

ScotPEN Wellcome Engagement Award

Reporting Template

This form, including relevant appendices, must be submitted electronically as a single PDF file upon completion of your project and in any case **no later than 8 weeks from the end date**.

Please send to: scotpen-wellcome-engagement-award@glasgow.ac.uk

Please note, this information will be shared with external evaluation consultants who have been commissioned by SWEA and Wellcome, and will be used for the purposes of evaluating this grants scheme. The data gathered is extremely valuable in understanding the value, outcomes and impacts of this scheme as a whole; what improvements need to be made; and will help to inform how Wellcome PE Enrichment grants are supported and awarded in the future.



1. Project Information

Project lead: Name and position	David Tollervey
Project title	Prader Willi Superheroes
Start date	01/06/21
End date	01/03/23
Total funding awarded	£56,720

Project summary

Please refer to the summary originally provided in your application and modify it if appropriate. (Summary for external publication; maximum 250 words).

Researchers from the Tollervey Lab worked with individuals with Prader-Willi syndrome (PWS), along with family members and carers, to co-create artworks which represent their experiences of living with PWS and their understandings of how biomedical research could influence their future experiences.

Researchers met with people with PWS, along with their families and carers, to chat, complete puzzles and create simple artworks together. Artists took inspiration from the resulting conversations, stories, drawings, and models to create comic strips and dioramas which detail the experience of living with PWS, the challenges, but also the 'superhero' attributes and skills that can come with the condition. Researchers were also represented in the artworks, outlining the challenges they face in working with RNA and the potential power of future discoveries.

All the resulting artworks were exhibited at the 2022 IPWSO conference, alongside workshops which encouraged attendees to use art as a vehicle to tell their own stories. The artworks are available as part of an online exhibition and will continue to be made available in other locations such the British-Interactive-Group conference (Belfast, 2022), Malta Science Festival (2023) and Glasgow Science Centre community space (2023)

We believe that the overarching aims of the project were met. These were: -empowering families to better access and understand research relevant to PWS and to have a voice about their experiences of living with the condition, increasing public awareness of PWS through engaging artworks, and building researcher appreciation of how their work connects to people's lived experience of a genetic condition.

2. Inputs

What resources were used in the development and delivery of the project?

For example: funding including any additional/partnership funding; in-kind support; key staff involved; partners – internal or external; training/support received.

The International Prader Willi Syndrome Organisation acted as project advisors – checking interview questions, reviewing comic book content, and connecting us with international families. They provided discounted conference rate (approximately half price) and provided space and facilities (tables, chairs etc.) for the exhibition display and running the workshops in Limerick.

Prader Willi Syndrome Association – UK, also acted as project advisors, reviewing content, and connecting us with families in the UK.

Clare House (residential home for people with PWS in Dunblane, Scotland) allowed us to have unrestricted access to their home, residents, and staff.

3. Outputs

- (i) **Audiences and partners.** What individuals/ public groups were involved? (e.g. young people; adults; families; schools; community groups; local residents; patient groups etc.). Please also include any demographic data collected (e.g. age; gender etc.).

Clare House

We collaborated with 11 adults (7 male, 4 females) with PWS during the project, and 5 of their carers (2 male, 3 female), visiting them at their beautiful home in Dunblane on four occasions. Unfortunately, we were unable to collaborate with family members of the residents as per the original project plans. **Total of 16 adults.**

Families

We collaborated with 6 families from across 4 continents and 6 different countries (Australia, Egypt, the Dominican Republic, Greece, England, and Republic of Ireland).

In all cases we had video calls with the family member with PWS (3 female and 3 males) and various members of their family (total of 10 family members, 9 females, 1 male).

At the IPWSO conference, we met a young adult with PWS, also from Ireland, who asked to also be part of the comic. She had an inspiring story we wanted share and so she was included, without her family members.

