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Evaluation of a school-based community-led genetics education program for teachers and students: Findings from The Science Within Us pilot

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Abstract

As genetic technologies become increasingly accessible, genetic literacy is crucial to ensuring that people can make informed genetics-related healthcare decisions and navigate the related ethical and societal issues. Schools provide a vital opportunity to advance youth genetic literacy in a universal and cost-effective way, yet there is a lack of evidence-based information and resources on how to best deliver genetics content in schools. The *Science Within Us (SWU)* is a novel Australian curriculum-aligned genetics education program for 10-18-year-olds conceived and led by a community organisation, the Genetic Support Network Victoria (GSNV), in partnership with Australian families with lived experience of genetic conditions. A mixed-methods pilot evaluation with teachers and students in three schools (Years 5–11) in Melbourne, Australia used surveys (teachers n = 9, students n = 114) and focus groups/interviews (teachers n = 6, students n = 12) to assess the program's impact on genetic knowledge and attitudes towards people with genetic conditions.

Findings showed that students' self-rated understanding of genetic concepts improved significantly, with students in grades 5/6 and 10/11 also showing significant improvements in program-specific genetics knowledge and attitudes towards social inclusion of peers with genetic conditions. The program's human-centred approach and use of authentic storytelling was highlighted as a key strength by teachers, supporting students to apply their learning, consider socio-ethical factors impacting genetics, and engage empathetically with the content.

These preliminary results highlight the potential of community-led interventions to build students' genetic knowledge in school and support educators to teach genetics with confidence.

Introduction

Scientific progress in genetics is rapidly accelerating the diagnosis, management, and treatment of genetic conditions (Mackley et al., 2025). Advanced genomic techniques that allow researchers to study the entire genetic makeup of an individual have the power and speed to translate research into diagnoses, assessment of risk and treatment prediction, particularly for rare diseases (Mackley et al., 2025). While rare diseases are individually uncommon, these complex conditions collectively impact 300 million people globally, with approximately 80% being genetic in origin and an estimated 70% having childhood onset (The Lancet Global Health, 2024; Wang et al., 2024). Genetic technologies are also increasingly integrated into mainstream healthcare beyond diagnosis, making foundational genetic literacy essential for informed engagement with contemporary health systems and for navigating related social and ethical issues (Chapman et al., 2019; Pereza et al., 2022).

Genetic literacy can be described as "sufficient knowledge and understanding of genetic information to allow for effective communication and application of learned information and informed decision-making in personal, societal, and professional contexts" (Daly & Kaphingst, 2023, p. 8). Genetic knowledge supports informed decision-making in healthcare contexts and awareness of the social and ethical implications of these decisions (Chapman et al., 2019; Kaphingst et al., 2012; Marteau et al., 2001).

Additionally, genetic knowledge is foundational to reducing stigma about genetic variation and genetic conditions and enhancing socially responsible, community-level engagement with genetics (Chapman et al., 2019; Donovan et al., 2024). Despite growing public exposure to genetics through the increased accessibility of mass media and the internet (Salunke et al., 2025), genetic knowledge remains limited, including within highly educated communities and professions such as healthcare and education (Chapman et al., 2019). These gaps carry real-world consequences: in clinical settings, limited clinician knowledge has been linked to diagnostic delay, misdiagnosis and inadequate ongoing clinical management of rare diseases even once diagnosis is made (Faye et al., 2024). Furthermore, among families, parents may overestimate their own understanding of heritability and act on inaccurate assumptions with misplaced confidence (Harding et al., 2017); and at a societal level, such gaps can perpetuate misconceptions that contribute to stereotyping and stigmatisation of individuals living with rare and genetic conditions (The Lancet Child & Adolescent Health, 2020; Wainstein et al., 2024). However, evidence for this stigma is drawn primarily from small studies outside Australia, and there is limited evidence examining how such stigma manifests or can be addressed within Australian school settings specifically (The Lancet Child & Adolescent Health, 2020; Wainstein et al., 2024).

