PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK

Impact Report
2025 – 2026

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.

Introduction from the Chief Executive

I am pleased to introduce our latest Impact Report for 2025-26. This is our third report and reflects the commitment, compassion and determination that runs through our organisation and the community we serve. Most importantly the report highlights the difference we have made to the lives of people with Prader-Willi syndrome (PWS) and their families.

Our impact this year is guided by three core objectives: reaching more people, advocating for families, and training professionals who care for people with Prader-Willi syndrome. By expanding access to trusted support, amplifying the voices of families, and sharing specialist knowledge with those working in health, education and care settings, we continue to improve understanding, confidence and outcomes for people with PWS across the UK.

This report highlights the tangible impact of our work: from providing expert advice and emotional support at critical moments, to offering training that increases understanding of PWS in education, health and care settings, and to amplifying the voice of our community at a national level. None of this impact would be possible without the trust of families, the dedication of our staff and volunteers, and the generosity of our supporters and partners.

As we look to the future, we remain committed to ensuring that every person with PWS has the opportunity to thrive.

Jackie Lodge
Chief Executive, PWSA UK

Our vision is to overcome the challenges of PWS. **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.

PWSA UK in Numbers 2025 – 2026

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

In total **1141** people accessed our services

As a result, we took **2252** actions to provide support and resolve issues

We delivered **28** events with **596** attendees

We delivered **41** training sessions for **539** health, education and social care professionals caring for people with PWS.

34 volunteers, **12** trustees and **16** adults with PWS worked with the staff team to deliver our ambitions.

81%

of the PWS community think that PWSA UK is responsive.

98%

of the PWS community think that PWSA UK is well organised.

> ***When we desperately needed some support, after years of advocating for our son without it, PWSA UK stepped up and provided the boost we needed to keep going.***
>
> - Parent of young person with PWS

> ***We meet up with other parents and carers so we can learn new ways of living together with people who have PWS. Just being in an environment filled with people that understand what you are experiencing is priceless.***
>
> - Parent of young person with PWS

> ***The training gave me a wider knowledge of the impact and characteristics of PWS and tips on how best to support individuals with PWS considering the impact of the syndrome on their daily life, their routine and their relationships.***
>
> - Professional caring for a person with PWS

> ***The level of expertise in the Association is incredible. Even before we are put through to the support team, the lady (or ladies) who answer the phone are friendly, reassuring and have a lot of knowledge.***
>
> - Parent of young person with PWS





Who we are and what we do

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 little information and understanding of PWS and very little support.

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.

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.

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.

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.

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.

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.

Advocacy and support

From supporting people with PWS and their families from helping to fill out benefit claims and attending meetings with professionals on families' behalf, all the way to assisting with behavioural issues and supporting a move into residential care.

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.

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.

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.

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.

