



INFORMATION SHEET FOR PARTICIPANTS

Paid or Family Carers or Others who know the person with PWS well

Covid-19: its presentation, course and outcome in people with Prader-Willi syndrome (PWS)

This information sheet is for family, paid carers or others who have supported a person with Prader-Willi Syndrome (PWS) who was suspected as having, or has been diagnosed as having, a COVID-19 infection. This survey has been organized by the International Prader-Willi Syndrome Organisation (IPWSO). They are responsible for the conduct of the study. The survey findings will be analyzed by Dr Joyce Whittington and Professor Tony Holland in the Department of Psychiatry, University of Cambridge, UK. The information sheet tells you what the survey is about. It is important that you read this information before deciding whether or not to take part.

Ethical Review of the Project

This project has been reviewed by the University of Cambridge Psychology Research Ethics Committee.

Who are we?

The International Prader-Willi Syndrome Organisation (IPWSO) is a Charity Registered in England and Wales. The Charity has 38 National PWS Associations as full members and contacts in over 100 countries. The main aim of the Charity is to support people with PWS and their families across the world. The Clinical and Scientific Advisory Board (CSAB) and the Professional Providers and Caregivers Board (PPCB) of IPWSO are responsible for overseeing the survey and for the interpretation of the findings and for the publication of any results. Joyce Whittington and Tony Holland, who are responsible for the analysis of the survey findings, have previously led extensive research into PWS at the University of Cambridge. Tony Holland is President of IPWSO and is Emeritus Professor at the University of Cambridge.

What is this research about?

COVID-19 is a highly infectious virus that is new to humans and is now affecting people in all parts of the world. Most people (particularly children) are only mildly affected but a minority can become seriously ill, usually due to breathing difficulties, some will require care in the Intensive Care Unit, and some may die because of the infection. The aim of this survey is to identify how COVID-19 infection presents in people with PWS, whether the course of the illness is different, and whether the risks of serious illness and death are increased. Because people with PWS may not develop a temperature with an infection and it is known that infections, even when serious, can be missed and not

diagnosed. For these reasons it is important that we identify what should alert people with PWS and their carers that they may have become infected. As obesity and a history of chest illnesses are known to increase the risk of complications from a COVID-19 infection, both of which are common in people with PWS, early diagnosis and treatment may be particularly important to prevent more serious illness developing.

Why are we asking for your help?

We are asking that anyone, such as family members, paid carers or others, who know someone with PWS who has either been thought to have had a COVID-19 infection and/or has been diagnosed as having a COVID-19 infection to participate in this survey on-line or on paper. The survey is anonymous and does not ask for any personal details about the person with PWS except their age and the country where they live. We are asking you as a carer to do this. If the person with PWS is able to contribute please involve them. However, we are primarily concerned with what you, as a carer or someone who knows the person with PWS well, observed prior to and during the course of the illness. Please do NOT complete the survey if someone else has already completed it about the same person and please make a record that the survey has been completed after you have submitted. This is to avoid more than one response about the same person.

Do I have to take part and what do I have to do if I take part?

Completing this survey is entirely voluntary. We understand that you may not wish to take part for various reasons but especially if the person with PWS you cared for has been very ill or has died as a result of the illness. As the participant in this survey we are asking for your observations about COVID-19 and how it presented and affected the person with PWS you support. For paid carers please consult with others if you are uncertain, for example, because you have had days off. If it is possible, we ask that you seek the agreement of the person with PWS before you take part. This may not always be possible because the person with PWS has developed serious illness or has died. The survey questions can be answered via the Internet or on paper. We anticipate that the survey will take no longer than 15 to 30 minutes. All information collected will be stored securely. The findings from the group as a whole will be analyzed and will be made available by IPWSO and may be submitted for publication in a scientific journal.

How will taking part help the person I care for?

It may not help the person you care for now but it will help us understand better how viral illnesses like COVID-19 present in people with PWS and whether people with PWS are more at risk for serious complications. This may help us recognise the onset of this type of illness in someone with PWS more quickly and therefore start treatment sooner.

Will you be paid for taking part?

We are unable to pay for your time.

What about confidentiality?

The survey is anonymous and we will have no information that allows us to identify the person with PWS. Information is entered via our website and is stored securely. At intervals the survey information will be downloaded from the IPWSO server and transferred to a secure computer in the Department of Psychiatry at the University of Cambridge, for the purpose of analysis by Joyce Whittington. Your contact details, if you include them, will remain with IPWSO until the end of the study and will NOT be given to the University of Cambridge. The anonymised information will be kept on the University of Cambridge secure system and deleted when no longer needed and no later than five years after the completion of the survey. General information on how the University uses personal data can be found at:

<https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>

What if I have questions?

If you have any questions please contact Agnes Hctor via e-mail office@ipwso.org in the first instance.

Completing the survey

For access to the survey please click on this link: <https://bit.ly/2yV3dfi>

If you would like a PDF of the survey please contact Agnes Hctor at the e-mail above.