PWSA UK
PRADER-WILLI SYNDROME
ASSOCIATION UK

Impact Report
2024-2025

This report is based on outcomes and other data which has been verified by independent evaluators, Insley Consulting.

Names have been changed, or quotes anonymised to protect the people with PWS involved, as well as their families. Some quotes have been edited slightly for readability.

Case studies are based on interviews with parents who have engaged with PWSA UK. Photographs used beside case studies and quotes are not of the people with PWS and families featured.

Contents

Introduction from the Chief Executive

I am pleased to introduce this year's Impact Report, highlighting the incredible work of Prader-Willi Syndrome Association UK (PWSA UK) and the meaningful difference we have made in the lives of individuals with Prader-Willi syndrome (PWS) and their families.

At PWSA UK, our mission is to provide unwavering support, advocacy, and guidance for those affected by PWS, ensuring they have access to the resources and services they need to lead fulfilling lives. Over the past year, we have expanded our reach, strengthened our partnerships, and continued to champion awareness and understanding of PWS within the wider community.

The resilience of the individuals we support, alongside the dedication of their families and caregivers, inspires everything we do. Through our helpline, specialist advice, support for research, and advocacy efforts, we have empowered more people than ever before. None of this would be possible without the generosity of our supporters, the hard work of our team, and the commitment of our trustees and volunteers.

This report is a testament to what we can achieve together. As we look to the future, we remain committed to ensuring that every person with PWS has the opportunity to thrive. Thank you for being part of this journey with us.

Jackie Lodge
Chief Executive, PWSA UK

PWSA UK in Numbers 2024 – 2025

PWSA UK supports people with PWS as well as their families and professionals.

The numbers of requests for support continues to increase as does the complexity of the issues presented to us.

> ***“The PWSA team have shown amazing resilience and generosity in helping our family navigate the deep lows of PWS diagnosis and the ups and downs of life with PWS.”***

- Parent of young person with PWS

> ***“The training will improve my ability to support individuals with Prader-Willi Syndrome, enhancing care, communication, and behaviour management strategies.”***

– Health and social care professional

> ***“We really enjoyed the weekend, it was great to meet up with everyone, it makes you feel a little less lonely and that you are doing the best you can. We come away from the weekends feeling a little bit stronger and encouraged.”***

– Parent of young person with PWS

In total **1160** people accessed our services

As a result, we took **2755** actions to provide support and resolve issues

We delivered **31** events with **896** attendees

85% of the PWS community think that PWSA UK is responsive.

We have **960** members an increase of 20% from the previous year.

We delivered **37** training sessions for **845** health, education and social care professionals caring for people with PWS.

37 volunteers, **10** trustees and **16** adults with PWS worked with the staff team to deliver our ambitions.

Who we are

PWSA UK is a small charity providing lifelong support to all those affected by Prader-Willi syndrome (PWS). PWS is a rare genetic condition causing an overwhelming and uncontrollable drive to eat that can be life-limiting, as well as learning and physical disabilities. We provide a dedicated helpline, a comprehensive information hub, a regional network of peer support groups with a varied programme of community events, training for professionals working with those with PWS, and support for vital research. Our aim is to help our amazing community overcome the challenges and live life to the full with PWS.

The Association was founded over 40 years ago, by parents of children with PWS, at a time when there was very limited information and support available, and very little understanding of PWS.

As the quality of medical care has evolved, people with PWS today are living longer, and PWSA UK has grown and developed to respond to the changing needs of the PWS community.

Vision

Our vision is to overcome the challenges of PWS.

Mission

Our mission is to ensure that every member of the community has access to high quality care and support, so they can live the healthiest and most fulfilling lives possible.

Our sustained impact goal

We work to support people with PWS to live a healthy and fulfilling life and help their families access the support they so badly need, when and how they need it, whether they are in crisis or not. In short, our aim is to help the PWS community to live life to the fullest.

What we do

We deliver a wide range of activities and services:

Helpline

Available through telephone and email to people with PWS, their families and also professionals.

Advocacy and support

Website with up-to-date information and publications about PWS, its impact and ways to manage its manifestations in various areas of life.

Information hub

Website with up-to-date information and publications about PWS, its impact and ways to manage its manifestations in various areas of life.

Webinars and Information events

Online webinars to share information and provide updates on a range of topics responding to the needs of the PWS community.

Peer support network

A UK-wide network that enables parents and carers of people with PWS to help each other, through meeting online and in-person, as well as interacting with Facebook groups. The network is run with the help of our volunteers.

Community events

A programme of events across the UK throughout the year, including days out and weekends, that provide a safe and relaxed environment for people with PWS and their families to meet other people and have fun.

Training and support for professionals

We train staff working directly with people with PWS and raise awareness of PWS among healthcare professionals to increase understanding.

Supporting research

Collaborating with the Foundation for Prader-Willi Research UK (FPWR UK) we support PWS research by connecting the PWS community with opportunities to participate in medical trials and studies.

Living with PWS

Living with a rare and complex condition like PWS, or supporting someone who does, is difficult and it can be hard to manage life without the right support in place. Challenges people with PWS and their families can face include:

Lack of knowledge and information about the condition

Due to its rarity many people, including healthcare professionals, have never come across someone with PWS before. It is essential that people with PWS, their families and anyone who cares for them understands the complexities of PWS and how to ensure the best possible care and support.