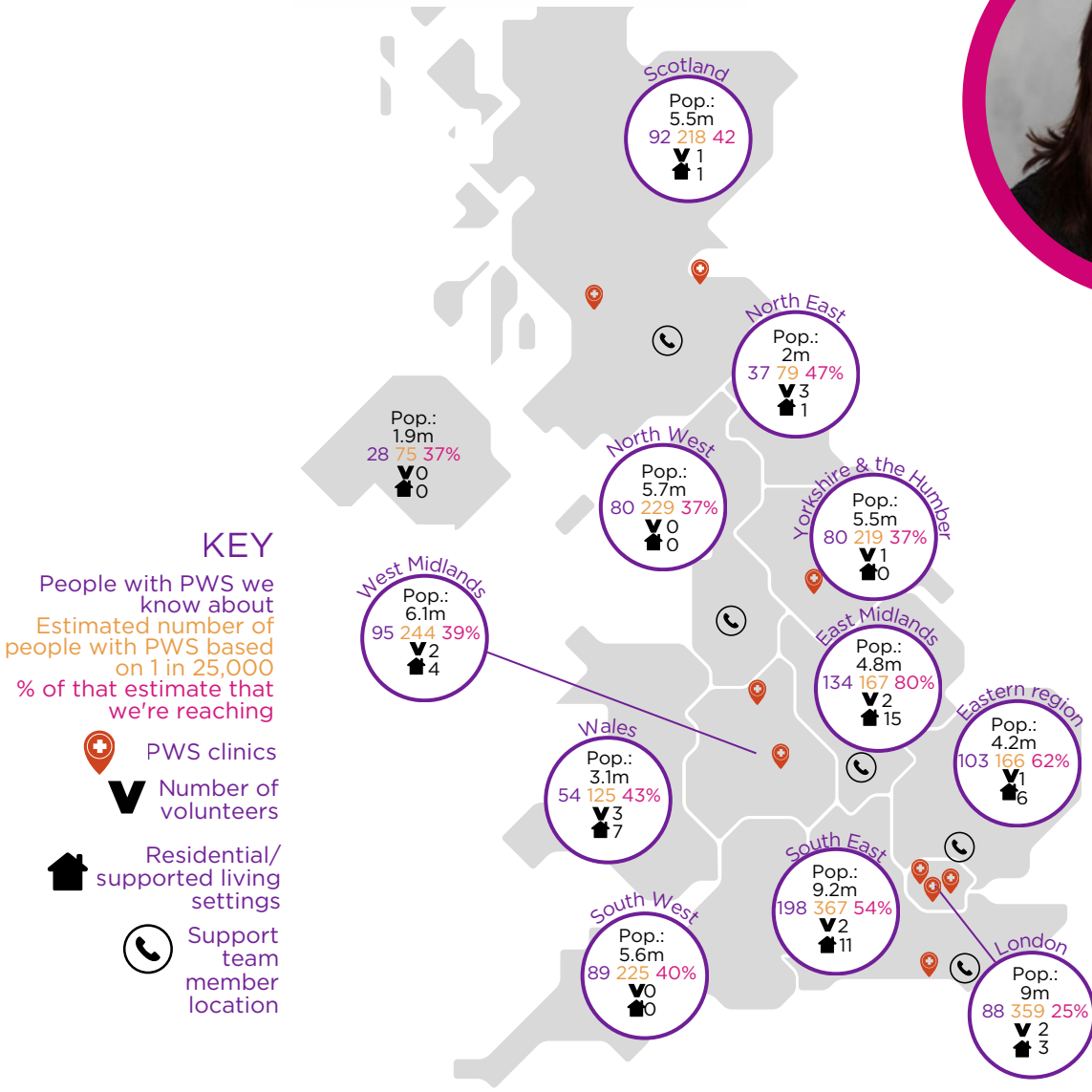
Over the past three years we have increased our reach to more PWS families by over 20% and are now in touch with over 1,000 people with PWS.

We are committed to improving our reach across diverse communities. Since introducing monitoring in 2023 and enhancing outreach efforts, we have seen an encouraging increase in representation from non-White British individuals, rising from 7.4% to 11.9%.

Building a strong, supportive community for people affected by Prader-Willi syndrome is vital to PWSA UK. Outreach and engagement strengthen advocacy, encourage peer support, inform policy and research, and help shape the future direction of the Association. We are also taking a more proactive approach to engagement, tailoring our updates and information to families at different stages of their PWS journey.

Last year we reported on the appointment of a support worker in Northern Ireland. Over the past year the number of PWS families we have contact with has increased from 21 to 36.

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



The difference we make

Our Theory for 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 unable 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
- Community events and peer support
- Advocacy, support and helpline
- Working with professionals
- Volunteer network and parent network
- Campaigning and influencing
- Supporting medical and social research
- 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.

Your voice matters, and we're grateful for your continued engagement and support.

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 February 2026. All responses informed our evaluation data for this report.

335
Total number of responses

274
Parents/carer survey respondents

10
Adults with PWS survey respondents

51
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.

This is our third Impact report, and we are starting to see trends over time, helping us to be increasingly responsive and accountable to the UK PWS community.

The rarity and complexity and 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
74,963 times
with
36,144 visits
in 2025 - 2026

91% of adults with PWS, parents and professionals agree that they are better informed about PWS because of the information and support from PWSA UK.

95% of professionals agree that the training and information provided by PWSA UK is likely to lead to an improvement in care given.

99% of adults with PWS, parents and professionals rate PWSA UK information and training as good or excellent.

"The PWSA has been a constant in our lives since birth. Our lives would have been very different without the PWSA. I'm only thankful that you have been there and are so readily available. Staff have been wonderful, and are really understanding and knowledgeable."

- Parent of young person with PWS

PWSA UK works to raise awareness and understanding of PWS with the ultimate goal of improving services and support for people with PWS.

42 Between April 2025 and March 2026, PWSA UK recorded 42 advocacy engagements, primarily through one-to-one meetings. Activity focused on disability organisations, government bodies, care providers, and healthcare stakeholders. Outcomes show strong relationship-building, with frequent follow-ups, growing awareness of PWSA UK's work, and increasing interest in collaboration and policy discussions.

