



Dissecting Androgen excess and metabolic dysfunction – an Integrated SYstems approach to PolyCystic Ovary Syndrome (DAISY-PCOS):

Research Enrichment Public Engagement

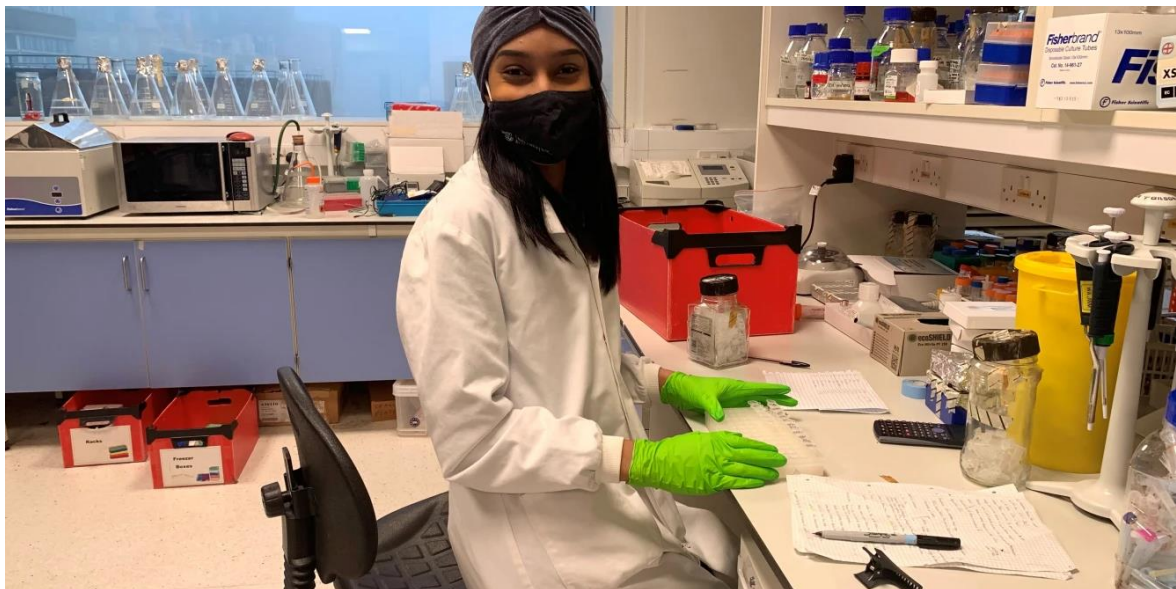


Portrait of DAISY-PCOS Leaders, December 2021

Research background

Dissecting Androgen excess and metabolic dysfunction – an Integrated SYstems approach to PolyCystic Ovary Syndrome (DAISY-PCOS) is a Wellcome Trust funded research programme led by Professor Wiebke Arlt, William Withering Chair of Medicine and Director of the Institute of Metabolism & Systems Research (IMSR) at University of Birmingham (UoB) [grant reference number 209492/Z/17/Z].

Polycystic ovary syndrome (PCOS) affects 10% of all women and causes irregular menstrual cycles and difficulties when trying to conceive. Increased levels of ‘male’ hormones in the blood, also termed androgens, are found in the majority of women with PCOS, who also have an increased risk of metabolic disease, such as diabetes, high blood pressure and heart disease. Professor Arlt’s team have found evidence that adipose (fat) tissue in women with PCOS overproduces androgens, resulting in a build-up of toxic fat in the blood, which could cause liver damage. Her team have also found that women with PCOS have an increased risk of fatty liver disease, the second most common cause of liver transplantation.



DAISY-PCOS PhD researcher Amarah at work in the lab, 2022

Current funding from Wellcome Trust covers the DAISy-PCOS Phenome Study which is in the process of recruiting approximately 1000 women with PCOS to assess their metabolic health and their androgen hormone levels, to identify markers that could predict the risk of metabolic disease in PCOS. Additionally, the funding also covers the 11OXO-PCOS study which examines the impact of two different types of androgens in women with and without PCOS, to understand how the androgens are converted and what their impact is on the metabolic function of the participant. A third study, will also test whether blocking androgen production with a new drug improves metabolic function in women with PCOS.

In summary, the research programme studies the mechanisms underlying the adverse metabolic effects of androgens in the laboratory, focussing on adipose tissue and liver. The overall aim is to develop new tailor-made approaches to treating and preventing metabolic complications in PCOS, thereby improving the quality of life of many women worldwide.

Enrichment background

Beginning in 2020, Professor Arlt and collaborators were awarded Research Enrichment funding from Wellcome Trust to support a public engagement project linked to DAISY-PCOS. The aim of this project was to build PCOS leadership in diverse women in Birmingham, supporting these 'DAISY-PCOS Leaders' to become experts in their own condition and empowering them to advocate alongside the research team. Collectively we hoped to raise public awareness of PCOS as a metabolic condition and to reduce 'reproductive disorder' stigma which compounds health inequality for many women affected by PCOS.

The team were particularly keen to involve as well as engage (British) South-Asian and university/college communities, as there is emerging evidence suggesting that PCOS disproportionately affects ethnic minorities, and the condition is typically diagnosed in early adulthood when young women are at college or university, often isolated from primary support networks such as their family. Together we aimed to share knowledge with each other and to co-create and deliver creative PCOS public engagement activities that appropriately engage similar and broader audiences. We also recognised that learning goes both ways and that members of our research team would also benefit from developing a more informed understanding of PCOS community needs, particularly cultural and youth barriers. Research team members therefore also committed to undertaking professional training in public engagement to enhance their skills in this area, which complemented the learning developed through their regular interactions with DAISY-PCOS Leaders during joint workshop sessions.

We aimed to deliver the following:

- 1. DAISY PCOS Leadership Programme:**

Recruiting and training 24 women to gain skills and confidence as leaders, cascading learning to others. Training to be covered included:

- Media Training
- Mental Health First Aid
- Public Engagement - including capacity building for the research team
- Leadership Skills
- Developing Expertise on Causes and Consequences of PCOS and options for monitoring and treatment

- 2. Public Engagement Programme**

A range of activities to engage wider communities on PCOS. Including:

- Approximately 12 'Share' events to provide up to date PCOS information and to better understand the priorities, barriers and support needs of women with PCOS - in particular challenges that might be unique to (British) South Asians and university/college students. In total we hoped to engage between 600-1200 people through such events.
- Approximately 4-5 Creative Festival Pop-Up events to tour local community festivals (e.g. Birmingham Mela - largest Asian music festival in Europe), highlighting PCOS lived experience to open dialogue with approximately 1600 local people - especially younger audiences e.g. teens, 20-30 year olds.

- 2 City-Centre Showcases (e.g. hosted at New Street Station) during PCOS Awareness Month September 2021/22 to target a broader Birmingham demographic (>10,000 people).