Loneliness and isolation

Due to the lack of understanding of the condition as well as its rarity, many families living with PWS feel isolated and lonely. The need for routine and food management makes it more difficult for families to leave their home and socialise. People with PWS may find it hard to interact with other people and make friends.

Financial Stress

Parents of people with PWS may have to give up work partly or completely so they can support their son/daughter with PWS as well as the additional costs of living with a disability.

Difficulty in accessing services and professional support that fully meet their needs

People with PWS usually need different types of medical care, including endocrinology, dietetics, orthopaedics and physiotherapy, psychiatry and psychology. Families may also need additional support during times of transition (for example, going to school or moving to residential care) to access appropriate support services and funding.

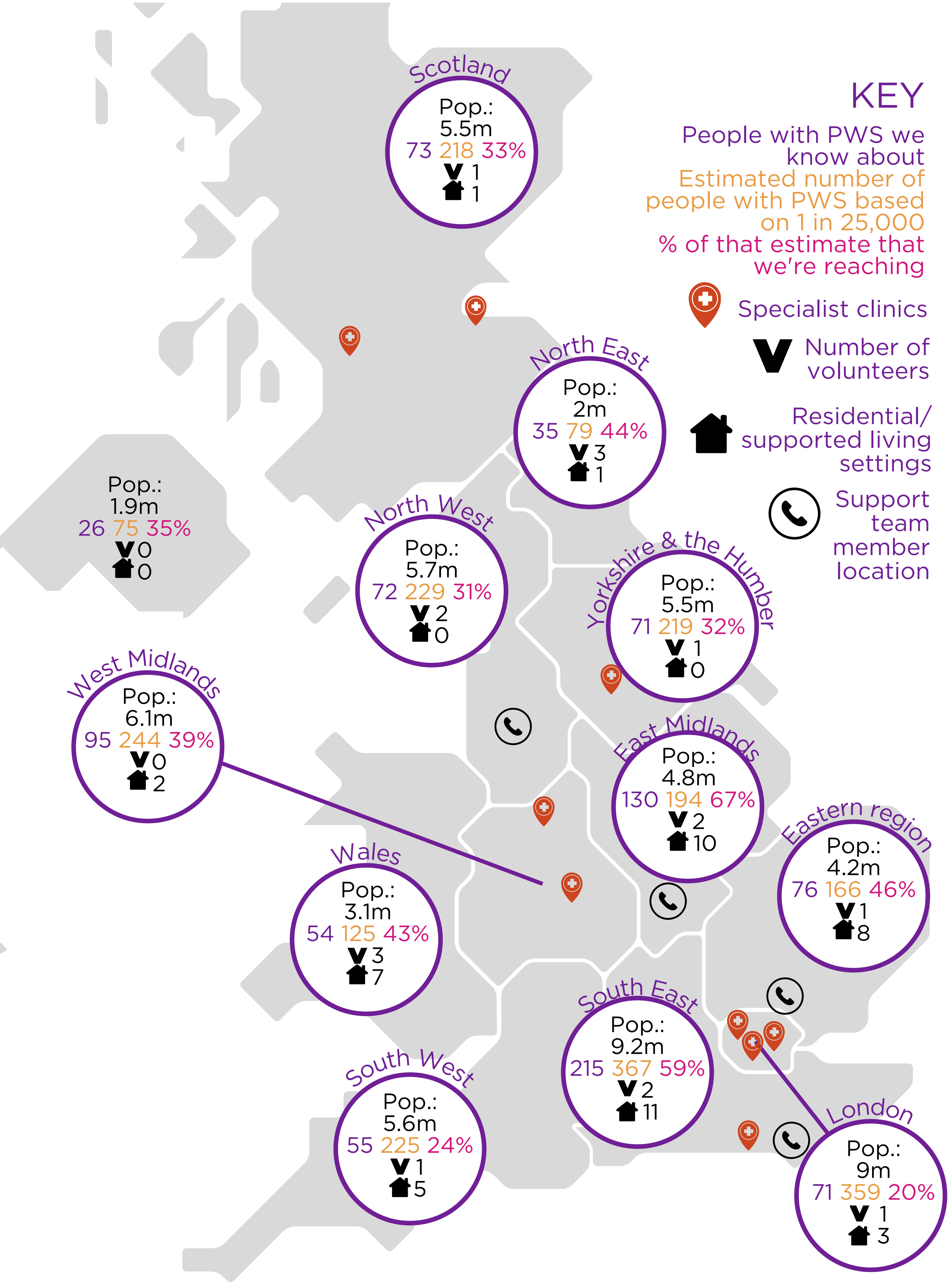
Pressure on wellbeing, relationships and family life

The range of complex needs and changes to daily living impact the lives of those with PWS and their families.

Worrying about the future

Living independently is not possible for many people with PWS. Many adults with PWS need specialist residential care and 24/7 supervision.

Our reach and engagement



Being a membership organisation is vital for PWSA UK to create a strong, supportive community for individuals affected by Prader-Willi Syndrome. Membership helps sustain advocacy efforts, fosters peer support, influences policy and research, and enables participation in the direction of the Association. A committed membership base ensures long-term sustainability, allowing PWSA UK to continue improving the lives of those with PWS.