Highlights of 2025 - 2026

House of Lords

In May 2025, we hosted an event for policymakers at the House of Lords to raise awareness of three key challenges faced by people with PWS:

- Hyperphagia - the persistent insatiable hunger people with PWS feel and the implications this has for support needs and mental capacity.
- The absence of warning signs in a medical emergency - how serious injury and illness can be missed in people with PWS.
- The need for specialist support for people with PWS across all areas of life.

www.pwsa.co.uk/Campaigns

The event was well attended by MPs, peers, NHS managers, health and social care professionals, and families affected by PWS. Since then, we have continued to progress our key campaign priorities in several areas. We are working with NHS England to explore a digital flag for people with PWS to help improve access to services, while also raising awareness that people with PWS may not show the usual warning signs in a medical emergency.

P *Persistent Hunger*

W *Warning Signs Absent*

S *Specialist Support Needed*

Mental Capacity

The Mental Capacity Act (MCA) protects adults' rights to make decisions. However, in the case of people with PWS, the application of the MCA, particularly around decisions about food or the use of money, can be a challenge. Over the past year we have developed key information and a toolkit to help assessors to understand PWS and how this needs to be considered when supporting a person with PWS.

www.pwsa.co.uk/mental-capacity-hub

Highlights of 2025 - 2026

BOSS Course

We ran the first BOSS (Building Our Social Skills) course which is a structured programme designed to give people with PWS tools to handle emotional and communication challenges. The curriculum helps people with PWS build skills to read facial expressions, tone of voice, and nonverbal cues. It can also help people try out problem-solving strategies, make new friends in the group and in real-world settings, and focus on what they can do better.

Our graduates had some brilliant feedback about how the course has helped them:

> ***What helped me most is learning about other people's emotions and learning how to cope when things get tough for me.***

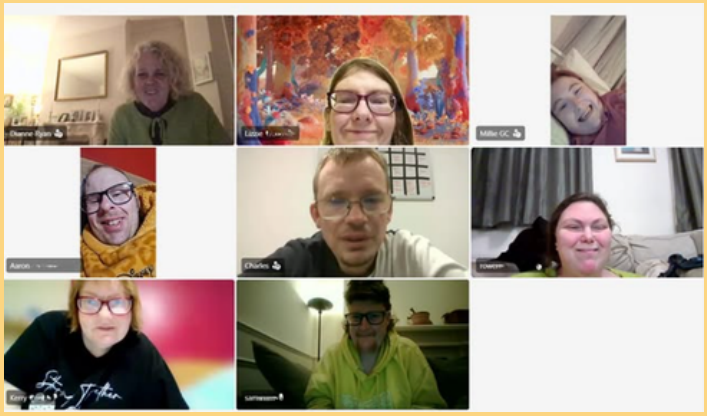
> ***A couple of things has helped me the most in the course and that is putting my point across to make myself heard, and helped me to try and relax and calm me down.***

> ***I feel most proud of myself for communicating clearly for help with what I needed.***

The BOSS course was developed by PWS specialists at Vanderbilt University in the US, funded by the Foundation for Prader-Will Research UK and the Foundation for Prader-Will Research in Canada, then delivered for the first time in the UK by staff and a volunteer here at PWSA UK! We're really proud to have been part of this collaborative effort.

Catherine Shaw, Chair of FPWR UK says:

"It's fantastic to see FPWR UK–funded research coming full circle through the BOSS programme, now making a meaningful difference in people's everyday lives. This shows how collaboration between research and support organisations can translate into real, tangible outcomes for the PWS community."



The difference we make

Reducing loneliness and isolation

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.

PWSA UK tackles loneliness and isolation by creating strong community connections, opportunities to share lived experiences, peer support, and specialist social events for people with Prader-Willi syndrome (PWS) and their families

92%

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

100%

of adults with PWS who attended a PWSA UK event said they had made friends as a result

73%

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

64%

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

52%

of parents/carers think their son or daughter will be less isolated

89%

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

98%

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

> ***"It has provided me with opportunity to connect with people I know who have PWS. I also made 2 new friends with PWS and shared contact details to stay in touch. So, I was very happy about that."***
>
> - Adult with PWS

> ***"I joined online groups with other parents/carers of children with PWS. PWSA told me about these groups which made me feel that I wasn't alone."***
>
> - parent of a young person with PWS

> ***"It helps me understand my PWS and I'm not alone and to speak and make friends who experiences the same condition as me. Also help other families that they're not alone."***
>
> - Adult with PWS

> ***"We feel less alone, we share ideas, we get to know other families, we feel part of a community."***
>
> - parent of a young person with PWS

The difference we make

Knowledge rights and entitlements

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

> ***"We feel less alone, we share ideas, we get to know other families, we feel part of a community."***
>
> - parent of a young person with PWS

88%	of parents/ carers have a better understanding of their son/ daughter's rights about their education and care.
100%	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 challenge decisions and get the care and support that they need.