Impact of the Pandemic

We set out an ambitious programme of public engagement activities which centred very heavily on our collective ability to visit communities in their own environment, as opposed to expecting them to come to us. This focus on face-to-face interactions created considerable challenges during the restrictions imposed by the coronavirus pandemic. Firstly, there was a direct impact on our research team and our collaborators. Medically trained research team members were, at the height of the pandemic in 2020, redeployed to frontline medical services (e.g., Punith Kempegowda, Eka Melson) and/or other national covid-19 -related frontline duties (e.g., Rachel Chapman, Head of Commissioning & Contracting for Public Health). Furthermore, Professor Arlt – as IMSR Director – had to navigate changing regulations and prioritise risk mitigation of teaching and research commitments across an entire biomedical research institute. Furthermore, even our community collaborator, Neelam Heera (CEO of charity Cysters) was directly employed in managing regional personal protective equipment (PPE) logistics for most of 2020, meaning she could not dedicate as much time to her charity and hence the project. Collectively, this created significant challenges in arranging joint planning meetings and in securing individual time commitments over a good part of 2020.

Whilst a public engagement manager (Caroline Gillett) was appointed part-time to coordinate the project from January 2020, by mid-March all of the original plans agreed during joint team meetings that had taken place early that year had to be drastically re-envisioned. This created further delays with initiating the project and forced us to change plans already in development. For example, we had planned to host a joint stall with Cysters at the Asian Woman Festival in Spring in Birmingham to support recruitment into our leadership programme. Paperwork and payments had already been submitted to the festival, however this event was ultimately cancelled. Similarly, we invited Birmingham Mela organisers to campus to meet our team in early 2020 to discuss plans and a collaboration was agreed, however their annual festival was ultimately cancelled in 2020 and again in 2021, leaving us unable to carry out two major activities with key target audiences – here (British) South Asian communities.

In response to the changing environment, the project team subsequently took a decision to shift the DAISY PCOS Leadership Programme training from in-person sessions to an online training programme. Given the time lost in making these changes and valid concerns about dropout rates for online activities generally, it was felt that all 24 women involved in the leadership programme should be recruited at the same time as opposed to recruiting two smaller cohorts in years 1 and 2. Recruitment took place in Summer 2020 with the leadership programme commencing in October to coincide with new academic term, when it was hoped the pandemic situation would have improved and students would be back at university.

DAISY-PCOS Leaders Recruitment

We aimed to recruit 24 women in total, ideally:

- 12 bilingual South-Asian women with PCOS from Birmingham
- 12 University/College students* with PCOS (any ethnicity)

Delays due to the pandemic meant that our face-to-face recruitment strategy with Cysters had to be scrapped and we shifted recruitment into spring/summer 2020. Digital advertisements were put out jointly on our social media channels (Twitter, Facebook, Instagram) and shortlisting took place in late summer ready for an October start date.



Example of social media advert used in online recruitment, 2020

In total we received 52 expressions of interest within the timeframe, although we continue to receive occasional emails even now about joining the programme.

Despite emphasizing a regional focus, we received applications from individuals from outside of this area. In general, we prioritised local applicants, however as our programme was now online we took a decision to not restrict applicants to Birmingham alone and to instead judge applications based on fit to criteria and the quality of personal statements. We also encouraged applications from other minority ethnic backgrounds, not just those with (British) South-Asian heritage e.g. Black, Afro-Caribbean, Arab etc.

The application process was designed to be light-touch. We requested a few demographic details and ensured applicants were aware of the likely time commitment involved. We also asked for a short personal statement simply telling us what motivated them to be involved. We received a lot of applications from people who did not have PCOS themselves, but who expressed an interest in being part of the programme. Typically they were studying medicine and wanted to better understand the condition. Often they had other family members or friends affected. As PCOS education and awareness within the medical community is often considered lacking by lived experience groups, the team took the

decision to accept a few medical students who did not have PCOS, but who expressed an interest in learning more about the condition to support women in their future care.

Our recruitment strategy was successful, though it was disappointing to have to turn many applicants down. However, this was always to prioritise candidates who were a closer fit to our criteria. In all such cases, we indicated that we would keep in touch with applicants if they were happy for us to do this and that we would alert them to upcoming events or opportunities. We increased capacity to 30 places, anticipating that we would have some drop-out as sessions got going, but we did not extend beyond this as costs were based on 24 people and whilst we anticipated making some savings from running things online, other training costs (e.g. Media Training) and future travel costs would be increased due to taking more people on.



Our DAISY-PCOS Leaders are individually profiled here: <https://daisypcos.com/daisy-pcos-leaders/>

Overview of demographics:

Ethnicity	#s	Age range	#s	Languages spoken	
White British or White Irish	12	18-24	18	Afrikaans	Punjabi
British South Asian or South Asian	11	25-30	11	Arabic	Russian
Black or Black British	2	31-35	1	French	Somali
White Other	2			Gujarati	Telugu
Mixed - White & (British) South Asian	1			Hindi	Tamil
Arab	1			Hindko	Urdu
Mixed Other	1			Kannada	Yoruba
				Potwari	

Research Team: Public Engagement Capacity Building

In our original application, we had budgeted for training for two members of the DAISY-PCOS research team (Dr Punith Kempegowda and Dr Eka Melson) to undertake training with the NCCPE Engage Researchers' Academy (see: <https://www.publicengagement.ac.uk/engage-researchers-academy-2019-20>). We contacted the NCCPE in 2020 to enquire about places for 2020-21. We were informed that their scheme was on pause due to the pandemic and as of early 2022 it has not been restarted. This is a scheme specifically for researchers, as opposed to the Engage Academy which targets engagement practitioners who have more advanced knowledge in the field. We therefore re-allocated this funding to similar training opportunities for the delivery team which included:

- Media Woman Media Training for DAISY-PCOS Trial Coordinator Dr Thais Rocha (September, 2021)
- 3-Day Public Engagement Masterclass Training with the Wellcome Genome Campus, UK (19-21 July, 2021) for Dr Punith Kempegowda and PhD student Amarah Anthony
- Evaluating Online Events training (July 2020) for public engagement coordinator Caroline Gillett

Please note: Eka Melson relocated to Dundee to start as a Foundation Doctor and Thais Rocha joined the project in his place as the DAISY-PCOS trial coordinator in 2021. Eka remains involved remotely. Amarah Anthony joined in 2020 as a PhD researcher supporting the DAISY-PCOS project.

DAISY-PCOS Leadership Programme

The DAISY-PCOS Leadership programme is delivered by our multidisciplinary team at the Institute of Metabolism & Systems Research with the support of specialists working at the Queen Elizabeth Hospital and the Birmingham Women's Hospital. In addition, some of the training skills sessions are led by project partners (e.g., Cysters charity) and/or freelance practitioners as appropriate. The programme is intentionally flexible to allow us to periodically review feedback and suggestions from the women participating in it, our 'DAISY-PCOS Leaders'. The group also meets to discuss and plan public engagement and/or advocacy activities.