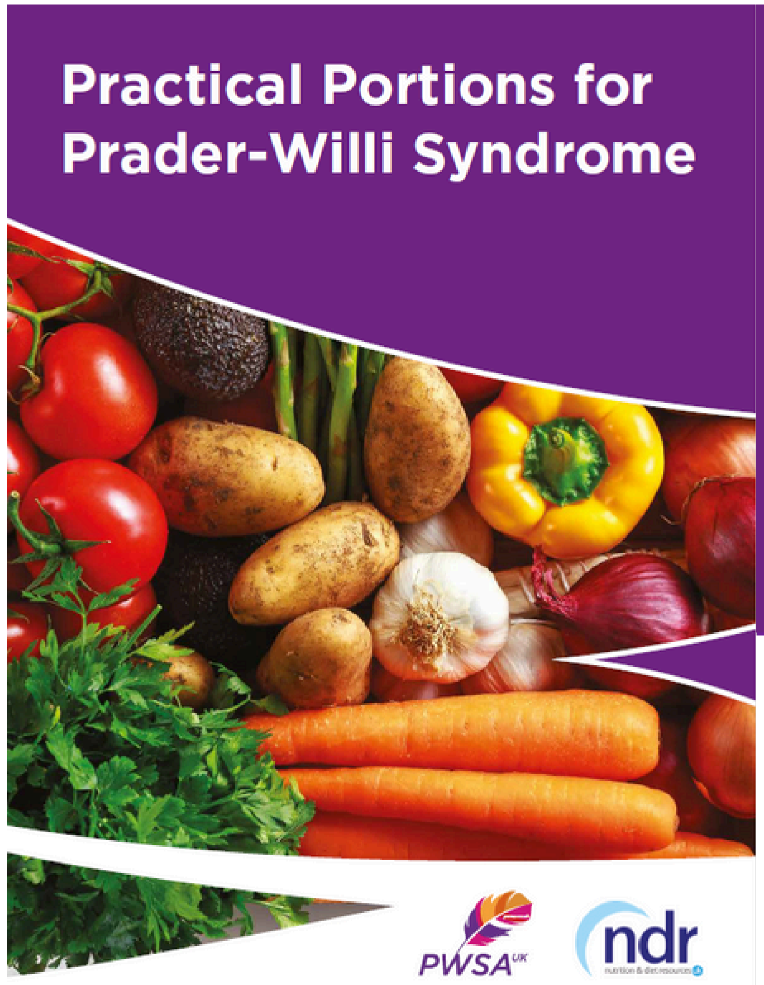
We have grown our membership by 20% during the past year and continue to reach out to more people in the PWS community. Membership is part of the Associations' DNA and relates to one of our 6 strategic aims (To be the Voice of those affected by PWS).

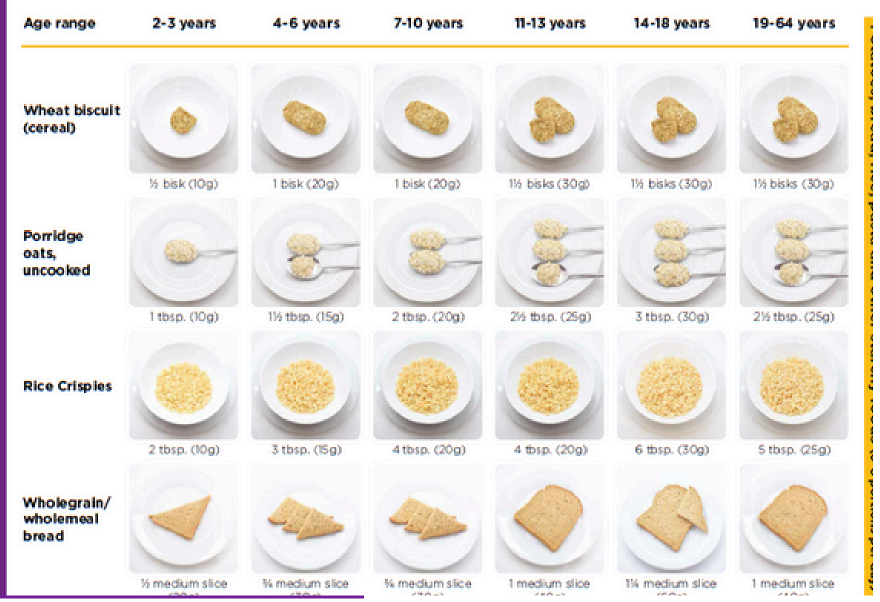
One of our ambitions is to reach out to everyone impacted by PWS across the UK four nations and to reach those isolated by geography, culture, language, financial barriers or other excluding factors.

We are delighted that we have secured funding to appoint a new PWS specialist advisor based in Northern Ireland. Tracey is supporting and connecting families in Northern Ireland.