Schools, recognised as influential platforms for change (Kung & Gelbart, 2012), offer a universal, cost-effective environment to build youth genetic literacy. They are not only the formal environment for students' science and genetics education (Jackaman et al., 2025), but are also well positioned to address public genetic literacy and foster empathetic understanding that supports social inclusion for students living with genetic conditions (Donovan et al., 2024; Hubbard & Monnig, 2020; Kung & Gelbart, 2012). School-based stigma toward young people with genetic and hereditary conditions can manifest through peer exclusion, being perceived as less capable by peers, and being singled out or over-protected by teachers and staff (Oliveira et al., 2025). Fostering empathy in young people can reduce stigma towards mental health difficulties (Song et al., 2023) and can potentially reduce the challenges experienced by individuals with genetic conditions within education and workplace settings (Baynam et al., 2024; Johansen et al., 2024). However, students have informal, unfiltered exposure to genetic information through mass media prior to establishing a formal understanding of the topic (Donovan & Venville, 2012), which in Australia does not typically occur until secondary school (Australian Curriculum Assessment and Reporting Authority (ACARA), 2020). This is compounded by the challenge of reshaping oversimplified and inaccurate genetic information students absorb from popular culture (McCartney, 2024).

School science education could establish the foundations of genetic and genomic literacy (McKnight et al., 2021); however, teaching genomics also places significant demands on teachers' content knowledge and pedagogy, with educators reporting a lack of current, evidence-based content delivered in an engaging and accessible way in primary and secondary schools (McKnight et al., 2021; Sabatello et al., 2019). Beyond building teacher capacity, genomics education should embed the social, ethical, and human dimensions of genetics content, moving beyond conceptual knowledge towards a more holistic model of genetic literacy (Boerwinkel et al., 2017; Donovan et al., 2020; Hubbard & Monnig, 2020). Narrative-based interventions provide one way to achieve this, grounding genetics content in authentic

human contexts to deepen student reasoning and foster meaningful connections between science and society (Pulimeno et al., 2020). Yet curriculum resources achieving this integration remain limited, particularly those combining genomics content with lived-experience narratives and socio-ethical reflection (Airey et al., 2019). This points to a specific gap: the pedagogical case for narrative-driven approaches is well documented in bioethics and health education (Chowning et al., 2012; Pulimeno et al., 2020), but its application to genetics education remains largely untested, with existing narrative-based genetics resources mostly restricted to senior secondary delivery. This concentration reflects that genetics is formally taught only from secondary school onward (Australian Curriculum Assessment and Reporting Authority (ACARA), 2020), and the evidence base for effective teaching resources is similarly concentrated at this level. Some existing secondary school curriculum resources have been shown to improve educator confidence and knowledge and deepen student understanding of genetic concepts and socio-ethical issues (McKnight et al., 2021). To our knowledge, no study has yet examined whether narrative-based genetics resources produce measurable gains in students' genetic knowledge or educator confidence. A resource that embeds socio-ethical, narrative-based content within a modular, engaging, teacher-supported platform has the potential to bridge the current gap between theoretically sound curriculum design and genuinely usable classroom practice. The Science Within Us (SWU) was developed to address this need for curriculum-aligned resources that are simultaneously educative for teachers, engaging and accessible for students.

Through its networks, the Genetic Support Network Victoria (GSNV) identified that children with genetic conditions often struggled with identity and simply wanted to fit in among their peers, a pattern also reflected in the broader literature on hereditary conditions (Oliveira et al., 2025). This highlighted the need for a classroom foundation that could support these conversations earlier, positioning genetics as both a human and scientific story. SWU is a curriculum-aligned genetics education program for Australian students aged 10–18 years (Years 5–12; Supplementary Fig. 2), developed in direct response to this identified community need. It was conceived, designed, and independently evaluated as a community-driven initiative led by the GSNV in collaboration with educators, clinicians, researchers, bioethicists, and individuals with lived experience of genetic conditions (see Supplementary Fig. 1 for sequential codesign framework). A Steering Committee and Panel of Young People with Lived Experience provided oversight from conceptualisation through to implementation, to ensure that the evaluation tools and materials were accessible, relevant, and did not reinforce stigma towards young people living with genetic conditions.

