Co-production of the Wales Gene Park Rare Disease Research Gateway

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Education and Engagement

Schools	Public	Health Professionals	Patients & Families
Genetics roadshows	Public talks & lectures	Study days	Events: meetings/family days/ information days
Sixth Form Conference	Community group talks	Conferences	Support groups
Teachers' Genetics Network	Public Genetics Network	Workshops	Policy work
Careers events	Public Genetics Conference	Genomics Roadshows	Patient network
Teachers' CPD			Campaigns

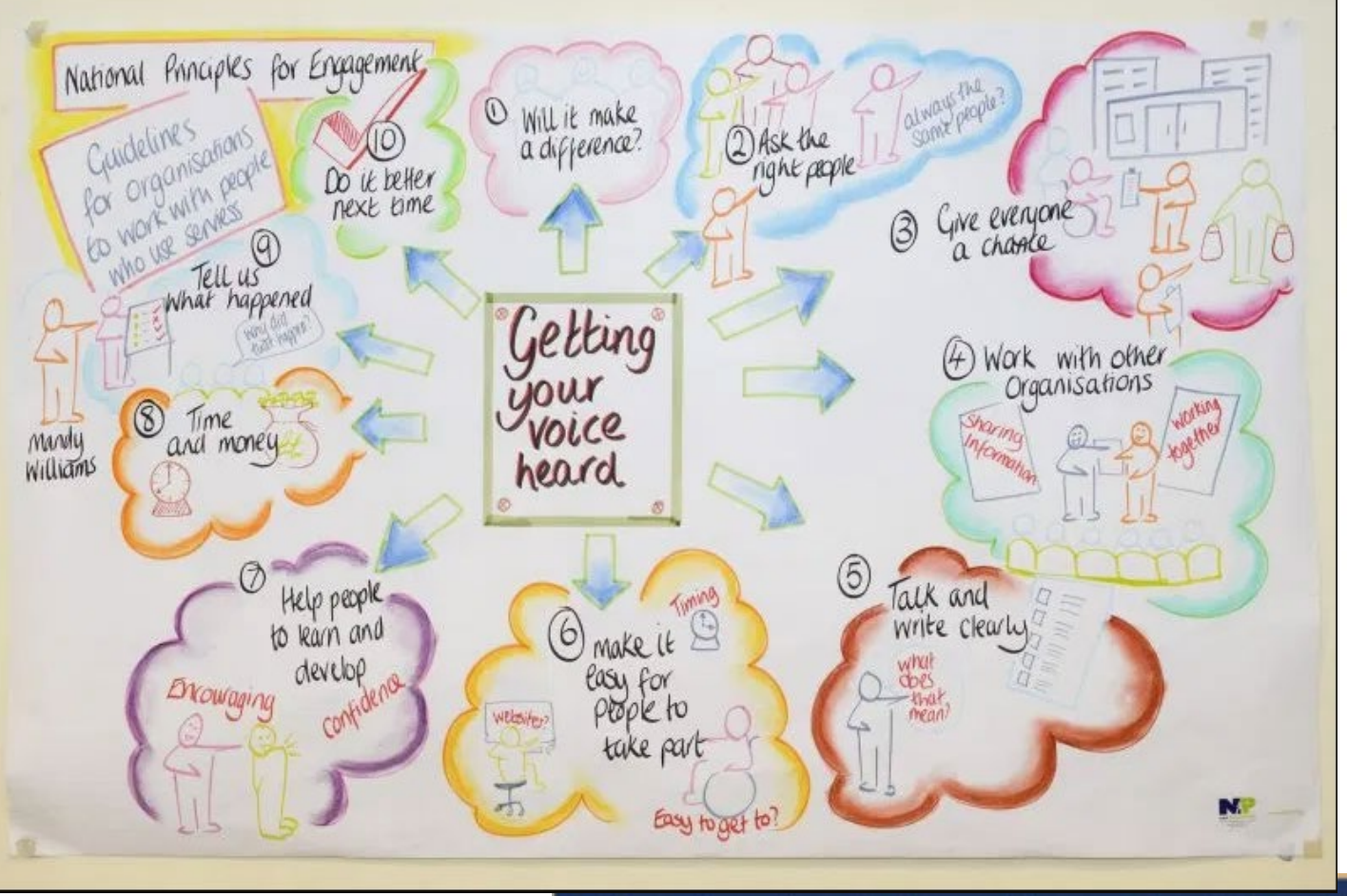
Networks

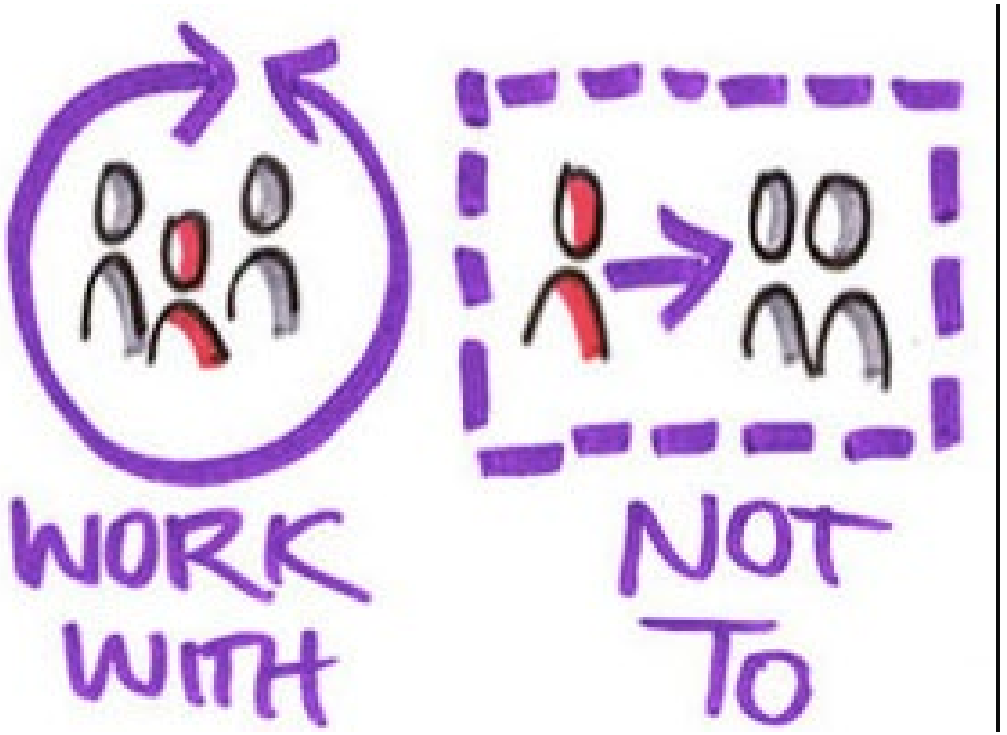
Rare Disease Patient Network

- Launched Oct 2015
- Over 150 members
- E-newsletter: information on activities, events and involvement opportunities
- Annual Meeting (October)

Public Genetics Network

- E-newsletter: information about WGP activities; genetics/genomics news
- Public Genetics Champions; involvement opportunities
- Annual Conference (summer – south Wales, autumn – north Wales)


National Principles for Engagement
Guidelines for organisations to work with people who use services
Getting your voice heard
1 Will it make a difference?
2 Ask the right people
always the same people?
3 Give everyone a chance
4 Work with other Organisations
Sharing information
working together
5 Talk and write clearly
what does that mean?
6 make it easy for people to take part
Timing
website?
Easy to get to?
7 Help people to learn and develop
Encouraging
confidence
8 Time and money
9 Tell us what happened
very dissatisfied
10 Do it better next time
Mandy Williams


WORK WITH
NOT TO


The 4 principles of prudent healthcare
Public and professionals are EQUAL PARTNERS through CO-PRODUCTION
CARE FOR those with the greatest health need FIRST
Do only WHAT IS NEEDED
and do NO HARM
Reduce INAPPROPRIATE VARIATION
through EVIDENCE-BASED approaches
For further information visit www.prudenthealthcare.org.uk

Scoping Workshop - Annual Rare Disease Patient Network meeting - 2017

The task…

- Bringing together information about rare disease research projects from many sources in one accessible website
- Ability to search for disease specific projects
- Connect with Health and Care Research Wales projects
- Include information about different types of research
- Create a network of researchers involved in rare disease research
- Highlight benefits of being involved in research

Rare Disease Research Portal

What?