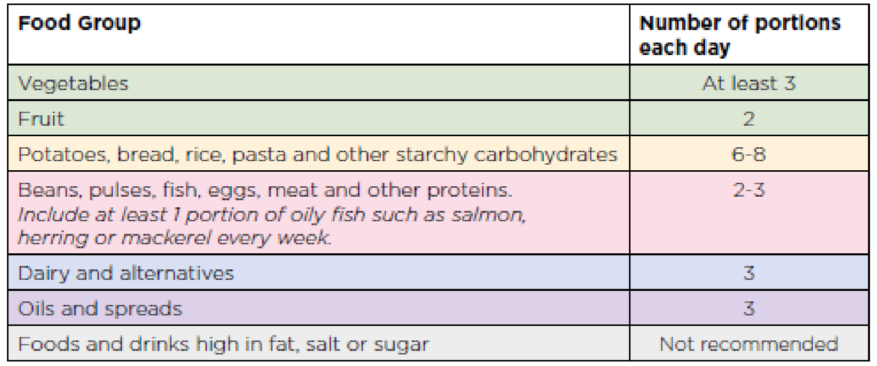
Our first engagement meeting in Northern Ireland

Tracey, PWS Specialist Advisor Northern Ireland


Practical Portions for Prader-Willi Syndrome



Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Wheat biscuit (cereal)	½ bisk (10g)	1 bisk (20g)	1 bisk (20g)	1½ bisks (30g)	1½ bisks (30g)	1½ bisks (30g)
Porridge oats, uncooked	1 tbsp. (10g)	1½ tbsp. (15g)	2 tbsp. (20g)	2½ tbsp. (25g)	3 tbsp. (30g)	2½ tbsp. (25g)
Rice Crispies	2 tbsp. (10g)	3 tbsp. (15g)	4 tbsp. (20g)	4 tbsp. (20g)	6 tbsp. (30g)	5 tbsp. (25g)
Wholegrain/ wholemeal bread	½ medium slice	¾ medium slice	¾ medium slice	1 medium slice	1¼ medium slice	1 medium slice



Food Group	**Number of portions each day**
Vegetables	At least 3
Fruit	2
Potatoes, bread, rice, pasta and other starchy carbohydrates	6-8
Beans, pulses, fish, eggs, meat and other proteins. *Include at least 1 portion of oily fish such as salmon, herring or mackerel every week.*	2-3
Dairy and alternatives	3
Oils and spreads	3
Foods and drinks high in fat, salt or sugar	Not recommended

PRACTICAL PORTIONS

Many families have told us how challenging it can be to judge appropriate portion sizes for children with PWS. In response, we created a national working group of experienced health professionals to help achieve the Practical Portions resource.

This team included two specialist dietitians, a paediatric endocrinologist, a therapy assistant, an endocrinology nurse, and a representative from PWSA UK. Together, we worked in partnership with Nutrition and Diet Resources UK, a charity that creates trusted nutritional materials, to develop a tool for families.

Practical Portions designed to help families understand what suitable portion sizes look like. It includes clear visual examples for 60 common foods across six age groups: 2-3 years, 4-6 years, 7-10 years, 11-13 years, 14-18 years, and 19-64 years.

Importantly, this guide was shaped by the valuable feedback of people living with PWS and their families, ensuring it is both helpful and easy to use.

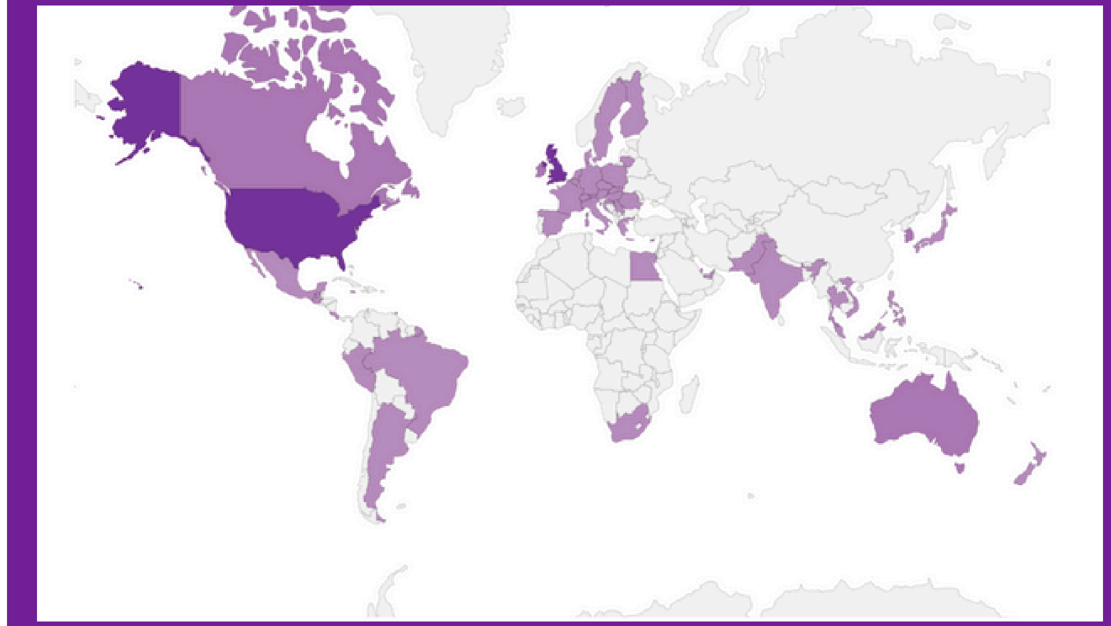
Since publication in October 2024- April 2025

2,105 Copies Ordered **313** Downloads **1,413** Online Reads

> ***This will be a great resource to share with the rest of the family as they never understand quantities that are suitable for our daughter.***
>
> -Parent of young person with PWS

> ***This would help me so I can provide myself with a balanced diet without putting myself at risk.***
>
> -Young adult with PWS

Top 10 countries



UK-	**545**
USA -	**446**
Canada -	**61**
Ireland -	**49**
Australia -	**41**
South Korea -	**38**
France -	**23**
Finland -	**19**
New Zealand -	**19**
Netherlands -	**18**

The difference we make

Our Theory of Change

Our Theory of Change below explains how our activities and services contribute to the positive changes (outcomes) we want to see in the people we support and our longer-term sustained impact goal.