The design of SWU was further informed by educational frameworks that focus on inquiry-based learning and social and emotional development (Supplementary Tables S1 and S2), positioning narrative as a core pedagogical tool for building understanding and empathy across diverse learners within an inclusive learning environment. By incorporating lived-experience narratives, SWU was designed to develop genetic knowledge that is personally relevant, ethically informed and accessible to all learners across multiple year levels. The program also includes short video soundbites from genetic health professionals and STEM scientists to build awareness of careers in genetics and genomics (Online Resource 3).

A mixed-methods evaluation was undertaken to assess the program's impact on educators and students in upper-primary and secondary school regarding knowledge, and their attitudes, particularly related to empathy and social inclusion. It was hypothesised that participation in SWU would result in an increase in students' genetic knowledge and lead to improvements in empathy, attitudes, and social inclusion towards individuals with genetic conditions and increase teachers' confidence in teaching genetics content.

Methods

This study employed a multi-site, mixed-methods study design. SWU was evaluated across three schools within metropolitan Melbourne, Australia, from July 2024 (Term 3) to December 2024 (Term 4). Ethics approval was received through the Human Research Ethics Committee (HREC) at The Royal Children's Hospital (# 105245) and approval to contact Victorian Government schools to undertake research through the Department of Education's Research in Schools and Early Childhood Settings (RISEC process) (24-02-263).

Participants

Of the eight schools that were approached, four consented to implementing SWU and participating in the evaluation activities. One school was excluded because they were unable to participate before the conclusion of data collection. Ultimately, three schools within Melbourne participated in the study, representing a sample of convenience. All participating schools were above the 90^{th} percentile on the Index of Community Socio-educational Advantage (ICSEA) (Australian Curriculum Assessment and Reporting Authority (ACARA), 2024), indicating very high levels of educational advantage compared to other Australian schools. Participants included teachers who delivered the SWU program, and their students.

Procedures

Participant Recruitment

Potential schools were identified through the research team's networks. Principals consented for their school to participate via an online REDCap form (Harris et al., 2019; Harris et al., 2009). Schools were eligible to participate if they were in Victoria and were willing to implement the program at the primary (grades 5-6) or secondary (grades 7-12) level.

Once consent from principals was obtained, eligible teachers were invited to participate via an email circulated by their school leadership. Classroom teachers were eligible if they taught health or science content to students in grades 5-12 and had sufficient English competency to participate in the study activities.

Participating teachers circulated a letter and online REDCap (Harris et al., 2019; Harris et al., 2009) consent form to their students' parents/caregivers. Students were eligible if their teacher was implementing the program, and their carer had provided consent. All students in participating classes were taught the SWU program, however, only students who had parental consent and provided assent themselves participated in the research activities.

Teachers were invited to participate in focus groups, conducted in-person or online. Students were eligible to participate in focus groups if they had parental/caregiver consent, responded to the baseline survey, and expressed interest in participating to their teacher.

Data collection

Surveys

Teachers and students were invited to complete surveys prior to commencing the program and again post-completion. The length of time between completing the program and the follow-up survey varied across schools and year levels due to scheduling difficulties, varying from one day post-completion to two months. All teachers completed the survey online via REDCap (Harris et al., 2019; Harris et al., 2009), while students had the option of completing the survey online or via hard copy. All students completed the pre-implementation survey immediately prior to beginning the SWU program in their classroom.

Survey instruments consisted of study-designed items developed by the research team in collaboration with an advisory panel of young people with lived experience of genetic conditions. This panel ensured that all survey items were accessible, relevant, and did not reinforce stigma towards young people living with genetic conditions.

