



# PREPARE Public Panel: information meeting

Thursday 12 October 2017, 17h30-19h00 (UK time)

Chapter Arts Centre, Cardiff, Wales

## Why did we meet?

We met to speak about forming a **public panel** for a large research group, PREPARE.

PREPARE does medical research if there is an infectious disease outbreak, like a new strain of flu. Results from PREPARE studies will help medical professionals, e.g. GPs or hospital doctors, know how to diagnose and treat patients who become ill. They will also help public health agencies make decisions about how to prevent the spread of the disease. PREPARE has studies in many locations across Europe. This is important because infectious bugs don't stop at geographical borders. We need to work together and across borders.

To make sure our research is person-centred, accessible and relevant to future patients, we need a public panel that we can work with over time to advise us on key aspects of how we design our studies and share our findings. In the event of an infectious disease outbreak, we would rapidly call on this panel to help us as we would need to set up studies as quickly as possible.

## Who was there?

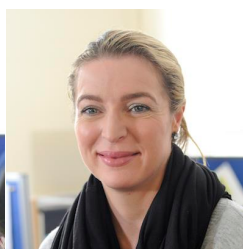
Members of the public in Cardiff who had taken part in a PREPARE qualitative study in 2015-2016 were invited to attend the session. Six members of the public attended.



Researchers from PREPARE at Cardiff University coordinate the panel and ran the session.



Micaela Gal



Angela Watkins



Nina Gobat

## What happened in the meeting?

Participants introduced themselves and discussed why they wanted to be involved in the panel. Key themes were that participants were interested in health and that, having received benefit from the excellent work of the NHS, participants wanted to give something back. An infectious disease outbreak would affect everyone, and participants want to be able to help.

During the meeting we did some tasks that stimulated questions and discussion about what an **infectious disease pandemic** was, what **clinical research** involves and how members of the public can help clinical research efforts during an **infectious disease outbreak**.



We spoke about the challenges of setting up clinical studies quickly enough that we can use results to help patients. In designing clinical studies it is important that we understand what is acceptable to patients who would be asked to sign up to the study. Ethics committees also want to hear what patients or members of the public think about research processes.

## What did we decide?

The purpose of the meetings is to **prepare the group** to give PREPARE researchers feedback on their research plans in an actual outbreak. Each meeting will cover a different topic, like:

- ❖ A more detailed look at the clinical studies being run in PREPARE.
- ❖ An overview of the research process and the role of ethics committees and medicines regulators.
- ❖ A practice exercise where we imagine that a flu pandemic is happening and the group has been asked to rapidly give feedback on study documents and processes to researchers.
- ❖ Brainstorming session about how taking part in clinical research is different from everyday medical care and how we can best explain this.

We decided that the group might have an advocacy role in the community. We also wanted to think about social inequalities and wanted to open panel membership up to more people if they were interested so that we can hear different points of view that represent our diverse communities. To do that we might need to engage with community groups in creative ways. In the future, these groups might be set up for PREPARE in other countries in Europe.

We decided to meet every three months in the early evening, to share information and to keep the panel updated in between sessions. In the future, panel members will receive a love-to-shop voucher to thank them for their time, and all expenses will be reimbursed.

## What's next?

Our next meeting will be in January/ February 2017. Date and venue to be confirmed.

For queries or further information about this panel, contact: Nina Gobat [GobatNH@cardiff.ac.uk](mailto:GobatNH@cardiff.ac.uk), 07913416907; Angela Watkins [WatkinsA6@cardiff.ac.uk](mailto:WatkinsA6@cardiff.ac.uk), or Micaela Gal [GalM@cardiff.ac.uk](mailto:GalM@cardiff.ac.uk)