Artists – Four artists worked on this project. One comic book artist, one model maker, one photographer (who photographed the exhibition and created the online exhibition for us) and one poet (who was on an internship with us at the centre) **Total of 4 adults (2 male, 2 female)**

Totals

10 family members, all adults, 9 female and 1 male

5 professional carers – 2 male and 3 female
13 adults with PWS – 7 male and 6 female
65 children with PWS (ages 10-17), 3 male and 2 female
3 artists (2 male, 1 female)
7 countries, across 4 continents

- (ii) **Activities.** Please indicate the types and numbers of activities or events delivered and/ or resources produced (e.g. festival; exhibition; workshop; walking tour; video; publication; online resource).

Clare House Collaborative workshop visits

Researchers and artists visited Clare House on four occasions.

On the first occasion we got to know residents and staff, completing puzzles together. The puzzles which had a mix of science and superhero themes were donated to Clare House after this visit.

On the second visit, we all drew and created artwork together whilst chatting. Comic artist Neil Bratchpiece took requests, drawing items for those who preferred to colour in. These drawings

On the third visit, we used modelling clay to make more artwork together. Residents chose to keep some artworks and donate others to the exhibition. Residents invited us to visit their rooms to see the things that were important to them – football, movies, crystal artworks and more.

As the visits progressed and trust was built, residents felt more confident to talk about their experience of the condition, the challenges they faced, their strengths and abilities and their lives more generally. Residents asked researchers about their jobs and their lives and staff asked about the centre's research and how it links to PWS.

PWS family virtual discussion sessions

We held a series of online video calls with families from around the world who have a family member with PWS. For all calls the comic book artist was present along with at least one researcher. Thanks to the language skills of our researchers, all calls were made in the first language of the family. During the calls we learnt about the families experience of living with PWS and they were given the opportunity to ask about centre research and how it links to PWS. Researchers had created a simple PPT to show to families but in the end, this was not required as the families preferred just to ask questions of most interest to them.

Comic strips, 3D models, and exhibition

Based on the insights obtained during the calls and sessions at Clare House, Neil Bratchpiece prepared comic strips exploring the life experiences of people with PWS and their care givers. Jo Fullerton then prepared a set of related dioramas.

IPWSO conference

Researchers from WCB, public engagement staff and Neil Bratchpiece then presented frames from the comic strips and the dioramas as an exhibition hosted by the International Prader-Willi Syndrome Organisation conference (University of Limerick; July 6-10, 2022). The artwork was subsequently displayed at the British Interactive Group conference in Belfast (13-14 July).

At the PWS family element of the conference, people with PWS and their family members, including siblings, were invited to view the exhibition and to make their own models to either take home, or add into the exhibition.

Exhibition display

The finished exhibition and comic strips were taken to Clare House, where it was greatly appreciated by the residents who had helped collaborate on it. They were delighted to see themselves in the comic and meet their model forms.

The online exhibition and supporting comic – Prader Willi Superheroes- are available online. We anticipate that the artwork will be displayed in further venues this year including at the Malta Science Festival.

4. Evaluation

What evaluation method(s) did you use to gather evidence and indicators of outcomes and impacts?

Members of the Tollervey Lab, and the three artists, were interviewed about their experience taking part in the project.

On being sent the comic strips, participating PWS families and carers, were asked to respond by email and share with us their experience being part of the project. The overwhelming response from families was that their young people with PWS felt important as a result of being part of the project, they were happy to be able to share their stories and delighted to see themselves in comic/model form.

Conference attendees interacting with the exhibition were surveyed with paper copies of the evaluation form available and QR codes leading to a digital version of the survey. 64% found the exhibition very informative, 92% found it engaging and 93% believed it should be shared with the wider public. A number of recommendations were made about where the exhibition should be shared in future and one suggestion we are investigating is in schools where one or more of the students have PWS.

At the IPWSO family workshops, children with PWS and their siblings, were surveyed using stickers, which they could fix to a poster with columns, asking them to rate their enjoyment of the PWS exhibition and workshops. Their adult family members were directed to the online survey. Photo of this evaluation method output is included in the attachments.

5. Outcomes/Impact

What happened as a result of the project? How many people did you reach/engage? Please refer to the intended outcomes provided in your Application. Please highlight whether these outcomes occurred, and any other outcomes, as may be appropriate.