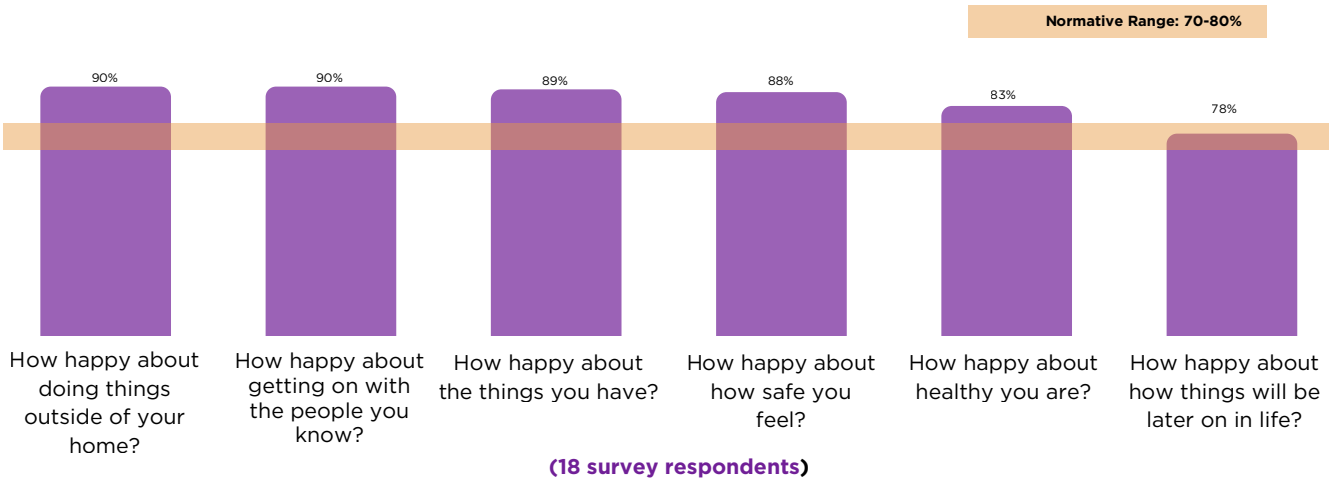
We know that people with Prader-Willi Syndrome experience low mental wellbeing because it is a life long condition that poses many challenges and affects their quality of life.

Outcome 4:

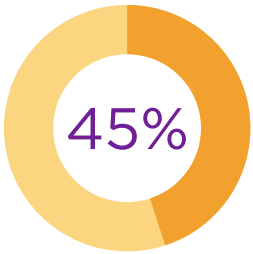
People affected by PWS will have increased mental wellbeing.

> ***"Without PWSA I am really unsure how we could have continued to cope as a family."***
>
> - parent of a young person with PWS

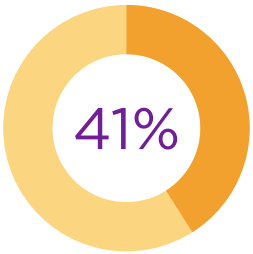
Personal Wellbeing Index of Adults with PWS Surveyed



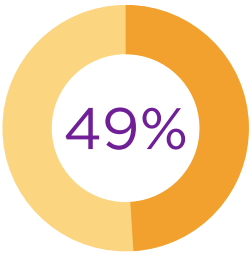
(18 survey respondents)



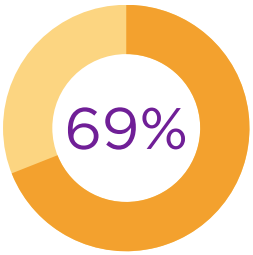
of parents/carers agree that their child feels/will feel happier as a result of PWSA UK



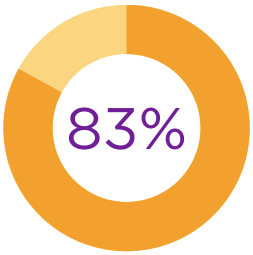
of parents/carers agree that their son/daughter will feel/feels less anxious as a result of PWSA UK.