The problem:

Prader-Willi syndrome (PWS) is a rare and complex genetic condition that causes excessive appetite and overeating. People with PWS often have learning disabilities and behavioural problems and it can be hard to manage life without the right support in place. Caring for a child or adult with the condition can have a devastating impact on the whole family, including their stress, mental health and finances. The education, welfare and health and social care system is hard to navigate, which means that families are often unaware of and able to access their rights and entitlements. It is difficult to find the right support, education and residential care setting (which is needed for most adults) that have appropriate behaviour and food management in place.

Who we support:

People with PWS (adults and children), their parents and carers, and the health, social care and education professionals who support them.

Activities

- Training, information & conferences
- Volunteer network and parent network
- Community events and peer support
- Campaigning and influencing
- Advocacy, support and helpline
- Supporting medical and social research
- Working with professionals
- Keeping abreast of relevant legislation and developments

Short Term Outcomes

People affected by PWS and professionals will be better informed about the condition

People with PWS and their parents/carers will feel less alone and be less isolated

Adults with PWS, parents & carers will have more knowledge of their rights and entitlements

Medium Term Outcomes

People with PWS will have increased mental wellbeing

People with PWS and parents/carers will have increased access to support they need

Sustained Impact Goal

People with PWS have a healthy and fulfilling life. Their families are able to access the support they so badly need, when they need it and how they need it, whether in crisis or not.

We asked all those who attended our events and training to complete a survey. We also asked our membership to complete a larger survey in January 2025. All responses informed our evaluation data for this report.

501
Total number of responses

380
Parents/carer survey respondents

20
Adults with PWS survey respondents

101
Health care professionals survey respondents

Thank you for taking the time to complete surveys and feedback to us.

Your feedback is incredibly valuable and plays a vital role in helping us improve and better respond to the needs of our amazing PWS community.

All the survey results and comments are entered into a dynamic impact dashboard that summarises and visually illustrates data from PWSA UK's Monitoring and Evaluation.

We are listening and we are learning.

Over time we will be able to see long-term trends that we need to respond to, helping us be more accountable to our membership.

The rarity and complexity in Prader-Willi Syndrome means that it is not widely understood in society and within the health, education and social care sectors.

Outcome 1:

People affected by PWS will be better informed about the condition

Our online information pages were viewed

24,634 times

in 2024 - 2025

88% of adults with PWS, parents and professionals agree that they are better informed about PWS because of the information and support from PWSA UK.

93% of professionals agree that the training and information provided by PWSA UK is likely to lead to an improvement in care given.

95% of adults with PWS, parents and professionals rate PWSA UK information and training as good or excellent.

> ❝ ***The training provided was so thorough and intensive that we booked further sessions for the whole team. The on-going support and wider network of PWSA is invaluable to the person we support.*** ❞
>
> -Health and social care professional supporting person with PWS

> ❝ ***PWSA UK is brilliant - it has always been an excellent source of information since our child with PWS was a baby. They are a wonderful support team who are friendly & very knowledgeable.*** ❞
>
> -Parent of young person with PWS

People with PWS, their parents and carers tell us that having this condition can be very isolating and lonely.

Outcome 2:

People affected by PWS and their families/ carers will feel less alone and be less isolated

95%

of adults with PWS have made friends through PWSA UK events

71%

of parents/carers agree that they feel less alone or lonely as a result of support from PWSA UK

91%

of people rate the quality of support and activities at PWSA UK as good or excellent

67%

of adults with PWS and parents/carers agree that the events and support from PWSA UK have helped them to be less isolated.

54%

of parents/carers think their son or daughter will be less isolated (up from 48% in 2023)

89%

of people think that training and events are well organised by PWSA UK.

92%

of adults with PWS agree that they feel less alone or lonely as a result of support from PWSA UK

We held our first ever conference for adults with PWS in April 2024. 37 adults with PWS attended a full day of updates, talks, debate and activity.

> ***“You feel supported, you feel less lonely and sad. It makes you feel less isolated and it’s good to chat to others going through very similar situations. We can laugh and feel comfortable together as everyone understands and you don’t feel judged.”***
>
> -Parent of young person with PWS

> ***“Making friends and connections and the chance to be in a community where you are not an outsider or someone that has to explain why you are the way you are!”***
>
> -Adult with PWS

People with PWS and their families aren't always aware of the much-needed financial support they are entitled to due to their condition. Families tell us that they often face challenges accessing appropriate education, health, residential and social care for their family member with PWS.

Outcome 3:

Adults with PWS, parents and carers will have more knowledge of their rights and entitlements

> ***Just knowing that there are other families going through the same things, especially when first diagnosed. Support letters for the endless forms has been brilliant.***
>
> -Parent of young person with PWS

> ***Advocacy, support, like minded experts who walk the walk and champion the rights of families and children who have pws. Knowing I'm not alone when surrounded by individuals who lack understanding and empathy on the complexities of the syndrome.***
>
> -Parent of young person with PWS

86%	of adults with PWS and their parent/ carers think PWSA UK has helped them to understand and access their rights and entitlements.
73%	of parents/ carers have a better understanding of their son/ daughter's rights about their education and care.
60%	of parents/ carers have a better understanding of their entitlements to financial support.

