

## THE POWER OF ENGAGING YOUNG PEOPLE IN RESEARCH

**Stephanie R. Partridge<sup>1,2\*</sup>, Mariam Mandoh<sup>1</sup>, Sara Wardak<sup>1,2</sup>, Allyson Todd<sup>1,2</sup> and Rebecca Raeside<sup>1,2</sup>**

<sup>1</sup>Susan Wakil School of Nursing and Midwifery, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

<sup>2</sup>Charles Perkins Centre, The University of Sydney, Camperdown, NSW, Australia

### YOUNG REVIEWERS:



**ERIC**

AGE: 13



**JUNIOR**

**MD**

AGES: 11–13

Youth advisory groups (YAGs) are super teams of young people who help scientists understand what is important to people their age. In our study, we wanted to find out how being involved in a YAG benefits young people and improves scientific research. We found that when young people joined a YAG for 1 year, they gained leadership and problem-solving skills. They told us that being in a YAG made them feel their voices were heard and included. They got to share their ideas, influence decision making, and make a difference in scientific research. But it was not always easy. We learned that YAGs face challenges, like not having enough time and difficulty meeting face-to-face. Yet, with some flexibility and supportive scientists, YAGs can succeed. We learned that a small group of thoughtful and committed young people can make a big difference and help make health research better.

## ENGAGING YOUNG PEOPLE IN PREVENTIVE HEALTH RESEARCH

In today's world, everybody is realizing how important it is to **involve young people in decision making** that impacts their lives [1]. Researchers like us use science to understand how to create healthier societies and healthcare programs that help young people eat well and stay active [2]. Who better to collaborate with when doing this science than young people themselves? They are the true experts in being “young people”, and they can provide unique insights that adults might miss. This is especially true in our digital world, where the experiences often look different for young people vs. grownups. Maybe you have seen influencers on social media, or the latest apps designed for young users—all aspects of being a kid nowadays that reflect your unique perspective. That is where **youth advisory groups** (YAGs) come in. YAGs are teams of young people like you who partner with scientists like us, to share what matters most to them and their friends.

In our research, we wanted to find out the good things that young people gain from being in a YAG focused on **preventive health research**. The goal of preventive health research is to prevent **chronic diseases** like heart disease before they even start, and to improve mental wellbeing. Chronic diseases often come from habits, like what we eat and how much we move. Many of these habits start during adolescence but are influenced by multiple factors outside our control. So, as researchers, we believe that it should be the norm for scientists to collaborate closely with young people.

### WHAT IS A YOUTH ADVISORY GROUP?

A YAG is a way for researchers to work closely with a small group of young people (usually about 16 people), who represent the audience the research aims to benefit. These young people become collaborators (part of the scientist's team), helping shape the research to meet the needs of other young people who will eventually participate in the research project. Doing research this way is becoming more popular, so young people can participate and co-design research projects, and they can even come up with research questions alongside researchers. But it is still not the norm! In 2019, only 1% of all research about young people reported using youth advice in their research [3].

You can spot YAGs in various places, from global organizations like the World Health Organization and United Nations to national governments like the Australian Government Office for Youth. At the local level, perhaps you have some in your school! One cool thing about YAGs is that they are not one-size-fits-all—instead, they are tailor-made for each project, adapting to the specific project's context, country, and the resources available. It is exciting to see these groups

### YOUTH ADVISORY GROUP

A team of young people who work with researchers to make sure decisions benefit young people. They share their ideas to improve things like programs, research projects, or policies.

### PREVENTIVE HEALTH RESEARCH

Research to help promote good health practice, prevent disease and keep people out of hospital.

### CHRONIC DISEASES

Long-lasting health conditions, like heart disease or diabetes.

thriving, but surprisingly, we do not know much about what it truly means for young people to be part of YAGs. That is exactly what our research aimed to uncover—to make sure that projects like this are helpful for the research and for the young people who take part in them.

