

Co-production of the Welsh Rare Disease Research Gateway

walesgenepark.cardiff.ac.uk/gateway

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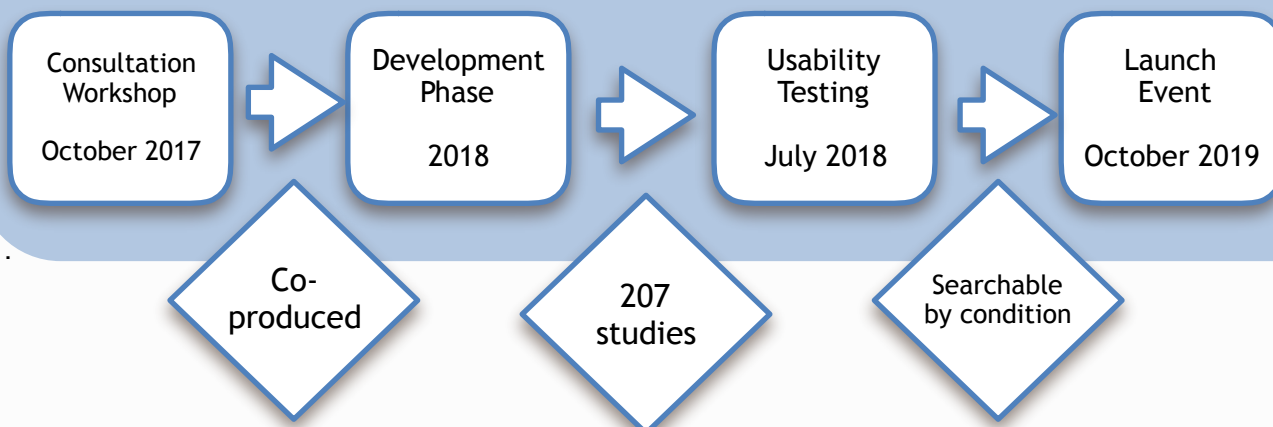
Background: Patient and public involvement (PPI) is a key aspect of Wales Gene Park's programme particularly across education and engagement and prioritisation and development of research. Wales Gene Park (WGP) collaborates with patients and the public to involve them in rare disease and genetic research. Here we describe:

- The Welsh Rare Disease Research Gateway to help patients and the public get involved in research

Approach: Following consultation with WGP networks, primarily patients and carers affected by rare diseases, we aimed to:

- bring together information about genetic and rare disease research projects from many sources in an accessible way.
- develop functionality to search for disease specific projects
- collate information about different types of research
- create a network of researchers who could recruit participants & advertise studies

Design, development and usability testing of the Gateway took place between 2017-2019:

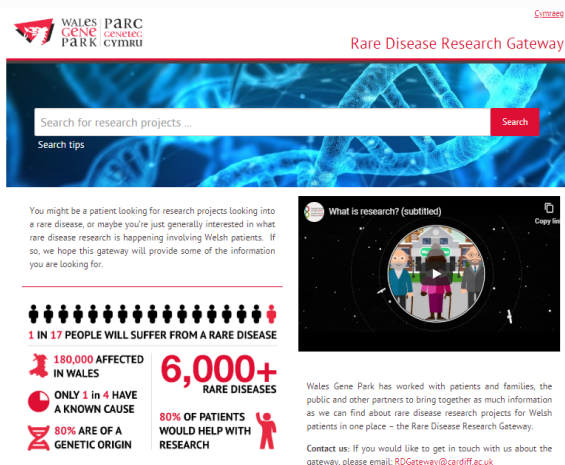


Conclusion: The Gateway is the first of its kind in Wales, a platform hosting relevant genetic and rare disease research studies.

It promotes involvement opportunities and signposts to research participation studies. It also collates information on training and up-skilling to empower and support participation in research.

At a recent Health and Care Research Wales conference, the Gateway was co-presented as an oral presentation. It has been highlighted as an example of good practice.

Future plans for developing Gateway include adding more studies, promoting its existence and working to improve its usability for patients and families.



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