Focus Groups/interview

Following implementation, educators and students were invited to take part in semi-structured focus groups/interviews. The interview protocols were also developed in collaboration with the lived experience panel and aimed to facilitate a deeper understanding of the program's implementation and impact within the classroom. All recordings were transcribed by an external transcription company and reviewed by a member of the research team. All focus groups and interviews were facilitated by SG, who is experienced in qualitative research with young people and in education settings. Two teacher focus groups (with group size ranging from 2-4 teachers) and one interview were conducted and recorded online via Zoom. Each session lasted for 25–45 minutes. Two focus groups with grade five and six students were conducted and recorded in-person during a classroom session, with each group consisting of six students. For students, the question guide was integrated with age-appropriate activities, such as using emojis on hardcopy paper to react to prompts to engage students and prompt discussions about the program (Constable et al., 2025).

Students were randomly selected across the five classes, with selection criteria ensuring balanced representation of all classes and teaching methods (online, paper, or hybrid). Two students that were

absent were replaced by another eligible child chosen by their classroom teacher. The research team was unable to schedule focus groups with secondary students due to conflicting school-related activities and a limited number of students expressing interest.

Outcomes and measures

Demographics. Participant demographics were collected on gender, age and school. Teachers were also asked about their role in the school, level of education, length of time teaching, subject they would be teaching in the SWU program, and which year levels they would be teaching the program to. Students were asked about their year level, class group, language spoken at home, and familial history of genetic conditions.

Impact. The preliminary impact of SWU on educators and students was assessed, including its impact on genetic knowledge and attitudes, empathy and social inclusion.

A. **Genetic knowledge** was assessed in two classes: conceptual and sociocultural knowledge (Boerwinkel et al., 2017). To assess conceptual knowledge of genetic concepts, study-designed items based on the year-level content in the SWU program were used with respondents ('True', 'False' or 'Don't know' to each item).

Most students received five questions; however, one school received four due to the items being updated during data collection to enhance clarity. Participants' conceptual understanding and sociocultural knowledge of the application of genetics to real-world settings were explored further in focus groups. Additional study-designed items also examined perceived impacts of SWU on students' understanding of genetics, and teachers' confidence in teaching genetics and discussing genetic conditions. The program's impact on genetics knowledge was also explored further in focus groups.

B. **Attitudes, empathy and social inclusion** towards people with genetic conditions were assessed using study-designed items, which included seven items on a 4-point Likert scale, ranging from strongly disagree to strongly agree. Some items differed depending on students' ages. Due to the absence of existing measures assessing attitudes towards people with genetic conditions, study-designed items were informed by the psychometrically sound Attitudes to Disability Scale (Power et al., 2010). The items used for this study were developed in consultation with the lived experience panel, to ensure that they did not reinforce stigmatised attitudes towards young people with genetic conditions. The program's impact on students' and teachers' attitudes was also explored further in focus groups.

Data analysis

All quantitative analyses were performed by a qualified statistician, using Stata Release 17.5. To present summary data, descriptive statistics were utilised for all key variables at baseline and follow-up. Inferential statistics were utilised to make comparisons in students between pre- and post-survey

scores. Linear mixed models were also used to compare means at each time point. Inferential statistics were not utilised for teachers' responses due to the sample size.

Qualitative data was analysed using NVivo software using a structured and systematic process incorporating pre-determined categories informed by the key evaluation questions (KEQs) and stakeholder discussions. Additional categories emerging from the data were also considered. Analysis comprised both descriptive analysis: categorising broadly according to KEQs using a deductive approach; and thematic analysis: further analysis to code into themes, specific ideas, concepts or points developed inductively from the data. Data was cross-coded into themes by an additional independent researcher to ensure coding accuracy and alignment. Both analysts independently followed the approach outlined by Srivastava and Hopwood (2009), after which the coding was further refined to ensure alignment. Themes identified from the focus groups and interviews were discussed by members of the research team (HRF, KA, RS, SJD and LAP) alongside the preliminary quantitative data to explore consistencies and differences in these findings. This triangulation allowed for the contribution of diverse perspectives from the broader research team, including those with lived experience, and ensured a comprehensive understanding of teachers' and students' experience of the program and its impacts.