## WHAT WAS THE AIM OF OUR STUDY?

As public health researchers studying ways to improve young people's health, we set out to create a YAG that could help us make sure we are researching topics that matter and are important to young people. At the same time, we also wanted to study what it meant for a young person to be a part of a YAG. So, our study had two main goals. First, we wanted to see how being part of a YAG for a whole year affected young people. Did it make them better leaders? Did it change how they saw research about preventive health? Second, we wanted to understand how to involve young people in a YAG so that they can influence the research process in a good way [4].

### PROTOCOL

A detailed plan for conducting a study, outlining methods, data collection, analysis, and ethical concerns.

### ETHICS

Ensuring that studies are conducted responsibly, with respect for participants' rights, safety, and wellbeing.

## HOW DID WE CONDUCT OUR STUDY?

We started with a study **protocol**, which is like a plan for the whole research process. Then, we sought **ethics** approval to make sure that our research was appropriate and that we could go ahead once our university gave us the thumbs up. We then invited 16 teenagers aged 13–18 years who were already members of our YAG to participate.

We used two methods to collect information. First, we asked questions online through surveys. Second, we had a deeper chat with young people through interviews, in which they shared their experiences at the beginning, after 6 months, and again after a full year in the YAG. In these surveys and interviews, we explored confidence, leadership skills, and collaboration. Being confident means being sure of yourself and your abilities. Leadership skills, like good communication skills, are abilities or strengths that help teams achieve a common goal. Collaboration means working in a team to achieve something together.

To guide our analysis, we used specific approaches from the **Youth Participatory Action Research Principles** and the **Lansdown-UNICEF conceptual framework**. These helped to make sure that our process was scientifically rigorous, meaning that the results of our research can be relied upon later [5]. That is why we also kept records of our meetings and chats, and maintained detailed researcher logs (like diaries where we write about what we are working on). Once we had all the data, we carefully analyzed what young people shared with us during their surveys and interviews. Think of it as solving a puzzle with

both words and numbers—officially, it is called a convergent parallel mixed-methods pre-post study design.

## OUR KEY FINDINGS

First, we observed that young people who joined our YAG for a year gained more leadership skills. We also dug deeper and identified three key themes from our one-on-one interviews (Figure 1).

### Figure 1

We found three main themes in interviews with our YAG participants. A theme is a big idea or an important topic that keeps coming up when you talk to different people. These themes help us understand what is really important in our study and what young people are talking about the most in the interviews.



These themes grew stronger as our YAG members worked together over the year. Young people in our YAG realized that influence, contribution, and empowerment were interconnected. Overall, having an opportunity for meaningful engagement, having a say in scientific research that affects them, and getting real results helped empower them to make an impact—they even wrote a scientific paper [5]!

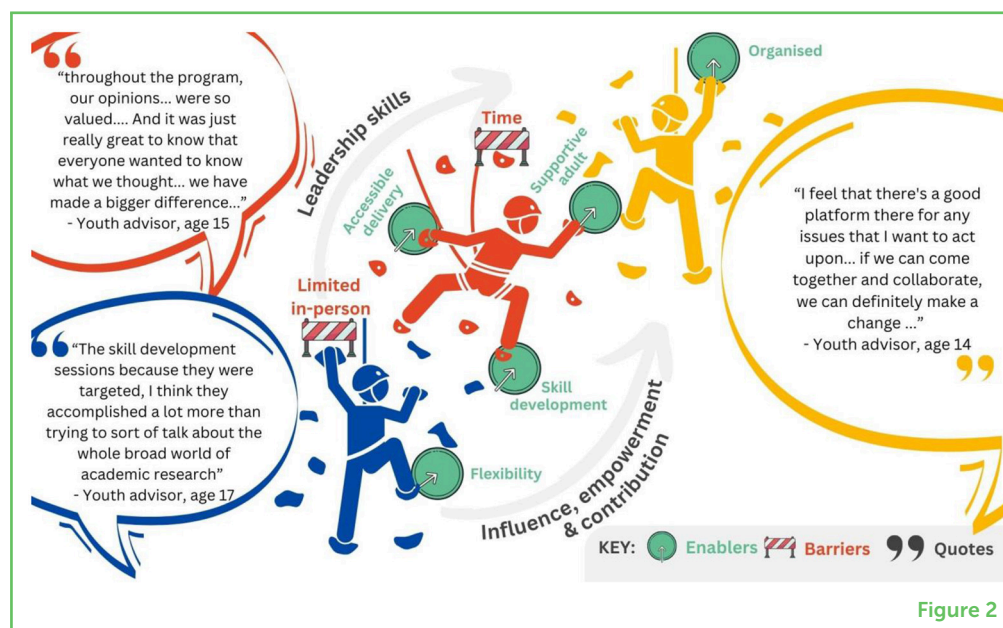
Setting up and running our 12-month YAG was not simple. It required careful planning, lots of teamwork, and we had to build upon and adapt the way we did things as we progressed. Our YAG members had very different schedules and commitments, and we wanted to make sure that everybody could contribute in their way, so we held online meetings and an in-person workshop. Our YAG member helped us to streamline our online communication during the project, so it was easier for us to share knowledge, stay connected, and collaborate.

