

Public Reference Panel

M Morgan, S Parsons, S Luzio on behalf of the DRU Cymru Public Reference Panel

Introduction

DRU Cymru recognise the value that patients, carers and the public can make to our research when involved as active partners. We are particularly interested in working with people who have experience of living with diabetes so that we can develop and deliver research that reflects their views and needs. To reach this group we advertised widely for volunteers to work as part of the Unit. Following an Open Day, we selected eight members of the public from across Wales to form our Public Reference Panel. All have experience of living with diabetes.

Method

We felt it important that the public contributors were clear in what their role involved so developed a role description with the group. Equally we thought it important for the public contributors to know what they could expect from us and how they could expect to be treated so also developed a Terms of Reference and Code of Conduct.

Our Evaluation

After our first year we conducted an evaluation to allow our public contributors to have a say in how we move forward. We also asked researchers who had worked with the panel for their views.

In response to comments we refined our payment structure and changed our review process to ensure we had a set number of reviewers for each review.

How We Have Grown

As the group became more established it became clear that the views of young people living with diabetes and their families were not represented. We therefore recruited three parents of children with diabetes to the group. We understood that it may be difficult for individuals to join an established group so panel members were asked to become mentors to the new members to help them settle into the role.

We thought it inappropriate to include children on the main reference panel so have made ad hoc arrangements when we have needed the views of young people on specific projects.

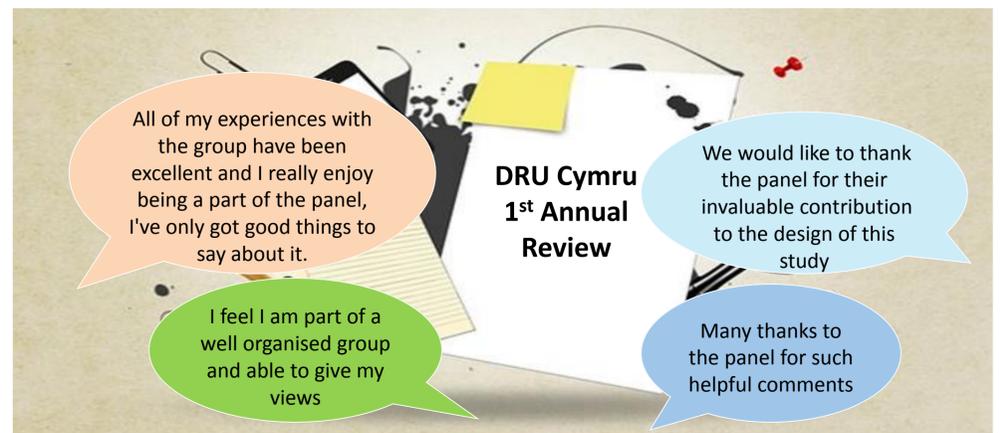
Future Plans

Due to an increasing workload we plan to expand our group further. We also plan to establish a young persons group. We will continue to review the panel annually, adapting as necessary to meet the needs of the diabetes research community.

The Reference Panel's Role

Members of the panel sit on the DRU Cymru Executive Board, Project Specific Trial Steering Committees and Research and Development Groups.

The panel regularly review research documents from researchers for funding applications and other material such as patient information sheets.



By working collaboratively with members of the public we have produced meaningful research relevant to the diabetes community in Wales