As of March 2022, the following training and public engagement events have been undertaken by the team and DAISY-PCOS Leaders:

DAISY-PCOS Leadership Programme

2020											
Women's History Month								PCOS Awareness Month			
January	February	March	April	May	June	July	August	September	October	November	December
Coordinator begins	Project planning meeting	Lockdown & redeployment	Lockdown & redeployment	Project planning meeting	Online recruitment	Online recruitment	Application shortlisting meeting	Perspectives on PCOS webinar feat. Cysters	Workshop 1: Welcome Induction	Workshop 2: PCOS & Metabolic Health	Workshop 3: PCOS & Skin
Project planning meeting	Mela Festival meeting	Distinguished Visiting Lecturer Application submitted (for Helena Teede to visit for DAISY-PCOS team) Asian Woman Festival (festival cancelled)	Website created	Body image inquiry co-writing	Evidence submitted to Changing the perfect picture: an inquiry into body image	Evaluating Online Events	Awareness month planning				Workshop 4: PCOS,Public Health & My GP
						Mela Festival (festival cancelled)					
2021											
Women's History Month								PCOS Awareness Month			
January	February	March	April	May	June	July	August	September	October	November	December
Workshop 5: PCOS & Obesity	Workshop 6: Programme Review	Our Health Matters, Period! webinar	Workshop 8a: Womens Health Strategy Co-Writing	Workshop 9a: Mental Health First Aid	Workshop 9b: Mental Health First Aid	Workshop 10: Public Engagement & Drama	Workshop 11: Event Planning & Crafting Social	Emotions, Experiences & Expectations webinar feat. PCOS Club India	Workshop 11a: Media Training	Workshop 12: Public Engagement, & Scicomm Illustration	Workshop 12: Leadership, Engagement & Review
	Workshop 7: PCOS & Fertility	PCOS at the Intersections webinar feat. Cysters	Workshop 8b: Womens Health Strategy Co-Writing	Evidence submitted to Women's Health Strategy: Call for Evidence	We Are IMSR Festival: 'Power of the Patient Voice' & 'How do we engage others on PCOS?' webinars feat. Verity	Public Engagement Masterclass	Mela Festival (festival cancelled)	PCOS Awareness Month: No thanks, aunty! Webinar	Workshop 11b: Media Training	DAISY-PCOS Leader Nikita participates in House of Commons Endometriosis & PCOS Debate, facilitated by Verity	PCOS Mothers focus group (DUCCHES)
	Event planning	PCOS Society: 21 Day Fitness Challenge		DAISY-PCOS App development focus group				SIMBA PCOS feat. Verity & PCOS Vitality	Media Training		
								New Street Station	DAISY-PCOS x SciComm Ladies Illustrations		
2022											
Women's History Month											
January	February	March	April								
Workshop cancelled due to illness	Workshop 12: Event planning	PCOS & The Pill webinar feat. Verity	Workshop 13: PCOS, Childhood & Adolescence								
DAISY-PCOS Leaders Video	DAISY-PCOS Researchers Video		Website refresh								
	DAISY-PCOS x SciComm Ladies Illustrations										
Key:							Public engagement activities	Training & skills workshops	Advocacy activities	Evaluation milestone	Team PE training

Further details about workshops:

Welcome Induction

Workshop Leads: Professor Wiebke Arlt, Dr Caroline Gillett and other DAISY-PCOS research team members.

This opening session served to welcome and introduce the DAISY-PCOS Leaders and project team to each other. The project coordinator explained the objectives of the research enrichment project and the researchers gave a brief overview about the research linked to the project. Everyone was sent a template ahead of time and asked to prep a single icebreaker slide on themselves and their motivation for being involved with the programme indicating:

- Why they wished to take part
- What leadership meant to them
- A fun or surprising fact about themselves

This session was also used to discuss preferred timings for workshops, with the group consensus being that workshops should ideally take place on weekday evenings (typically 6-8pm or occasionally at weekends) to allow those finishing work to get home in time and to not interfere with daily work schedules. Sessions would take place approximately every 4 weeks (sometimes more regularly, sometimes less regularly) and the group also suggested that Doodle polls be used to agree the most suitable dates for each workshop, as the group felt that committing to one specific day of the week would be too restrictive. As not everyone would always be able to make each session, it was agreed that where appropriate, recordings of talks would be made to be shared with DAISY-PCOS Leaders who were unable to attend a session. These recordings excluded the group discussion to allow people to talk freely without fear of private stories being shared beyond the group.

PCOS & Metabolic Health

Workshop Leads: Professor Wiebke Arlt, Dr Punith Kempegowda and Dr Eka Melson

This session focused on the aims of the DAISY-PCOS research project and key research it built from, including work on the metabolic links between PCOS and other conditions such as non-alcoholic fatty liver disease and insulin resistance. The group as a whole also discussed the historical 'reproductive' emphasis on PCOS and the stigma associated with this focus, highlighting why raising awareness of the metabolic nature of the condition was important as well as debating the name PCOS. Professor Wiebke Arlt, Dr Punith Kempegowda and Dr Eka Melson led this session.

We also ran a 45-minute break out room session in which six groups were asked to work together to create a 'mood board' (using online collaborative tool Padlet) to depict their own experiences and awareness of PCOS. They were invited to include the aspects which were most important to them and to discuss commonalities and points of difference across their stories to collectively agree a set of up to 10 images for their mood board. After this set period, the groups reconvened in a joint session

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PCOS & Skin

Workshop Leads: Dr Ser-Ling Chua and Dr Helena Gleeson

This session focused on visible symptoms of PCOS on skin and hair, including acne, hirsutism, hair loss and acanthosis nigricana (dry, dark patches of skin that can be linked to insulin resistance and hormone disorders). The group were also given an overview of current and emerging treatment options, with plenty of time for questions and discussion. It was delivered by Dr Ser-Ling Chua a Consultant Dermatologist and Dr Helena Gleeson Consultant Endocrinology and Clinical Service Lead for Endocrinology, both employed at University Hospitals Birmingham NHS Foundation Trust.



PCOS, Public Health & My GP

Workshop Leads: Dr Sarah Hilman and Dr Rachel Chapman

This workshop was split into two group discussions which switched over mid-way through. The first discussion was led by co-applicant Dr Sarah Hilman – a clinical lecturer in General Practice. It focused on women's experiences of PCOS and primary care. The group debated the 'overdiagnosis' argument (based on reading material sent in advance) and they also talked about what they wished GPs knew about PCOS. It also covered how best to approach and advocate for oneself in a GP setting. The second discussion was led by co-applicant Dr Rachel Chapman – an NHS consultant in Public Health. She discussed asset-based approaches to healthcare and appreciative inquiry, inviting the group to discuss what this might look like for PCOS.



PCOS & Obesity

Workshop Leads: Dr Jonathan Hazlehurst and Dr Abd Tahrani

This session focused on PCOS and obesity. It was led by Dr Jonathan Hazlehurst, an academic clinical lecturer in endocrinology, and Dr Abd Tahrani, a senior lecturer in endocrinology and obesity. The session covered obesity as a disease and the

challenges around its treatment and management. The group also discussed weight stigma in general and within the context of PCOS-related weight gain, using a recently published consensus paper to frame the conversation. The links between PCOS and other obesity-related conditions such as obstructive sleep apnoea were also touched upon.



