

## Interview schedule

These questions are taken from an interview schedule that was used for the research that was submitted in September 2024 to the University of Birmingham, UK, by Kamila Lipiec, as a part of the conditions needed to complete her Masters of Research Thesis in Clinical Psychology. The research was supervised by Kate Woodcock and is being prepared for publication in a scientific journal.

### Interview Schedule for Listening to the voices of people with PWS across the world.

Firstly, I would like to find out a little bit about you.

1. Could you tell me a bit about the time you spend with your family please?
  - What do you enjoy / not enjoy about it
  - Why is it important to you to meet with your family/friends?
  - Support received – in what way, from who---- (to meet with the family)
  - Anything you would want to change about it---- (change about meeting with the family)
  - What would need to happen for that to change
  - Family versus friends
2. Are you employed/or studying? →use answer to tailor following question – if neither find out which is most relevant for them e.g. which they would want to be doing / have done and enjoyed

Could you tell me a bit about your job / school / college?

  - What do you enjoy / not enjoy about it?
  - Why is it important?
  - Support received – in what way, from who?
  - Anything you would want to change about it?
  - What would need to happen for that to change?
  - Future

Thank you. You are doing very well. In the survey people told us that food is very important to them, the struggles they experience and how they are managing their food.

3. Could you tell me a bit about your experience with food?
  - What do you enjoy/ not enjoy about food?
  - Why is it important to manage your food?
  - Support received – in what way, from who?
  - Anything you would want to change about it?
  - What would need to happen for that to change?

Thank you. Now, I want to talk to you about the way you travel.

4. Could you please tell me a bit about how you travel?
  - What do you enjoy/ not enjoy about travelling?
  - Why is travelling important to you?
  - Support received – in what way, from who?
  - Anything you would want to change about it?
  - What would need to happen for that to change?

Thank you. Are you okay if we continue? (If no offer a break. In the survey some people have said that they are not being listened to- (here I am finding out, about the persons' knowledge of self-advocacy and their communication).

5. Can you tell me about a time when you felt like you were not listened to?
  - What happened, where were you, what were you trying to communicate?
  - Why do you think it's important to be listened to?
  - Support received – in what way, from who?
  - Anything you would want to change about it?
  - What would need to happen for that to change?
  - What can help you tell someone what you need/Is there anything that would be helpful to help you communicate what you need?

Some people in the survey explained that they want to make decisions on their own- (here I want to know about their decision making).

6. Could you tell me a bit about your experience of making decisions please?
  - Why do you think it's important to make decisions?
  - Support received – in what way, from who?
  - Anything you would want to change about it?
  - What would need to happen for that to change?

Very well done. Now, let us talk about meeting others. In the survey some people answered that they would want to meet with other people with PWS to talk about Prader-Willi Syndrome, hobbies, interests, and everyday life.

7. Could you please tell me a little bit more about whether you would enjoy talking to people with PWS?
  - Do you think it's important to meet with other people with PWS?

If they already meet with people with PWS ask:

- Anything you would want to change about it?
- What would need to happen for that to change?

8. Could you tell me a bit about how you cope with your feelings?
  - Bullying – ever treated badly by others?
  - How did it feel?
  - How cope?
9. Could you tell me about your experience of working with other people? (e.g. at school / at work depending on if they are employed or not)
  - Did you ever lead the group?
  - Why? Why not?