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



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



of adults with PWS who feel happy with their life as a whole

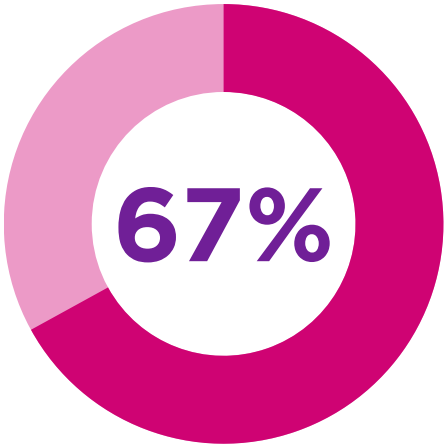
> ***"PWSA UK made my life so much easier when I was at my lowest point. When I rang up desperate for advice on how to deal with my child's mental health problems, I was taken seriously and never once patronised or pushed aside which is something that I will always remember."***
>
> - Parent of young 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.

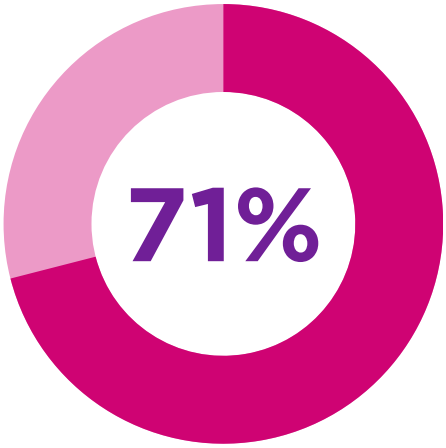
Outcome 5:

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

> ***Provided support with EHCP which has been invaluable.***
>
> - Parent of young person with PWS



of parents agree that PWSA UK has helped them to access better support. Services or benefits from external organisations (up from 63% in previous year)



of parents/ carers agree that their son or daughter with PWS is in a setting that meets their needs. (up from 59% in previous year)

> ***I was given support and advice on how to fill out PIP firms. A PWSA support worker read my application and helped to word some answers better. I feel I need PWSA especially at my son's milestones.***
>
> - Parent of young person with PWS

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

PWS Stronger Together

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.

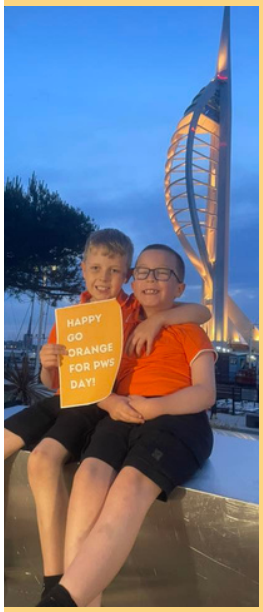
Rare conditions are little understood and often underfunded both in terms of support services and research to find effective medication and treatment. Support for research, translating research into practice and supporting families with each step of the PWS journey requires joined-up thinking and effective use of limited resources.

Throughout May 2025 we jointly promoted awareness of PWS, raising funds for ageing research, going orange and jointly hosting the awareness event in the House of Lords.

We continue to collaborate to promote understanding and engagement in research and clinical trials.

www.pwsstrongertogether.co.uk/trials





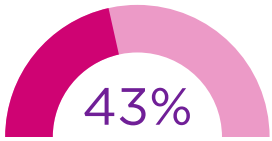




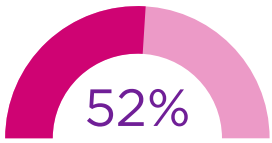
We haven't got it all right

Our monitoring and evaluation findings show where PWSA UK is making a strong difference, and also where we need to keep learning, improving, and developing our services.

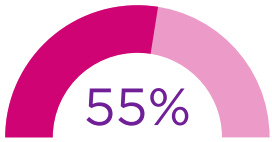
The areas with the lowest scores (below 60%) show where some parents feel we are not yet making enough difference for their child with PWS. These findings help us identify where further support and improvement are needed.



Only 43% of parents said their child feels, or is likely to feel, less anxious as a result of support from PWSA UK.



Only 52% of parents said their child feels, or is likely to feel, happier as a result of support from PWSA UK.



Only 55% of parents said their child feels, or is likely to feel, less isolated because of PWSA UK.

In previous years, the PWS community have told us that we need to increase our geographical reach and in particular supporting families in Scotland.

We have listened and now have an in-country support worker to respond to the specific needs of PWS families in Scotland.

The PWS community also told us that we need to find ways to support adults with PWS.

