets should not be directly from the main waiting area
- Water and other refreshments should not be located near to the toilets; provision of coffee/tea facilities and snacks were also suggested
- Some suggested background music whilst others preferred having relevant health information on a TV screen without any sound
- Walls should not be bare but have interesting, relevant health information displayed; similarly, relevant information leaflets could be available on the tables
- Donated toys and recent magazines and toys could be provided
- Provision of different waiting area options was suggested to meet patient needs, including 'quiet'/individual rooms, family rooms, separate area for adults and children

Clinic Session

- Chairs should be comfortable and not too low
- Walls should not be bare but display interesting artwork, personal touches such as photographs and relevant health information
- Distractions (fidget toys, books) should be available for children or adults with learning difficulties
- Provide ability to use visual aides (e.g. iPads, diagrams, pictures, etc.) and ensure that any technology used works reliably
- If blood is to be taken this should be done at the same location but in a different room
- 'Satellite' clinics were discussed and the challenges of using temporary spaces in some hospitals; the provision of a resource box was suggested which would contain relevant health information, and toys/books for children/vulnerable adults

Further Suggestions

- Upskilling of GPs and specialty doctors to ensure appropriate referral of patients to the Service
- Dedicated clinic space for the Service across Wales; away from hospital sites for ease of access; purpose-built facility

Summary & Next Steps

Consultation 1: Website

Your Say

- Focus on doing the important things well and signpost elsewhere for the rest
- Make it easy to navigate, reduce the irrelevant information
- Welsh and English should be given equal priority
- Clear information about the service – the website is often the first port of call
- Useful to be able to communicate with the service digitally – email or chat box
- Make it patient focused!

Your Impact

- Your feedback has been relayed at the All-Service meeting
- The design preferences you have shared with us will be passed to the web designer for incorporation into the final product
- Once a working copy of the website is developed, you will be asked for your feedback
- Your input and suggestions about the content will be kept as a central focus as the website is developed

Consultation 2: Patient Journey

Your Say

- Existing facilities at UHW are not 'fit for purpose' – they are dark, very bare and clinical
- Despite this, those of you who had used the service were very satisfied with the quality of care provided
- Better signage on doors and better directions would help in the 'satellite' clinics held in various hospitals outside of Cardiff
- 'Resource/Clinic in a box' would be useful to create consistent 'brand' and 'feel' at these 'satellite clinics' and would be reassuring for patients
- Preparing patients for what to expect ahead of the appointment (e.g. length of appointment, whether bloods to be taken, etc.) would reduce anxiety
- 'Satellite' clinic arrangements not always 'fit for purpose', dedicated clinic space required

Your Impact

- Main waiting area within AWMGS in Cardiff has been rearranged following your suggestions – seating and water dispenser have been moved!
- 'Resource/Clinic in a box' to be developed to for 'satellite' clinics to improve the experience for patients
- AWMGS clinic spaces due a redesign, your views will be taken into full consideration when designing new clinic/waiting areas
- Quick fixes will be addressed sooner, with longer term improvements planned strategically
- Letters to be reviewed and where possible plain English to be used and consideration given to the provision of more detail ahead of/during/after the appointment if a patient requests this

Thank you for your participation



Contact GPW

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