We provide practical assistance in applying for benefits – with form filling, collecting supporting evidence and supporting families through the appeal process, if needed.

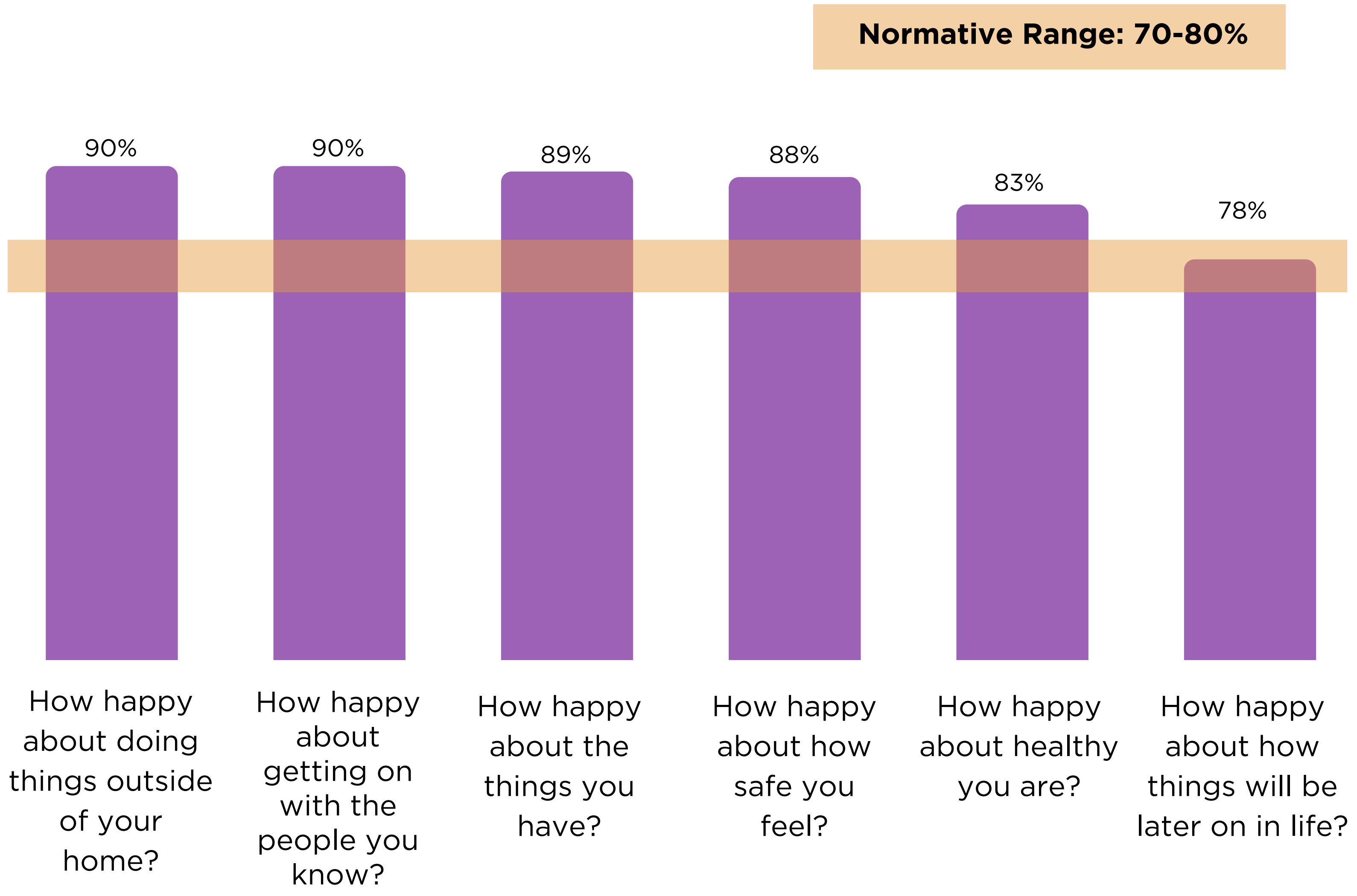
We also advocate for families who are facing difficulties accessing appropriate education, residential and social care. We attend meetings, write supporting letters, provide evidence, talk to social workers, care homes, local authorities and help families to challenge and get the care and support that they need.

We know that people with Prader-Willi Syndrome experience low mental wellbeing because it is a lifelong condition that poses many challenges and affects their quality of life.