Of course, there were challenges along the way. Young people are busy, so time was one challenge. We also could not meet in person as much as we would have liked, due to COVID-19 restrictions. But we found ways to overcome these barriers to make sure that everything went smoothly. Overall, our study showed that being part of a YAG can

make a difference in the lives of young people and improve research in ways that truly matter to them (Figure 2).

**Figure 2**

Scaling the peaks of youth engagement. Enablers, things that make other things possible, are like parts of the rock wall that are easy to grip, providing essential support and stability. Our youth advisors were boosted upward by these enablers, which helped them improve their leadership skills while developing a sense of influence, empowerment, and contribution. Barriers are something that gets in the way, like the tricky sections of the climbing wall. Our YAG faced barriers that required creative approaches to overcome them. The quotes from our youth advisors offer insights into their experiences and show the importance of meaningful youth engagement.



## WHAT IS NEXT?

We are super excited about what our results mean for the future. They show that being part of a YAG can positively impact young people. It helps them develop important skills and changes how they engage in preventive health research. We also found that the YAG process works well, and it enables meaningful engagement of young people at all stages of research. Before our study, there was not a lot of evidence out there about YAGs and their impact on young people and preventive health research. Our study helps fill this gap. Other research also emphasizes the importance of involving youth in research because of the great pay-off for health research when young people are engaged.

Of course, our study has some limitations. The young people who joined our YAG often had prior leadership experience or were already curious about research or health careers. This could limit the diversity of perspectives. Also, our YAG was small, so that our young people could meaningfully engage with us and with each other—but results may be different in larger groups.

We found that meaningful youth engagement in a YAG benefits young people and preventive health research. It enhances leadership skills and empowers young people to influence and advocate for health research that matters to them. For a YAG to succeed, we need to be flexible and adaptable, overcome challenges, and make it easier for all kinds of young people to participate. This is just the beginning,

and we hope to see more YAGs positively impact research and young people's lives.

## HOW CAN YOU GET INVOLVED?

You can join a YAG, too! Reach out to your local school, government, or university, or even explore [global opportunities to join YAGs](#). Remember, young people like you should be heard in all research and policies that affect your lives. You have unique perspectives, experiences, and ideas that can shape the future for the better. So, do not hesitate to get involved!

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## REFERENCES

1. Wardak, S., Raeside, R., Jeyapalan, D., Kapeke, K., Dogra, S., and Partridge, S. R. 2023. Adolescent rights-based approaches to health research about us. *Lancet Child Adolesc. Health* 7:826–7. doi: 10.1016/S2352-4642(23)00273-0
2. Mandoh, M., Redfern, J., Mihrshahi, S., Cheng, H. L., Phongsavan, P., and Partridge, S. R. 2021. Shifting from tokenism to meaningful adolescent participation in research for obesity prevention: a systematic scoping review. *Front. Publ. Health* 9:789535. doi: 10.3389/fpubh.2021.789535
3. Sellars, E., Pavarini, G., Michelson, D., Creswell, C., and Fazel, M. 2021. Young people's advisory groups in health research: scoping review and mapping of practices. *Arch. Dis. Child.* 106:698–704. doi: 10.1136/archdischild-2020-320452
4. Mandoh, M., Raeside, R., Todd, A., Redfern, J., Mihrshahi, S., Cheng, H. L., et al. 2023. Evaluating the effect of a 12-month youth advisory group on adolescent's leadership skills and perceptions related to chronic disease prevention research:

a mixed-methods study. *BMC Publ. Health* 23:2344.