Project Review

Workshop Leads: Professor Wiebke Arlt, Dr Caroline Gillett

This session provided an opportunity to evaluate and review learning to date through breakout room group discussions which aimed to provide feedback on the structure of the programme so far. The group were also encouraged to consider other topics that might be of interest for future sessions.

After discussion in the groups, breakout rooms reconvened in a joint room and shared feedback with the team, led by Professor Arlt and coordinator Dr Caroline Gillett. Feedback indicated that the DAISY-PCOS Leaders found the science very interesting, but that some of the slide content was still a bit too complex at times. The group were also keen to have more time built in for questions and discussion within each session. The group understood that a degree of science language might be necessary but indicated that jargon and data visualisations should always be explained rather than assuming that all group members would understand them or feel confident asking for them to be explained. As such we agreed a number of suggestions with the group. Firstly, future speakers would be briefed to create shorter, more lay-friendly presentations (ideally no longer than 30 mins in duration). Secondly speakers would be briefed to stop after every 2-3 slides to check whether there were any questions. Whilst questions were encouraged at any point, this allowed a more structured way for the group to ask questions as they went along rather than waiting until the end of a presentation. Furthermore, one or two of the DAISY-PCOS Leaders would be asked to nominate themselves as the 'Question Buddy'. This meant that if someone did not want to ask a question directly, they could send a private message in the Zoom chat to this the Question Buddy, who would then ask the question anonymously on their behalf.

The group were generally happy with the timing and frequency of sessions, though exam periods were tough for many and we were asked to avoid these periods where possible. Another suggestion was in lieu of face to face interactions, for us to try to build in the occasional informal social session to allow general catch ups without 'learning content'.

PCOS & Fertility

Workshop Leads: Dr Rima Smith and Dr Lynne Robinson

This workshop covered what fertility is and why it can be affected in women with PCOS. It highlighted that pregnancy was possible for most women with PCOS and that there are several treatments to help those who might be struggling with conception where desired, ranging from lifestyle interventions and drug therapies through to more invasive treatments such as IVF. It also discussed the higher miscarriage rates seen in PCOS and current research underway to compare the effectiveness of two treatments (Letrozole and Clomifene, with or without metformin), as well as other emerging treatments under research. Leading this session was clinical lecturer Dr Rima Smith who specialises in reproductive medicine and Dr Lynne Robinson, the clinical lead of the Birmingham Women's Fertility Centre. Both speakers work at Birmingham Women's and Children's Hospital.



Women's Health Strategy: Co-Writing Workshops x 2

Workshop lead: Dr Caroline Gillett

In early March, the UK government sought views on women's health issues and women's experiences of the healthcare system in England. The DAISY-PCOS Leaders were asked whether they would be interested in submitting a written response as a collective. The group were keen to support this (many had also submitted individual responses to the online survey) and as such we arranged two writing workshops to devise the content and structure of a written submission. Prompt questions from the callout information were used as the basis of different breakout room discussions, enabling DAISY-PCOS Leaders to join the discussions and contribute to the questions that most interested them. The work was finalised post session using a shared Google document and the final version was submitted by the project coordinator ahead of the June deadline.

A summary of the written submissions can be read here:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1068832/Womens_Health_Strategy_written_responses_from_organisations_and_experts.pdf

Please note: PCOS and metabolic health are mentioned on page 10 and 22 under a discussion of areas for further research.

Mental Health First Aid Training plus coursework

Workshop Lead: Neelam Heera (Cysters)

Over May and June, Neelam Heera CEO of Cysters was contracted to deliver Mental Health First Aid (MHFA) Training for the group. This training course programme was delivered using MHFA England's online training platform and recording of sessions was therefore not possible. Course materials (textbooks) were purchased by our team from MHFA England and mailed out to the DAISY-PCOS Leaders ahead of time.

Training consisted of two-day long sessions plus some additional coursework to consolidate learning. This coursework needed to be completed individually within a month of the last session. There were two of each session delivered (as the platform restricted training numbers of 16 max), but in general this allowed people some flexibility in which slot they would select. Neelam delivered the training through the MHFA video platform which included presentations, group work exercises and videos on common mental health conditions to aid learning.



PCOS & Public Engagement: Drama for Engagement

Workshop Lead: Anna Himali Howard

In July 2021 we began to explore public engagement approaches with the group and worked with director and theatre maker Anna Himali Howard to explore the use of theatre/drama as one approach in engaging others and sharing experiences. In the session, the group were invited have a go at some short creative writing activities, including imagining what a successful short theatre piece on PCOS would look like.

PCOS stigma and complications around having discussions with family, friends and partners – as well as GPs – came out very strongly. This ended up being a very emotive session and the group expressed an interest in working with Anna again in future.



PCOS Awareness Month planning meetings + crafting session

Workshop lead: Dr Caroline Gillett

Over August many of the team and DAISY-Leaders were taking time off to enjoy annual leave, after another challenging year of pandemic lockdowns. We therefore decided to run a very informal lunch session which centred on discussing plans for PCOS Awareness Month activities and catching up over a 'crafting social'. Those who could make the session (approx. 10) were posted out a small crafting package consisting of small pieces of cloth, threads, fabric pen, needles and some other decorative items (beads, sequins). Attendees started their PCOS inspired craft piece during the session and they were encouraged to share photos of their completed pieces once finished on their social media.

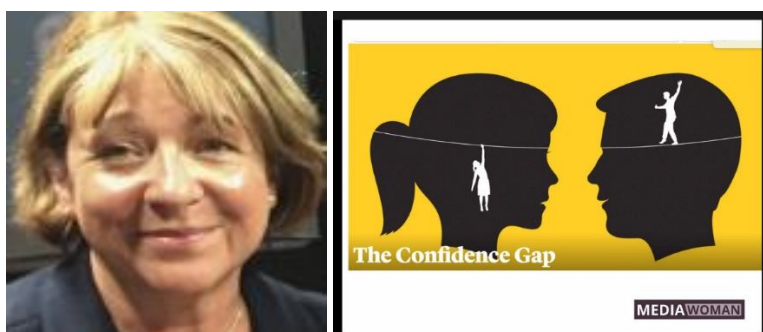


Example of small artworks pieces created from Crafting Social

Media Training with Media Women

Workshop lead: Julia Barry, Media Woman

In October 2021 we arranged media training from the award-winning Media Woman specialists, after a recommendation from our local equality, diversity and inclusion leads who use the company for an internal training programme with female academics. Media Woman “specialise in all-female training courses where our focus is on giving women the confidence, skills and enthusiasm to take on the media and presentation opportunities wherever they arise”. We briefed them on the DAISY-PCOS Leadership programme, including the women involved in the programme, the research project and PCOS as a condition ahead of training. Training was online and involved two sessions. The first session was a joint session that everyone attended and the second ‘practical’ session was split into small groups of 3-4 people. In total 6 of the practical sessions were run, allowing some flexibility in which session DAISY-PCOS Leaders could attend. In general, feedback was very positive, however we did receive some feedback about how the training had failed to take into account the extra barriers faced by women of colour. In addition, some of the training clips used men rather than women to get across particular point. This put off some of our attendees who felt the training was out of touch with the diverse make-up of the group. We fed this back anonymously to Media Women and we also approached our local EDI team, Cysters and DAISY-PCOS Leaders for recommendations on other trainers who might be able to better address these additional barriers and the skills needed to help overcome them. We are still in the process of finding a suitable trainer for this, but plan to arrange a follow-up session in 2022.