Outcome 4:

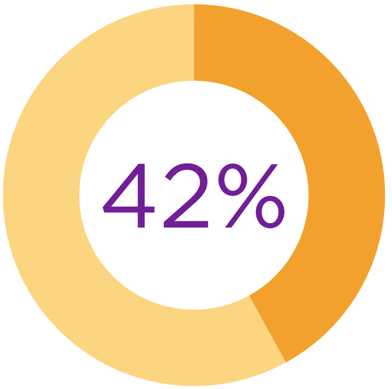
People affected by PWS will have increased mental well being

Personal Wellbeing Index of Adults with PWS Surveyed

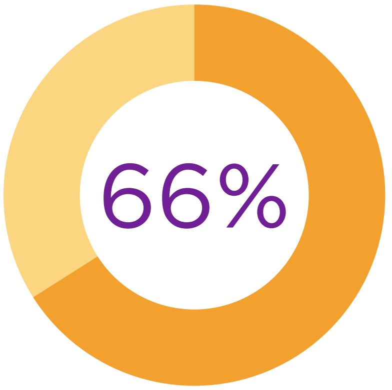


(18 survey respondents)

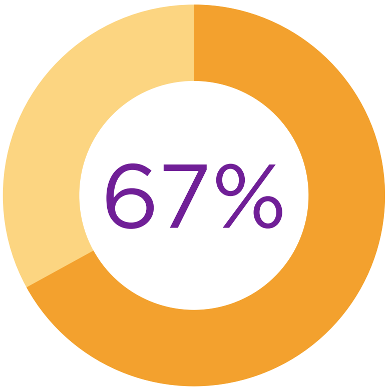
of parents/carers agree that their child feels/will feel happier as a result of PWSA UK



of parents/carers agree that their son/daughter will feel/feels less anxious as a result of PWSA UK



of parents agree that PWSA UK has helped them to manage their son's or daughter's behaviour



of parents/carers agree that they are better able to mange their worries as a result of PWSA UK

> ***“It stops you from being isolated. PWS is like a 'disability within disability'. It feels like you can never switch off. To be around other people who just 'get it' about what you are going through is fantastic.”***
>
> -Adult with PWS

> ***“Knowing I'm not alone when surrounded by individuals who lack understanding and empathy on the complexities of the syndrome.”***
>
> -Parent of young person with PWS

Children and adults with PWS face challenges that require extra support from professionals in the education, health and social care sectors. Professionals don't always have the necessary understanding of PWS to meet the specific needs of people with this syndrome.

Outcome 5:

People with PWS and parents/carers will have increased access to the support they need.

63%

of parents/carers agree that PWSA UK has helped them to access better support. services or benefits from external organisations

62%

of parents/carers agree that their son or daughter with PWS is in a setting that meets their needs.

> ***Just having access to professionals is so enlightening. Such good advice and things explained so well. Having professional PWSA input was vital and much appreciated. Really affected outcome of situation. Thank you PWSA!***

-Parent of young person with PWS

> ***Advocacy, support, like minded experts who walk the walk and champion the rights of families and children who have pws.***

-Parent of young person with PWS

PWS Stronger Together

PWS
STRONGER
TOGETHER
A PARTNERSHIP
FPWR.ORG.UK & PWSA.CO.UK

PWS Stronger Together is a collaboration between the two charities: The Foundation for Prader-Willi Research UK and Prader-Willi Syndrome Association UK. United in our mission to push research and development forward, driving positive change for the PWS community in the UK and beyond. While both organisations maintain independent operations, they join forces for this initiative.

We know that by working together our two organisations will be able to achieve more. We want to ensure the effective use of limited resources to further knowledge and understanding of PWS and support all those impacted by PWS in the UK.

Throughout May 2024 we jointly promoted awareness of PWS, raising funds for ageing research and finished with buildings lighting up in orange to shine a light on PWS.

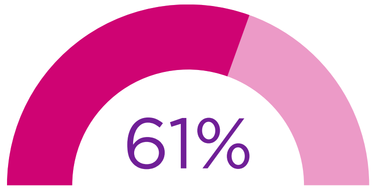
We jointly held three webinars to update on PWS clinical trials and research.

https://www.pwsstrongertogether.co.uk/

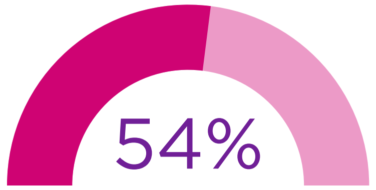
We haven’t got it all right

The Monitoring and Evaluation report highlights where we are making a difference but also where we need to improve and develop our services.

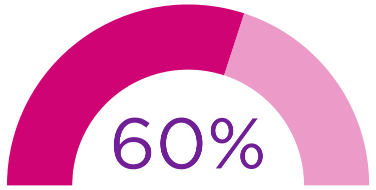
We need to improve how we help families better understand financial entitlements.



Only 61% of parents/carers feel they have accessed better support, services or benefits from external organisations.



Only 54% of parents/carers think their son or daughter will be less isolated.



Only 60% of parents/carers have a better understanding of their entitlements to financial support.

- We need to improve how we help families access better support, services or benefits from external agencies.
- We need to continue to increase our geographical reach and in particular supporting families in Scotland.
- We need to continue to seek ways to support adults with PWS.
- We need to help young people with PWS feel less isolated.
- We need to help parents and carers understand their entitlements to financial support.

We are thankful for your feedback and we are listening!

