

## PRADER-WILLI SYNDROME - SCALE for the UNAWARENESS of the DISORDER (APW-SUD)

**Name and Surname of the patient:**

**Name and Surname of the Main Caregiver:**

**Name of the Researcher:**

**Date:**

**Ambit of application:**

**1- Awareness of the medical disease (Prader-Willi Syndrome)**

**Awareness (CAREGIVER)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**Awareness (CLINICIAN)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**2- Awareness of the effect of the psychopharmacological treatment (if there is any)**

**Awareness (CAREGIVER)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**Awareness (CLINICIAN)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**3- Awareness of the Social Consequences of the disease (Prader-Willi Syndrome)**

**Awareness (CAREGIVER)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**Awareness (CLINICIAN)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**4- Awareness of the Obesity / Overweight (if it is present)**

**Awareness (CAREGIVER)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**Awareness (CLINICIAN)**

0. non relevant item

1. awareness

2.

3. intermediate awareness

4.

5. unawareness

**5- Awareness of Increased food Appetite (if there is any)**

**Awareness (CAREGIVER)**

0. non relevant item

1. awareness

2.

**Awareness (CLINICIAN)**

0. non relevant item

1. awareness

2.

- |                           |                           |
|---------------------------|---------------------------|
| 3. intermediate awareness | 3. intermediate awareness |
| 4.                        | 4.                        |
| 5. unawareness            | 5. unawareness            |

6- Awareness of the <b>Increased amount of food eaten</b> (if applicable)
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- | <b>Awareness (CAREGIVER)</b> | <b>Awareness (CLINICIAN)</b> |
|------------------------------|------------------------------|
| 0. non relevant item         | 0. non relevant item         |
| 1. awareness                 | 1. awareness                 |
| 2.                           | 2.                           |
| 3. intermediate awareness    | 3. intermediate awareness    |
| 4.                           | 4.                           |
| 5. unawareness               | 5. unawareness               |

## Instructions

This scale requires that the subject suffers from Prader-Willi Syndrome with one (or all) of the symptoms detailed below. For each symptom or item on the scale, first, it must be verified that the subject has presented this particular symptom during the period under investigation. The severity of the symptom is not relevant, it only needs to be clearly present. Verification of the symptom list should be carried out before filling out the scale to determine which symptoms or items are relevant.

The three "general" items (numbers 1, 2 and 3), which do not correspond to specific symptoms, are usually relevant and must be completed if this is the case.

In the column "CAREGIVER", the maximum current level of consciousness of the patient is rated according to the appreciation of the main caregiver.

In the "CLINICIAN" column, the maximum current level of consciousness of the patient is rated according to the assessment of the clinician or professional who evaluate the patient. The clinician need enough experience in the treatment of these patients (and preferentially an expertise in the area).

Shorter or longer periods of time can be used for the current and retrospective assessment of consciousness, depending on the research objectives.

### General Items:

Item 1. Awareness of the Genetic disorder (Prader-Willi syndrome).

*In general terms, does the person believe he/she has a genetic disorder, a hormonal problem, a health difficulty called Prader-Willi Syndrome, etc.?*

Scores:

0 It cannot be valued.

1 Awareness: the subject clearly believes he/she has a genetic disorder (Prader-Willi syndrome).

2

3 Intermediate Awareness: he/she is unsure of having a genetic disorder (Prader-Willi syndrome), but he/she may consider the idea that she/he may have it.

4

5 Unawareness: he/she thinks he/she does not have a genetic disorder (Prader-Willi syndrome).

Item 2. Awareness of the effects obtained with psychopharmacological medication.

*What does the person believe about the effects of the medication? Does the person believe that the medication has decreased the intensity or frequency of their symptoms (if applicable)?*

Scores

0 It cannot be valued or not relevant item (there is no psychopharmacological treatment).

1 Awareness: the subject clearly believes that the medication has decreased the intensity or frequency of their symptoms.

2

3 Intermediate awareness: he/she is unsure whether the medication has decreased the intensity or frequency of your symptoms, but she/he may want to consider the idea.

4

5 Lack of awareness: he/she believes that the medication has not decreased the intensity or frequency of his/her symptoms.

Item 3. Awareness of the social consequences of genetic disorder (Prader-Willi syndrome).

*For example, what is the person's opinion about the reasons why he/she has been admitted to a hospital, outpatients department, carried out tests, strict diets, etc.? Do you think it affects you in your social relationships, in the search for work or leisure (outings, excursions ...)?*

Scores

0 Cannot be valued or non-relevant item (there are no social consequences).

1 Awareness: the subject clearly believes that the relevant social consequences are related to having a genetic disorder (Prader-Willi syndrome).

2

3 Intermediate Awareness: he/she is unsure whether the relevant social consequences are related to having a genetic disorder (Prader-Willi syndrome), but he/she may want to consider the idea.

4

5 Unawareness: He/she believes that the relevant social consequences have nothing to do with having a genetic disorder (Prader-Willi syndrome).

### **Symptom's Items**

Item 6. Obesity / overweight awareness (if applicable).

*Does the person realize that he/she is obese or has overweight and, especially, is this situation perceptible compared to the others (who do not have it)?*

Scores

0 Cannot be valued or non-relevant item (there is no obesity or overweight).

1 Awareness: the subject clearly believes that he/she is obese or has overweight.

2

3 Intermediate Awareness: he/she unsure of being obese or having overweight, but he/she can consider the idea.

4

5 Lack of awareness: she/he thinks she/he is not obese or has not overweight.

Item 7. Excessive food appetite awareness (if applicable).

*Does the person realize that he/she has an excessive food appetite, or an increased appetite, compared to others?*

Scores

0 Cannot be valued or not relevant item (there is no excessive food appetite).

1 Awareness: the subject clearly believes that he/she suffers from an excessive food appetite.

2

3 Intermediate Awareness: she/he are unsure of having an excessive food appetite, but she/he can consider the idea.

4

5 Unawareness: she/he think she/he doesn't have an excessive food appetite.

Item 8. Awareness of excessive food intake (if applicable).

*Does the person realize that he/she has an excessive food intake or an increase in the amount of food eaten, compared to others?*

Scores

0 Cannot be valued or non-relevant item (there is no excessive food intake).

1 Awareness: the subject clearly believes that he/she suffers from excessive food intake.

2

3 Intermediate Awareness: she/he is unsure of excess food intake, but she/he can consider the idea.

4

5 Unawareness: she/he think she/he does not suffer from excess food intake.