

Engaging and Involving the Rare Disease community in Wales through Genomics Cafes

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Background

Through its well-established genetics and genomics [Education and Engagement programme](#), Wales Gene Park - in collaboration with Genomics Partnership Wales, Genetic Alliance UK and others - works in partnership with the Rare Disease community in Wales, facilitating many opportunities for engagement, participation and involvement. Cutting-edge genomic technologies are revolutionising medicine and health. In its [Genomics for Precision Medicine Strategy](#), Welsh Government has identified key actions to ensure people in Wales benefit fully from this. To help shape progress, it is vital that the public - including those affected by rare, undiagnosed and genetic conditions - are part of these advances. Here we describe a pilot Genomics Cafe initiative, aimed at engaging and involving the Rare Disease community and others about genomics in an informal, environment.

Approach

Cafes are free, open to all and held in accessible venues throughout Wales. They include short, relaxed talks about genomics relating to health and medicine, and guest slots from researchers, health professionals and, crucially, those affected by genetic and rare conditions who share personal experiences. The events provide a channel through which information including policy and research involvement and participation opportunities, events and networks are shared. There are also opportunities to chat, ask questions and meet others including members of the rare disease community, health professionals (e.g. Genetic Counsellors) and researchers. Attendees are invited to shape future cafes, providing suggestions on logistics, speakers and content. Informal on-the-day feedback is gathered by asking attendees to 'top up the teapots' with ideas.

Meeting others face-to-face in a relaxed environment has been so beneficial. Despite having different rare conditions, so many common concerns and issues. Great to have the opportunity to hear and share experiences and the good practices that can make life easier and more manageable.
Rare Disease Parent Carer & Advocate



I regularly speak about Genomics at a variety of events, but never anything quite like the Genomics Café. I really valued the opportunity to engage with a small group and form our discussions around the aspects of my talk that interested them the most. All with a cup of tea in hand!
Genomics Cafe Speaker



As a patient and patient charity founder it is very important to get the patient voice heard in the work of organisations such as Wales Gene Park. Being involved in their rare disease and genetics education projects is very rewarding and well received in the community. Indeed, the patient is the expert in their own condition.
Rare Disease Patient Advocate & Charity Founder



Findings

Future cafes will be themed around topics (e.g. mental health, access to medicines) or clinical fields, and include interactive sessions (e.g. focus groups, workshops). Feedback from pilot cafes is informing the next phase with ongoing evaluation ensuring relevant content. Once fully established, stakeholders will be involved in running cafes with support. Initial responses have been extremely positive with good participation from professionals and the public. Outcomes have already included talks about Rare Diseases for health professionals, research participation interest, and recommendation of the cafes for wider adoption by Wales' Chief Scientific Adviser for Health.