Researcher characteristics and reflexivity:

The project and evaluation were influenced by the project lead's (HRF) lived experience as a parent of a child with a rare genetic condition and desire to create opportunities for students like her son and peers to engage in informed, and empathetic conversations about genetic variation and identity within the classroom. This perspective combines lived experience with professional practice, and guided decisions about program structure, ethics, and evaluation. For many involved, SWU became more than a science education resource; it strove to create a platform for advocacy and dialogue about identity, health, and social belonging. Recognising that these underpinnings could introduce bias, the evaluation was conducted by a team of independent researchers to maintain rigour. Within this independent evaluation team, the qualitative analyst (LAP) has lived experience of genetic and acquired conditions; and the project coordinator (KA) has lived experience of an acquired condition.

Results

All nine educators that agreed to implement the program in their classroom provided consent and completed both the pre-implementation and follow-up survey. Of the 220 eligible students, 128 students had parental consent to participate, with 114 providing assent and participating in the baseline survey. 100 of these students also responded to the follow-up survey. A sub-sample of 52 primary students were eligible to participate in qualitative data collection activities, with 27 expressing interest and 12 students participating in the focus groups. Five teachers participated in the focus groups, with one teacher completing an interview and one teacher providing written feedback in lieu of attending the focus group. Two teachers did not participate in the qualitative activities due to scheduling conflicts. Demographic information for participating students and teachers is presented in Tables 1 and 2 respectively.

Table 1. Student demographics

	Students (n = 114)
Participants	n (%)
School 1	23 (20.2)
School 2	35 (30.7)
School 3	56 (49.1)
Gender	
Male	57 (50.0)
Female	54 (47.4)
Other	1 (0.9)
Prefer not to say	2 (1.8)
Year Level	
Grade 5/6	56 (49.1)
Grade 8	11 (9.7)
Grade 10/11	47 (41.2)
Has someone in their family had a history of a genetic condition?	
No	44 (38.6)
Yes	14 (12.3)
Don’t know	55 (48.3)
Prefer not to say	1(0.9)

The SWU program was implemented in all participating classes, with the number of lessons completed varying across year levels (table 3). The program was delivered in varying formats across the participating schools. School One implemented SWU in two grade 11 biology classes, using a mix of printed and electronic material that formed the basis of an assessment task. School Two implemented SWU in three grade 11 biology classes and one grade eight class, allowing the students to engage autonomously with the online platform (Online Resource 1). School Three implemented the program across five classrooms of composite and single-grade year five and six students, with teachers delivering the program using printed materials, the online program, or a hybrid approach.

Table 2. Educator demographics

	Teachers (n = 9)
Participants	n (%)
School 1	2 (22.2)
School 2	2 (22.2)
School 3	5 (55.5)
Age	
26-35	5 (55.5)
36-55	3 (33.3)
56+	1 (11.1)
Gender	
Male	2 (22.2)
Female	7 (77.8)
Other	0 (0.0)
Prefer not to say	0 (0.0)
Highest level of education	
Bachelor's degree	2 (22.2)
Postgraduate teaching degree	5 (55.5)
Postgraduate degree (other)	1 (11. 1)
More than one postgraduate degree	1 (11.1)
Years Teaching in Schools	
0-5	3 (33.3)
6-10	4 (44.4)
11-15	0 (0.0)
16-20	1 (11.1)
21+	1 (11.1)
Grade SWU program taught	
Secondary (Year 8[a], 10[b] & 11)	4 (44.4)

Primary (Year 5/6)	5 (55.5)

[a] One teacher implemented the program in their grade 11 and grade 8 class.