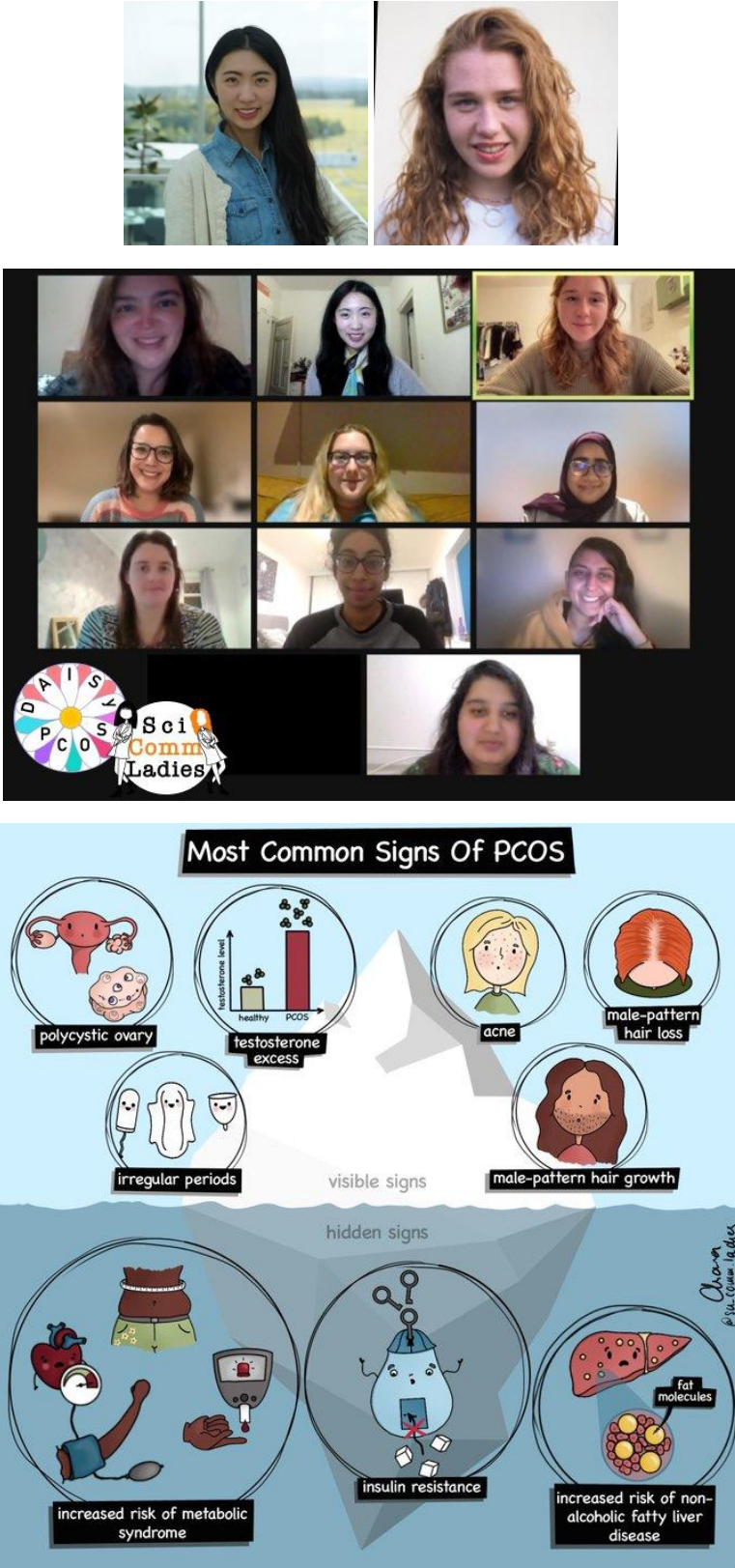
PCOS & Public Engagement: Science Communication & Illustration

Workshop leads: Weiwei Xu and Chiara Obermüller, SciComm Ladies

Carrying on with the public engagement training, we brought in the SciComm Ladies who spoke about their passion for fusing science and art within the context of science communication. Specifically, they spoke of how illustrations and cartoons can be powerful tools for communicating complex science concepts and/or data. Led by Chiara Obermüller and Weiwei Xu, we used the session to co-create ideas for 4 cartoons depicting key PCOS stories that the group wanted to get across. These are currently being worked on by the SciComm Ladies and a feedback session on initial drafts is scheduled in Spring 2022.

Thais Rocha and Caroline Gillett have already been working with the SciComm Ladies on a number of illustrations related to PCOS science concepts, but we hope to

complement these with the co-developed illustrations borne of conversations with the DAISY-PCOS Leaders e.g. focusing on stigma issues and the key messages from the lived experience perspective.



Screenshot from SciComm Ladies workshop and an example of an illustration created in collaboration with the research team

DAISY-PCOS Meeting: Leadership, Engagement & Next Steps

Workshop Leads: Professor Wiebke Arlt, Dr Caroline Gillett, Tam Gulati Kaur, Anna Himali Howard.

In late 2021, as restrictions started to lift somewhat, we decided it would be very important to bring the group together face to face for the first time. In late October we doodle polled a date to meet up in December to celebrate and review the first year of activity together. The most promising date chosen was the 4th of December with about two thirds of leadership group initially available. Ultimately 10 of the DAISY-PCOS Leaders were able to make it on the day, as many of the cancellations came last minute (Covid-related sickness, family or work commitments which could not be arranged) and some of the others could not attend for other reasons such as being abroad, having recently given birth etc.

Where possible those who could not attend sent in video messages which were played on the day as part of the welcome session. These pre-recorded video messages were compiled by DAISY-PCOS Leader Sunila Siddiqui and can be viewed here:

<https://photos.app.goo.gl/7A4Z64LLzX5QFXTs7>

One of our session leads, Neelam Heera, also unfortunately fell ill the day before the event. This meant that a mental health refresher session had to be cancelled. The time scheduled for this session was re-allocated to other activities on the day

The day consisted of

- DAISY-PCOS research update from the team
- Leadership skills workshop facilitated by DAISY-PCOS Leader Tam Gulati Kaur
- Public engagement workshop facilitated by Caroline Gillett and Anna Himali Howard who lead a Drama workshop (building on work from her previous workshop)
- Voxpop feedback generation on the programme so far. Filmed by an independent videographer and turned into a short legacy video:
https://youtu.be/9_8rrBQhzM
- General photography
- Celebratory dinner to mark a year of activities with the DAISY-PCOS Leaders