- (i) **Public.** Number reached/engaged; key outcomes.

IPWSO conference exhibition

The conference, held in Limerick, July 2022, was attended by 519 delegates (197 Irish, 322 internationals - from 37 different countries - approximate split of 50:50 male to female).

The exhibition was on display in the atrium (where lunch and other breaks were served), immediately outside the auditorium where all the conference sessions were held. It was also moved to the location for the Gala dinner on the final night. Therefore, all delegates would have been exposed to the exhibition in some respect. Project researchers and the comic book artist manned the exhibition during conference hours, answering questions about it. Approximately half of all delegates (n=250) would have been interacted with in this more engaged manner. **Total of 519 adults**

IPWSO conference workshops

Over the 2 drop-in workshop sessions were held at the PWS family weekend element of the conference, a total of 28 families engaged with us to view the exhibition, work with researchers to make their own models to add to the exhibition and have our comic book artist draw them as superheroes. We interacted with a total of 28 families, approx. 42 adults and 56 children, ranging in age from 2 to 17. **Total of 56 children and 42 adults.**

TOTALS –

561 adults, 56 under 18's.

Approx. 50/50 male to female ration

20 children with PWS, 8 adults

- (ii) **Research/Researchers.** Number reached/engaged; key outcomes.

Five researchers actively participated in the project.

David Tollervey
Aleksandra Helwak (Tollervey lab)
Alexandra Lehmann (Tollervey lab)
Sofia Esteban-Serna (Granneman lab)
Amandine Hong-Minh (Chambers lab)

Researchers reported feeling that their understanding of the effects of PWS had been enhanced and feeling motivated by meeting people whose lives might be affected by their research. In all cases, this was their first-time meeting people who had a condition linked to the area of scientific work. Researchers reported finding this “a moving experience”. They reported enjoyment in taking part in the project as a whole and would all be eager to do something similar in the future.

The project’s outputs have been shared with researchers from across the centre in our monthly “good news” mail out and across the School of Biology in its monthly newsletter (August 2022 editions).

(iii) **Other outcomes:** e.g. for partners, institution or unexpected.

The project enhanced our interactions with the Foundation for Prader-Willi Research (FPWR). **David to add more here???**

PWSA-UK staff were only able to attend the IPWSO conference due to the funding provided by this SWEA grant. This allowed them time to engage with the exhibition, our researchers and other PWSA researchers from across the world as well as meet other organisations with similar goals from elsewhere in the world.

Professional Footballer Coby Rowe, a role model to one of our PWS Superheroes, who stars in her comic strip, was very supportive of the project, making himself available for interview and sharing information about the project on his social media.

6. Legacy

Did this project generate long-lasting resources or partnerships and/or lead to additional PE or research projects being developed?

Although not a direct consequence, links with FPWR that were fostered by the project led us to successfully apply for research funding. This is helping support our ongoing research into the molecular basis of PWS.

The PWS comic book and exhibition will be available online indefinitely at **?????????????SJ to insert the link when provided it**
(please note, that comic is currently being translated into additional languages and will soon be made available to download in Spanish, Arabic and Greek. Videos of researchers, artists, and people with PWS will also be added to the exhibition after editing is completed)

The working relationship with Neil Bratchpiece has grown from this project, with another PE projects being developed and successfully funded using comic artworks as a key element. Engage Nepal with Science Climate Comic (funded by the British Council) is a comic story being developed based on characters developed by school children in twinned schools in Scotland and Nepal.

7. Additional Information

Please include any relevant information and/or links here relating to your project, which could be used to raise awareness of your project work to others.

For example: links to an online resource, a film, internal/ external communications, news coverage or social media posts about the project; quotes from project partners or public participants/ audiences.

Please send/share relevant high-quality images/ photographs of the project 'in action' and/or project team.

Photos from Clare House visits

Photos from Limerick

Photos of models

The individual comic strips

Tweets/ social media – footballer and IPWSO

Screen shots of the newsletter