[b] Year 11 classes also included advanced students from Year 10.

Table 3. Number of SWU lessons completed, reported by teachers

# Lessons Completed	Teachers		
	Yr 5/6 n = 5	Yr 8[b] n = 1	Year 11[b] n = 4
1-2 lessons	1 (20.0) [a]	1 (100.0)	2 (50.0)
2-4 lessons	4 (80.0)	0	1 (25.0)
4-6 lessons	0	0	1 (25.0)

[a] One grade 5 teacher was absent during the first lesson.

[b,] One teacher implemented the program in their grade 11 and grade 8 class.

For most younger students, the SWU program was the first time they had been exposed to genetics content at school. While all year 10 and 11 students reported having previously been taught genetic content at school, most grade five and six students (95%) and grade eight students (82%) reported they had not learnt about genetics at school previously. All secondary teachers reported having previously incorporated genetic or genomic education into their teaching, while no primary school teachers had experience incorporating this content. Most teachers reported that they had the background knowledge necessary to use the program (89%) and that the resources were adaptable (67%), easy to access and use (89%), and aligned well with the curriculum (78%).

The adaptability of SWU also emerged as a key theme in the teacher focus groups, with most teachers appreciating the way in which the material allowed for autonomous learning, though one teacher found this aspect challenging for their teaching style. At the year 10/11 level, the SWU content was either used in a “somewhat supplementary” (Teacher B) capacity alongside established curriculum or was more extensively used in one school as the basis for a year 11 Biology assessment. For younger classes, students were more likely to be encountering this material as a stand-alone topic which functioned as an introduction to genetics, with the material being spread over several classes, including at-home activities.

The strongest engagement was reported around the use of videos with one student expressing interest in more stories. This was consistent with Teacher F’s reflections that the material “opened up” topics of

discussion and areas of interest for students, working as an introduction to a new subject area.

Impact on genetic knowledge

There was a statistically significant increase in the proportion of correct genetics knowledge responses for students in grades 5/6 (p=0.022) and grades 10/11 (p<0.001), but no significant increase for students in grade 8 (p=0.386) (Table 4). Students' self-rating of their understanding of genomic concepts also significantly increased following completion of the program across all year levels (Table 4). The proportion of students who provided correct responses at the individual item level is outlined in Table 5. Students were also asked to reflect on the impact of the SWU program on their understanding of genetic concepts, and consideration of ethical and social issues relating to genetic technologies (Table 6). While most students, regardless of grade, indicated that the SWU lessons increased their understanding, a smaller proportion of students in grades 5, 6 and 8 agreed that SWU helped them to consider these issues (Table 6).

Table 4. Linear mixed models, student genetic knowledge

			Baseline		Follow-up		*p*
Item	Grade	n	M	95%CI	M	95%CI	
Percentage of genetic knowledge items correct							
	5/6	56	47.86	(41.58,54.14)	56.86	(50.12,63.59)	0.022
	8	11	43.64	(28.62,58.66)	54.29	(35.46,73.11)	0.386
	10/11	47	40.74	(32.91,48.58)	67.07	(59.06,75.08)	<0.001
How would you rate your current understanding of genomic concepts? [a]							
	5/6	56	1.84	(1.54,2.14)	3.70	(3.38,4.03)	<0.001
	8	11	2.27	(1.59,2.95)	3.46	(2.52,4.41)	0.039
	10/11	47	3.62	(3.37,3.86)	4.00	(3.74,4.25)	0.005

Note. Grade 8 students received only one lesson of the SWU program

[a] Scale values range from 1 to 6, with higher values representing greater understanding.