Photos from Leadership and Public Engagement workshop sessions, December 2021

International Women's Day event planning

Workshop lead: Dr Caroline Gillett and Dr Thais Rocha

An informal planning workshop was arranged in early February to design and finalise plans for a webinar to mark International Women's Day (IWD) in March. The event was chosen to focus on PCOS and the Pill, as suggestions and questions at previous events often cropped up on this topic and the group had previously discussed wanting to do an event related to this. It was felt that IWD would be a good opportunity to run a more focused event on this topic. Dr Thais Rocha put herself forward to lead the scientific content and we also invited another Birmingham researcher, Ms Anuradhaa Subramanian, to share her recent work (which also involved DAISY-PCOS PI, Professor Wiebke Arlt) showing the pill reduced the risk of type 2 diabetes in women with PCOS. A few of the DAISY-PCOS Leaders volunteered to be chairs/speakers and others were happy to help behind the scenes with promotion and other tasks. For example, one of the Leaders worked with Dr Thais Rocha to create simple lay-friendly visuals for her presentation using BioRender and others created a set of poll questions for use on the day. A follow-up meeting was also scheduled a few days before the event to run through last minute questions and speaker order.

PCOS, Childhood & Adolescence

Workshop leads: Dr Jan Idkowiak, Dr Pallavi Latthe, Wojood Ben Said.

An upcoming workshop will look at the transgenerational impacts of PCOS and on PCOS-like symptoms that may appear in adolescence. It will cover some of the research evidence of transgenerational 'transmission' of PCOS and discuss new research underway to longitudinally track the metabolic health of infants born to PCOS mothers. This will be led by Dr Jan Idkowiak, an academic clinical lecturer in paediatric endocrinology and diabetes who also works at Birmingham Children's Hospital, supported by his PhD student Wojood Ben Said. Pallavi Latthe, a subspecialist in urogynaecology at Birmingham Women's NHS Foundation Trust will also talk about her extensive work in the clinic supporting young women challenged by PCOS-like symptoms who are too young to be formally diagnosed. The plan is to discuss the impact of PCOS-like symptoms in youth and the types of informational resources that would be useful for adolescents to better understand PCOS.



DAISY-PCOS Public Engagement Events & Advocacy

A list of the public engagement events and advocacy activities delivered through the programme is below. The vast majority of these have been developed and delivered in collaboration with and involving DAISY-PCOS Leaders. In addition, some of the DAISY-PCOS Leaders have run activities themselves, so not all activity may be captured here. For example, some of the members set up the PCOS Society – a student society at the University of Birmingham and they have self-run their own activities and socials not captured here.

- June 2020 Changing the perfect picture: an inquiry into body image call for evidence
Submission: <https://committees.parliament.uk/writtenevidence/7874/pdf/>
- September 2020 PCOS Awareness Month: Perspectives on Polycystic Ovary Syndrome webinar
Recording: <https://youtu.be/jDzGVjuihO>

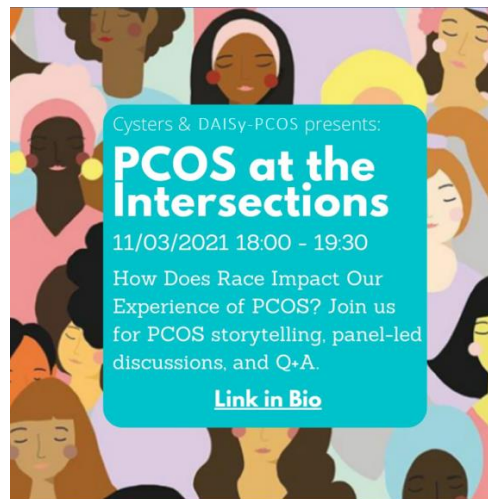


- March 2021 International Women's Day: Our Health Matters, Period!
Recording: <https://youtu.be/BfK8uglHsHU>



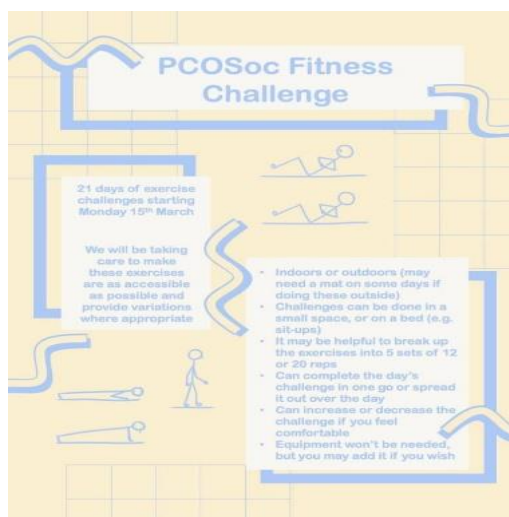


- March 2021 Women's History Month: PCOS at the Intersections
Recording: <https://youtu.be/ly97jAmEYal>



PCOS at the Intersections event panellists

- March 2021 PCOS Society 21 Day Fitness Challenge



- May 2021 Women's Health Strategy: Call for evidence
Report summarising all written evidence:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1068832/Womens_Health_Strategy_written_responses_from_organisations_and_experts.pdf
Please note: PCOS and metabolic health are mentioned on page 10 and 22 under a discussion of areas for further research.
- June 2021 We Are IMSR Festival: Power of the Patient Voice
Recording: <https://youtu.be/hRzdD2f9wRU>



- June 2021 We Are IMSR Festival: How do we engage others on PCOS?
Discussion session, not recorded.



- September 2021 PCOS Awareness Month: Emotions, Experiences & Expectations
Recording: <https://youtu.be/Y6rBzdLx5g0>



- September 2021 PCOS Awareness Month: SIMBA PCOS
SIMBA is a simulation-based learning initiative led by Punith Kempegowda and Eka Melson, researchers involved in DAISY-PCOS. DAISY-PCOS was involved the first session to include people with lived experience of a health condition under study. This session was not recorded, but it has been presented within poster sessions. Further generic information about SIMBA can be found here:
<https://www.endocrinology.org/endocrinologist/139-spring-2021/features/simba-simulation-based-learning-created-by-and-for-students-and-junior-doctors/>



18 September 2021 from 1000 to 1500 BST


In collaboration with



Supported by



- September 2021 PCOS Awareness Month: No Thanks, Aunty!
Recording: <https://youtu.be/jDzGVjuihnQ>
Video of 'The Aunties' created as discussion tool for the event:
<https://photos.app.goo.gl/HGmtFJ3ZhcejgmNY8>




PCOS Awareness Month:

NO THANKS, AUNTY!

Wednesday 22 September 6pm GMT

Join us for a light-hearted discussion event exploring what it feels like to manage **PCOS** symptoms such as **weight gain** and **excess facial hair**, whilst also having to deal with other people's *(not always helpful)* attitudes & advice!