Plans for the Future

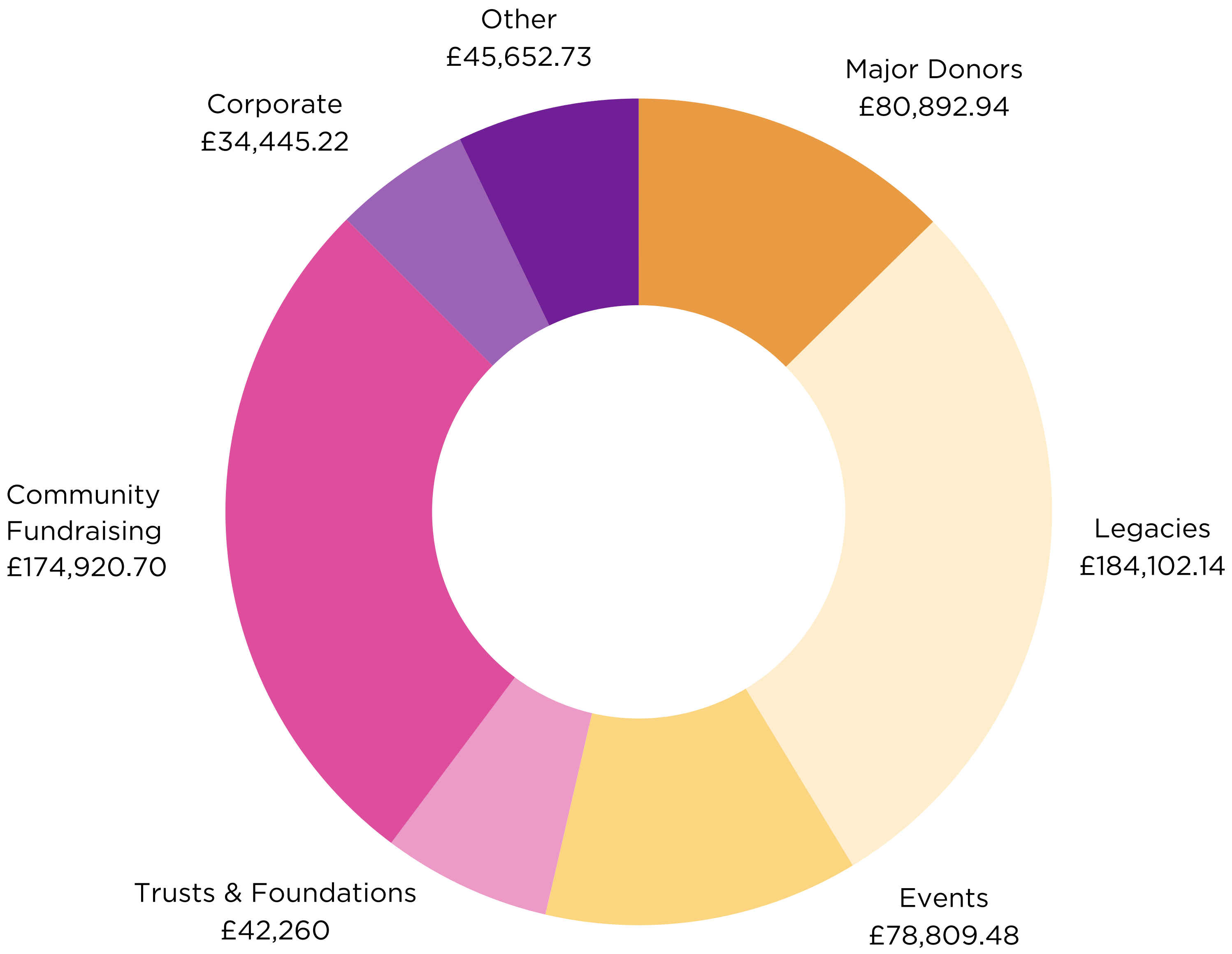
- Research and develop resources and support for behaviour and mental health for people with PWS.
- Develop information for adults and parents of adults supporting transition to adulthood.
- Deliver training for adults to helping young people with PWS to build social skills.
- Review and increase our training capacity to improve the care and support provided to people with PWS.
- Continue to develop the services and support we provide for adults with PWS.
- Growing our presence to reach all areas of the UK and partnering with PWS specialist clinics.
- Improving our support to families through key transition stages in the life of their family member with PWS.
- Increasing opportunities for peer support and establishing support for parents of older adults with PWS and those with different subtypes.
- To be a stronger voice for the PWS community and to influence systemic change and improve support and service delivery.
- Increasing our support to people with PWS living in residential settings and working with service providers to raise standards in these homes.

How we are funded

Our work is funded with huge thanks to the tremendous fundraising efforts of our members as well as income from Trusts and Foundations. We are immensely grateful for the ongoing support of all the PWS community and all our funders.

PWSA UK does not receive any funding from the government or other statutory sources.

Where our income comes from



Total income in 2024-2025
£649,899.37

We want to thank all of you – we simply could not do it without you!

The generous participation of all the people who completed the surveys – a special and heartfelt thank you for your time and contribution to demonstrating the impact of PWSA UK's work and helping us understand how we can improve.

The trust placed in us by all the children, young people and adults with PWS we work with, as well as their families – we are privileged to be a part of their lives.

The vision and determination of the founders of the Association – you inspire our work every day.

The support and funding from all of the people who have backed PWSA UK's work over the years.

The unwavering work of PWSA UK's amazing staff team, in supporting the PWS community.

The commitment of our Board of Trustees and our volunteers.

The collaboration of all the health, social care and education professionals that we have trained and supported throughout the years.

The work of our evaluators, Insley Consulting

INSLEY
CONSULTING

PWSA UK
PRADER-WILLI SYNDROME
ASSOCIATION UK

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