Table 5. Proportion of correct responses to genetics knowledge items

		Baseline		Follow-up	
Item	Grade	n	%	n	%
An example of a physical trait is a loud laugh	5/6	29	51.8	23	47.9
A scar from an injury is an inherited trait	5/6	39	69.6	39	83.0
The most common physical trait in the world's population is having brown hair	5/6	23	41.1	21	43.8
It is rare to have a genetic condition	5/6	12	21.4	22	46.8
Genes control the characteristics we inherit from our parents	5/6	31	55.4	30	63.8
Changes in DNA are called variables	8	3	27.3	6	85.7
Genetic conditions are always visible on your body	8	8	72.7	5	71.4
The circulatory system in the body is affected by a genetic condition called Cystic fibrosis	8	5	45.5	1	14.3
The shape of a healthy blood cell is biconcave	8	6	54.6	7	100.0
People with respiratory conditions get blood transfusions in hospital to make them better	8	2	18.2	0	0.0
Newborn Bloodspot Screening can diagnose all genetic conditions	10/11	20	42.6	39	86.7
The Newborn bloodspot test is done a few days after a baby is born	10/11	28	59.6	39	86.7
A bioinformatician is the health professional that studies information from newborn screening blood spot test	10/11	12	25.5	28	62.2
If a doctor/geneticist thinks they know which gene is involved in a genetic condition, they will test all of the person's DNA (whole genome)	10/11	9	37.5	13	59.1
A geneticist may order a whole genome test when they have some idea of what gene may be causing a condition	10/11	10	43.5	12	52.2
A de novo gene is a term used to describe a change in DNA that has not appeared in previous generations	10/11	7	29.2	20	44.4

Table 6. Students' perspectives on impact of SWU on genetic knowledge (Agree/Strongly Agree)

	Grade 5/6 n (%)	Grade 8 n (%)	Grade 10/11 n (%)
The SWU lessons increased my understanding of genetic concepts	30 (63.8)	6 (85.7)	37 (84.1)
The SWU lessons helped me consider ethical and social issues relating to genetic technologies	11 (21.6)	4 (36.4)	36 (76.6)

Note. Students that didn't respond to these items have been removed from this table. Grade 8 students received only one lesson of the SWU program

In the focus groups, Teacher C reported that two of their students, from different classes, had shared examples of genetic screening information they had encountered outside of school in General Practice settings.

"It is starting to resonate, and I've not had that before. I've taught this for a long while. So, they are starting to observe and see connections with the real world which I think was really important." [HS2 Teacher C]

This practical dimension formed what Teacher B called "life-worthy learning" opportunities to connect scientific material to students' wider experiences.

Impact on Confidence

Although inferential statistics could not be calculated due to the small teacher sample size, both primary and secondary teachers reported greater confidence discussing genetic conditions with their students after implementing the program (Figure 1). Additionally, most teachers (n = 6, 66.7%) agreed that they felt supported in teaching genetics content as a result of the SWU program.

Impact on attitudes, empathy and social inclusion

Changes in students' responses to social inclusion items from pre- and post-implementation are displayed in Table 7. There was a statistically significant improvement for students in grade five and six for '*a person living with a genetic condition is an important member of the community*' (p=0.013) and '*having a genetic condition shouldn't be a factor in whether you hang out with someone*' (p=0.001). A significant improvement was also observed in grade 10 and 11 students for *'I understand what it can be like to live with a genetic condition'* (p = 0.027). A significant difference in grade eight students' responses were not observed for any social inclusion items. After completing the program, 67% of teachers agreed that SWU helped their students understand genetic conditions that may affect other children, and 65% of students agreed that the resource helped them understand genetic conditions that could affect others.

In focus groups, teachers reported that the SWU curriculum was most impactful in its use of real-world examples and storytelling:

“The human touch, the added element of human touch was what made it stand out”. (HS1 Teacher A)

This humanising focus was seen by teachers as enabling students to empathetically engage with genetics topics, particularly through the program’s use of videos. Teacher A reported that after marking their students’ exam, they felt that student responses to questions regarding the ethics of genetic screening were “informed” by SWU materials as “there’s a bit more of a humane approach.” Teachers noted that social inclusion messages were strong focal points at their schools, and that the SWU content provided a means for some students to connect that message to genetic science, though some examples were noted of students who had not yet fully made that connection.