Register now, all welcome!
tinyurl.com/w7vurme2


@daisypos

- September 2021 PCOS Awareness Month: Birmingham New Street Station Showcase



Photos from Birmingham New Street Train Station Showcase event, September 2021

- November 2021 House of Commons Endometriosis & PCOS Debate
Video submission from DAISY-PCOS Leader Nikita Chadha:
<https://twitter.com/HoCpetitions/status/1455865726959501318?s=20&t=4ndMAejko1sa7szWRVYWCw>
- January 2022: DAISY-PCOS Leaders video
Recording: https://youtu.be/9_8rrBQhzM
- February 2022: DAISY-PCOS Female research team video
Recording: <https://youtu.be/jyMzcZYS-TE>
- March 2022 International Women's Day: PCOS & The Pill
Recording: <https://youtu.be/tMV401-SOK4>
- SciComm Ladies illustrations
Those created so far can be viewed at www.daisypcos.com/research

Attendance & Feedback

Almost all of our events have been online and we have seen sign ups of roughly 1300 people (Zoom registration and Eventbrite figures) in total, with an average attendance rate of 45%. We estimate that between 550-600 people have engaged with our events online. This attendance rate seems consistent with most other event series we are aware of. Signups and attendance were noticeably higher in 2020-21 and have started to decline towards the end of 2021 as people are spending more of their free time out and about 'post-pandemic'.

We have sought to evaluate many of these events through polls and short feedback surveys post-event. Some events were more discursive in nature and feedback was generated more informally during discussions themselves and in the chat function of Zoom. We have debated collecting demographic data but have kept a flexible and optional policy in place to be sensitive to DAISY-PCOS Leaders recommendations, where they have suggested collecting these details might put people off. For example, our No Thanks, Aunty! Event was primarily aimed at (British) South-Asian audience and we did collect data which showed over 60% identified as (British) South-Asian, with approximately 20% identifying as white and the rest of attendees identifying as another ethnicity and/or preferring not to say. The PCOS at the Intersections event did not collect such data formally however as this was the preference of those DAISY-PCOS Leaders leading on the event. We also saw quite a lot of international attendance at our events, which was one of the benefits of hosting events online, although optimising time zones to be convenient to all was impossible. Due to the interest from India in particular, we ended up collaborating with PCOS Club India for one of our PCOS Awareness Month 2021 events.

In general, feedback from our events was very positive with people indicating they had found content useful and that their support for research in the area of PCOS had increased. We also had many comments highlighting how valuable including lived experience perspectives had been and that attendees were pleased to see stigma, culture and mental

health aspects also raised alongside the biomedical science, as these issues often resonated strongly with them.

We did manage to run one in-person city-centre showcase event in September 2021 at Birmingham New Street station with a volunteer team of 12 (researchers and DAISY-PCOS Leaders) rotating in shifts of 3-4 people. Birmingham New Street is the busiest train station in the UK outside of major London stations. Typically, numbers entering the station are 170,000 per day but commuters were considerably reduced during the pandemic period and we were informed by station staff leads that current numbers were approximately 100,000 per day during the September 2021 time period. We were restricted on the size of stall we were allowed to set up (partly because of social distancing measures which aimed to reduce crowd bottlenecks), but we had a prime location in the main atrium located directly below the stations' main travel information boards. This meant that many commuters and other shoppers visiting Central Station shopping mall would see us. We were set up ready for 8am and packed down at 6pm, so we conservatively estimate that at least 20,000 would have seen our stand throughout the course of the day. We directly interacted with approximately 2000 people (based on flyers) which typically involved handing out a flyer or answering a very brief question such as "What is this stall about?" when approached. We had more in-depth (>3 minutes) conversations with approximately 500 people (often families or groups of friends).

We were incredibly pleased with the diversity of people we spoke with at the station, as roughly 70% were non-Caucasian. We also spoke with several men who saw our banner and wanted to pick up flyers for partners and daughters affected by the condition. One of the challenges of this type of activity however was that many of those who were 'highly engaged' took up quite a lot of time (>10 mins) asking questions and more typically telling us about their PCOS experiences. On the one hand this was fantastic engagement and they expressed how grateful they were to see our group raising awareness of PCOS awareness and to be able to talk to someone who understood their difficulties. However, the trade-off was that it limited our ability to reach and engage more people and those perhaps less aware of PCOS.

It was also clear from many of the conversations we had and from a mini 'myth-busting' drop-token quiz that we had set up that a lot of women – even those with PCOS – had no idea about the metabolic risks linked to PCOS. Furthermore, quite a few did think getting pregnant was near impossible and we heard a number of repeat stories of stigma and women with PCOS being told they "could not get pregnant". A few people told us they subsequently became pregnant as they had not taken extra precautions and whilst they reported being happy about this outcome it had come as a surprise for them. It was a concern to hear such advice had been given to some women, in a couple of cases from doctors. We note that most of these women were probably aged 45+ and we would hope that guidance has moved on since the time these women were given such advice.

Whilst we have been pleased with what we have managed to achieve during the past two years, it has not been without its challenges. All of the public festival events we hoped to run pop-up activities at were cancelled in 2020/21 and there have not been equivalent community events online that we could readily transfer activities to. Some of the online training delivered (such as media training and mental health first aid) understandably also lacked some of the practical elements that can only be delivered in person e.g. practice in front of a real camera and with a handheld mic, body language techniques etc. As of

January 2022, Facebook has also removed detailed targeting options that relate to 'sensitive' topics such as causes (e.g. PCOS Awareness) and race or ethnicity, for example. Previously we used these features to support targeted advertising of our events to groups we were keen to connect with, however going forwards this is likely to be more challenging. Information about this change:

<https://www.facebook.com/business/news/removing-certain-ad-targeting-options-and-expanding-our-ad-controls>



Event experience rated as:
"Excellent" (85%) or "Good" (15%)
Average score of 4.85/5

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85% stated awareness of PCOS had increased & 40% changed their attitude or perception of PCOS

"I'm more aware of the studies that ARE happening in the medical field, but also more aware of how little PCOS is covered in traditional medical studies. It's shockingly little."

"More awareness of intersectionality of experiences and in particular, Asian women having a higher chance of having PCOS."

"I feel much more informed about how to approach conversations with my GP."

30% said their behaviour or practice would change

"I have personally learnt over the years to give space to others to share their perspective and this event has further reinforced this practice."

"I am pushing through with the GP for a referral, I'm also more aware of the spectrum of the symptom's"

"I will definitely want to attend future events and hear more about research progress."

"I will attend more events around this topic, seek out support groups and individuals who also have PCOS to find spaces to be able to discuss this topic, I will also work on becoming more comfortable speaking about my experiences."

Audience Feedback
"Our Health Matters, Period."
IWD2021 Event

Stay in touch for future events
www.daisypcos.com
 @daisypcos

N = 20, representing a response rate of approx. 36% of attendees on the day - 56 people

95% "Strongly Agreed & 5% "Agreed" support for women's health researchers has increased due to event

100% "Strongly Agreed" public engagement on women's health research is important

"Thank you all so much for sharing your experiences and being open and vulnerable."

"Thank you to everyone, this has been really valuable and hearing individuals experiences makes PCOS a lot less intimidating."

"I'd like to say an enormous thank you. This is the first event of this kind I've attended and I really appreciate the time of all of the panellists."