- A gateway for patients and public to become involved in research
- Highlight research opportunities in Wales; signpost to other organisations and information
- Provide information on training and up-skilling to empower and support participation in research

How?

- Consultation Workshop: Rare Disease Annual Patient Network Meeting - 2017
- Development - 2018 - 2019
- Usability testing - July 2019
- Launch & Feedback 10 October 2019

walesgenepark.cardiff.ac.uk/gateway/

Cymraeg

Wales Gene Park | Parc Geneteg Cymru

Rare Disease Research Gateway

Search for research projects ...

Search

You might be a patient looking for research projects looking into a rare disease, or maybe you're just generally interested in what rare disease research is happening involving Welsh patients. If so, we hope this gateway will provide some of the information you are looking for.

Wales Gene Park has worked with patients and families, the public and other partners to bring together as much information as we can find about rare disease research projects for Welsh patients in one place – the Rare Disease Research Gateway.

Contact us: If you would like to get in touch with us about the gateway, please email: XXXXXX

Rare disease research today

Joining rare disease research

Learn more about research

Finding support for rare disease

You have searched for "polyposis"...

3 item(s) found

View as ▾ Sort by ▾

A prospective Europe-wide Study of Duodenal Disease in MUTYH-Associated Adenomatous Polyposis (MAP)

Posted 2 months ago by Wales Gene Park

We will undertake a prospective study of adult MAP patients with confirmed bi-allelic mutations across collaborating European centres. Data from upper GI surveillance procedures including endoscopy and histopathology findings will be collated as an ongoing process by the Institute of Medical Genetics, Cardiff, UK where it will entered into a database and stored safely. We will also collect prospectively data on other incident cancers diagnosed in these patients. All causes of death and all dates of death will be recorded. Recruitment of patients from the European centres and consent will be obtained using local procedures, and ethical approval will be obtained in each country. As MAP is a rare disorder, and the interval between surveillance procedures may be as much as 5 years, this study is planned to take place over 20 years.

MUTYH-Associated Adenomatous Polyposis (MAP) / Cardiff University

NSCCG

Posted 2 months ago by Wales Gene Park

National Study of Colorectal Cancer Genetics There are several different factors that can increase risk of developing bowel (colorectal) cancer. One is an inherited faulty gene (genetic mutation). An inherited genetic mutation may mean that several people in the same family develop bowel cancer. This is called a strong family history'. Inherited conditions such as familial adenomatous polyposis (FAP) or hereditary non-polyposis colorectal cancer (HNPCC) also increase risk. The increase in risk will depend on which gene is damaged, or even on which part of the gene is damaged. Some genetic mutations are 'high penetrance' and increase risk a lot. Others are 'low penetrance' and don't increase risk very much. The aim of this study is to find out more about high penetrance genes, and how much they increase risk. And to look for new low penetrance genes.

Rare Non-specific / Wales Wide

A prospective Europe-wide Study of Duodenal Disease in MUTYH-Associated Adenomatous Polyposis (MAP)

Posted 3 months ago by Wales Gene Park

MUTYH-Associated Adenomatous Polyposis (MAP) / Cardiff University

Rare disease research today

Joining rare disease research

Learn more about research

Finding support for rare disease

GENETIC ALLIANCE UK

Come along and find out more…

WALES GENE PARK | PARC GENETEG CYMRU

- Genomics Cafes throughout Wales - upcoming:
  -Newport - 4th November
  - Swansea - 7th November
  - Wrexham - 12th November
  - Cardiff - 2nd December
  - Carmarthen - 5th December

- Rare Disease Patient Network Annual Meeting – 10th October

Emma Hughes

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