We have listened and have increased our support for adults through targeted information and resources, support and training for residential care settings and putting the OWL group at the heart of the organisation.

During 2026 and 2027 we will be reviewing our strategic plans and will be learning more about changing needs of the PWS community and how we can best develop our support services over the coming years. If you want to share your thoughts on the future of PWSA UK, please do email the CEO at jlodge@pwsa.co.uk

We are thankful for your feedback and we are listening!

Plans for the Future

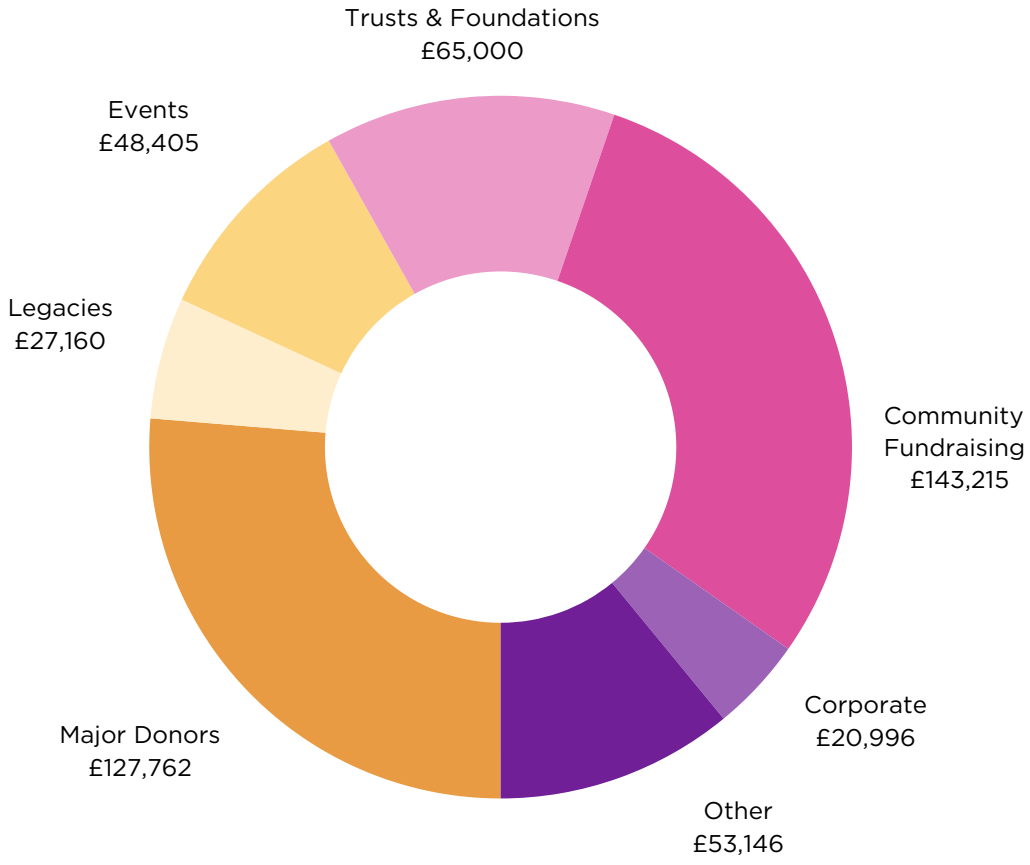
- Strengthen PWSA UK as the leading knowledge and information hub through high quality, accessible information, resources and a strong digital presence.
- Expand reach to more people affected by PWS, focusing on earlier engagement, underrepresented groups, and all four nations of the UK.
- Provide high quality support, advice and casework to individuals with PWS and their families, including peer support and community events.
- Advocate for families and individuals with PWS, amplifying lived experience to influence policy, practice and standards of care.
- Train and engage professionals caring for people with PWS, increasing understanding and confidence across health, education and social care.
- Develop and implement the Learning Management System (LMS) to improve access, quality and consistency of professional training.
- Promote and embed consistent standards of care, including through professional networks, care homes and statutory services.
- Increase awareness of Prader-Willi syndrome, including delivery of Awareness Month and targeted campaigns.
- Support and promote research into PWS, including deaths, ageing, late diagnosis and participation in clinical studies.
- Ensure the long-term sustainability of the charity, through strong governance, effective systems, diversified income and support for staff and volunteers.

How we are funded

Our work is funded with huge thanks to the tremendous fundraising efforts of our members as well as income from trust 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 2025-2026

£485,683.10

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

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