"Thank you for making this platform available online. As a long term 'cyster' I am so happy of the journey I have been on. The session today was so insightful and the panellist experience experiential knowledge was relatable. Great Job!"

"It was fantastic"

"Thank you for sharing your experiences and being so open about it. Thank you Amina for your efforts in making PCOS more understandable and for bridging the distance between patients and doctors."

100% of feedback (n=183) rated usefulness of @DaisyPcos #PCOS webinar as Very good or Good. 39.4% stated behaviour/practice would change! 76.9% 'Strongly Agreed' their support for PCOS research & researchers increased! 85.2% think further PCOS #publicengagement 'Very Important'.

Really informative and insightful event. The patient voice in this so crucial to capture.

I was so grateful to hear that there are people out there that are actively trying to find out more about the condition and spreading awareness.

I really appreciate that you mention culture regarding PCOS since I belong to a certain ethnic group.

It was great to have such well known researchers disseminating their work. This was definitely an opportunity to listen to some of the greatest minds in the business.

It opened my eyes how differently it affects individuals.

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AUDIENCE FEEDBACK!

Thank you so much for organising such a wonderful webinar in the name of PCOS awareness month with an outstanding speakers and experts in PCOS!

It is nice to be treated as intelligent adults and have information provided for us to absorb and understand.

I appreciate the diversity of researchers and their different focus and expertise. I also appreciate how hard it must be trying to raise the profile of the condition and their commitment to find answers instead of just speculating.

I especially liked the section discussing culture as another complexity to PCOS conversations!!

I really admire the different views of the panel, be it in their settings, their management, and the support for patients having PCOS. thank you for having this kind of webinar. I hope to join another interesting presentation on your next topic.

Feedback summaries from DAISY-PCOS events

You and 8 others

2 5 24

Feedback summaries from DAISY-PCOS events

Attendance headlines:

- Online share events: 550-600 in attendance. This hits the lower target we were aiming for with the rest of 2022 to go. We will update the website soon to include video content which will provide a resource for others.
- In-person city centre showcase: 20,000 views, 2000 direct interactions, 500 in-depth engagements. This surpasses the 10,000 views we hoped to achieve but we are keen to do more to engage people less aware of PCOS in more-in depth ways.
- Most community festivals did not run in 2020-21 due to pandemic-related cancellations, therefore we hope to have opportunity to run more community-based activities from summer 2022 onwards.

Feedback headlines:

- Overwhelmingly positive feedback indicating attendees had found events valuable and engaging, with greater support for scientists working in PCOS research
- Inclusion of lived experience perspectives and involvement strongly commended
- Recurring themes of stigma, poor medical/health education, cultural sensitivities and mental health highlighted
- Mixed awareness of metabolic risks

Impacts and Next Steps

Over the past two years our project team has learned a great deal about the priorities and concerns of women with PCOS, outside of a clinical or research setting through more informal interactions and dialogue. The workshops and discussions we have had with the DAISY-PCOS Leaders have been instrumental to this and have immensely impacted our team's ongoing approach to societal engagement. For example, we have widened our awareness of the everyday challenges women with PCOS face and increased our understanding of the type and sources of misinformation which these communities often find themselves having to navigate. We are more aware of the many unanswered questions that remain for these women e.g. 'What diet is best for PCOS?', 'What happens during menopause?', 'Why doesn't the pill work for me?'. These are questions which leave many women vulnerable to pseudoscience and those who seek to profit off 'PCOS cures'. Despite guidelines, significant confusion over PCOS health management still permeates the PCOS community, with poor mental health and low body confidence being a very significant recurring concern for lots of women.

This has highlighted the need for more robust research to address the support needs animating these very tangible needs-driven research questions. DAISY-PCOS research is one project starting to answer some of these questions and our engagement work has had a direct impact on the team who are now more committed to better thinking through how to harmonise our research outcomes wherever possible to begin to address some of the wider challenges raised. An example of this impact has been the work of Dr Punith Kempegowda who developed and ran the 'Blue Morpho' project in 2021. This was a rapidly formulated piece of standardised questionnaire-based research looking at emotional, sexual and psychological wellbeing in women with self-reported PCOS. This was directly developed off the back of conversations with the DAISY-PCOS Leaders who highlighted body concerns and cultural differences in experience which the study also

probed through respondent demographics. The work is currently being written up for submission to a journal and it has significantly shaped and motivated Punith's ongoing research interests.

The metabolic nature of the PCOS is also still not widely understood by many of the women we have engaged with and unfortunately many women still report poor quality interactions with healthcare professionals. This too, has motivated new types of activity spearheaded by DAISY-PCOS research team members. For instance, Punith Kempegowda and Eka Melson have gone on to include lived experience representatives in SIMBA – a simulation-based case study training initiative they have pioneered “for and by medical students”. SIMBA PCOS was the first ‘pilot’ patient engagement session i.e. the first to include patient stakeholders within training discussions. This session included Professor Arlt and Dr Caroline Gillett as session chairs, alongside DAISY-PCOS Leader participants and other women affected by PCOS linked to relevant charities. The SIMBA team has subsequently gone on to run other patient engagement training sessions focused on different health conditions with respective patient groups and charities. SIMBA PCOS therefore served as a blueprint for training around other medical conditions, ensuring the medical students involved also learned to value patient input on what represents good practice. Indeed, the inclusion of lived experience voices at events run by DAISY-PCOS team members is far more commonplace than previously and this is a principle which Professor Arlt has been able to champion more broadly across the Institute of Metabolism & Systems Research (IMSR) as its Director. IMSR's public engagement strategy now actively encourages other academics across the institute to consider sharing public platforms with lived experience representatives where feasible and to reduce access barriers to their engagement.

The DAISY-PCOS Leaders also report better understanding of the science and current research in PCOS, but moreover greater confidence and public engagement skills. Perhaps the biggest impact reported by the group has been feeling part of a community who are motivated to advocate on PCOS and women's health equality, engaging others to validate their experiences and to encourage other women to seek the support they are entitled to if they need it. Voxpops were recorded December 2021 by an independent videographer who was asked to capture feedback on experiences so far. This can be watched here: https://youtu.be/9_8rrBQhzM

Looking forwards, we want to use 2022 onwards to prioritise as much in-person activity/events as we can, as our proposed pop-up events have been unable to take place so far and this is where we have been unable to achieve targets to date. Hopefully now that community festivals and activities are starting to take place again, we will be able to reach key audience targets (1600 people) in community spaces. Whilst online events have helped reduce access barriers in many ways, we also appreciate online events can also inadvertently create barriers too – as not everyone engages with these platforms and disadvantaged groups may not have necessary equipment or sufficient digital skills proficiency to take part. We also hope to create a collaborative art installation ready for PCOS Awareness Month this September and would like to use remaining funds to make these events as collaborative, visible and engaging as possible whilst reducing barriers (e.g. travel costs) for our DAISY-PCOS Leaders to take part as the past two years has seen significant changes to how everyone is working. We seek to embrace the positives of online engagement whilst engaging communities on the ground for maximum impact.

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