doi: 10.1186/s12889-023-17283-2

5. Valanju, R., Barani, M., Mautner, D., Hadaya, I. A., Cross, A., Gunawardana, M., et al. 2022. Youth perspective on chronic disease prevention. *Lancet Child Adolesc. Health* 6:456–8. doi: 10.1016/S2352-4642(22)00131-6

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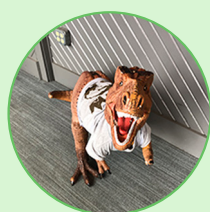
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## YOUNG REVIEWERS

### ERIC, AGE: 13

Eric is currently in 8th grade and is 13 years old. He enjoys playing percussion, reading, and playing video games with his friends. He is involved in Science Olympiad with his school, and also participates in math competitions every so often.



### JUNIOR MD, AGES: 11–13

We are a group of students at Quail Valley Middle School in Missouri City, Texas. In 2023, we founded the Quail Valley Middle School Junior MD club to unite the students at our school who are passionate about science and medicine. Our group is composed of students in the 6–8th grade (ages 11–13) who are focused on fostering a community of cooperative learning and promoting our development into future scientific leaders.

## AUTHORS



### STEPHANIE R. PARTRIDGE

Stephanie is a Senior Research Fellow at the University of Sydney, Australia. She works with young people to understand how we can use technology to create healthy societies and improve the health of young people. She leads a team of five researchers and works with over 20 young people, including her Youth Advisory Group. What she loves most about her job is that she gets to work with motivated and interesting people from all over the world. In her spare time, she loves walking her dog, Wally, gardening—including tending to her native beehive and worm farms. \*[stephanie.partridge@sydney.edu.au](mailto:stephanie.partridge@sydney.edu.au)



### MARIAM MANDOH

Meet Mariam Mandoh! She is not your average dietitian—she is a food expert with a Ph.D. from the University of Sydney! Her research focuses on creative ways to keep kids healthy and prevent diseases like diabetes. Mariam has worked in clinical, community, education and research settings—ensuring that everyone’s backgrounds are respected. Passionate about improving young people’s health, she is always brainstorming fresh ideas. When not being a dietitian superhero, Mariam enjoys time with her three kids, Fatimah, Zaynab, and Abbas, plus their mischievous parrot, Sultan, and two cute cats, Cheeto and Skittles.



### SARA WARDAK

Sara Wardak is a Research Assistant at the Faculty of Medicine and Health and is a Bachelor of Science (Genetics and Genomics)/Bachelor of Laws student and Dalyell Scholar at the University of Sydney. She is actively involved in research and community engagement. Sara’s passions lie in the nexus between law and science and her research focuses on themes of justice and health. She is a current volunteer in science communication and serves as an Ethnocultural Officer at the Sydney University Law Society.



### ALLYSON TODD

Allyson Todd is a Research Officer and Ph.D. student at the University of Sydney, Australia. Her research aims to include young people in public health research to build a healthy and sustainable future. She has an interest in preventing chronic diseases such as obesity and heart disease in young people. This includes looking at risk factors that impact how young people eat and access healthy food. In her spare time, she loves hiking, surfing, and teaching Pilates.



### REBECCA RAESIDE

Rebecca Raeside is a public health researcher. She is passionate about helping young people to lead healthy lives by eating well, being physically active, and keeping good mental wellbeing. Her research focuses on understanding ways we can use every day digital technologies, like text messages or social media, to help improve young people’s physical and mental health. By working with young people, she incorporates their unique perspectives and concerns within her research.