“I think more inclusivity and consideration of others was more at the forefront of Session 3 because you had those videos.”[PS Teacher G].

“You could see almost just visually how students were put in this theoretical idea of autosomal mutation into an actual person’s life. There was a definite aha moment” [HS2 Teacher C].

“They really liked the fact that there were people there to I guess make the theory real. That was good” [HS2 Teacher C].

“I just feel like the fact that they were kids involved as well, that helped, close to their ages” [HS1 Teacher A].

In focus groups, students reported positive engagement with the videos featuring stories of real families **(**Online Resource 2**)**, with one student also expressing interest in stories from adults and further exploring additional aspects of lived experience such as the “struggles” faced by people with genetic variations in daily living. This curiosity in learning more about “what they [children with genetic conditions] do on a day-to-day basis” was explained further:

“Because they’ve got genetic conditions, they might have struggles with things and it would be interesting to know their struggles.” (Primary-aged student).

While these students indicated an understanding that genetic conditions may impact daily life, they described interest in learning more about what that specifically meant in practical terms, including across the life course:

“Maybe we could do a video with kids and also maybe with adults who’ve had it their whole life.” (Primary-aged student).

“One of the activity questions could be like comparing the adults to the kids [inaudible]... had it their whole lives and the kids might be new to it.” (Primary-aged student)

This curiosity was expressed in terms that indicated some understanding that genetic conditions can have differing impacts for children and adults, and that they can change over time. It also indicates an awareness that these conditions might involve practical “struggles” in daily life, without knowing yet what these might involve. Students indicated an existing understanding of bodily variation as part of social inclusion topics prior to engaging with SWU but also referenced how the program had helped think further about genetic variation.

“I know that some people have disabilities and conditions, then I always thought …they’re thinking differently but then those videos kind of made me think that they kind of connect. Even though they do have some sort of disability, like our brains kind of work the same, and then we all meet at the same spot, match.” [Primary-aged student]

For this primary-aged student, the SWU content helped them understand that “having disabilities and conditions” might involve starting from different sets of experiences, but that it is still possible for them to connect and “meet at the same spot” regardless of those differing starting points.

Table 7. Changes in students' responses to social inclusion items

	Baseline		Follow-up		*p*
Item	M	95%CI	M	95%CI	
A person living with a genetic condition is an important member of the community					
Grade 5/6	3.13	(2.94,3.31)	3.37	(3.17,3.57)	0.013*
Grade 8	3.09	(2.70,3.48)	3.13	(2.65,3.61)	0.896
Society recognises the worth of someone living with a genetic condition.					
Grade 10/11	2.81	(2.52,3.09)	2.76	(2.47,3.05)	0.622
Having a genetic condition shouldn't be a factor in whether you hang out with someone					
Grade 5/6	2.96	(2.70,3.22)	3.48	(3.20,3.76)	0.001*
Grade 8	3.36	(2.79,3.94)	3.25	(2.57,3.92)	0.714
People living with genetic conditions are fully included and accepted by society					
Grade 10/11	2.34	(2.17,2.51)	2.40	(2.23,2.58)	0.536
People living with genetic conditions are treated the same as people who are not living with genetic conditions					
Grade 5/6	2.54	(2.33,2.74)	2.60	(2.38,2.82)	0.597
Grade 8	2.73	(2.13,3.32)	3.00	(2.26,3.74)	0.575
People living with genetic conditions are treated the same as people who are not living with genetic conditions					
Grade 10/11	2.11	(1.93,2.29)	2.23	(2.04,2.41)	0.297
People think that if someone has a genetic condition, it is only a small part of who they really are.					
Grade 5/6	2.89	(2.68,3.10)	3.04	(2.82,3.26)	0.210
Grade 8	3.00	(2.43,3.57)	3.15	(2.42,3.87)	0.756
People think someone's identity is defined only by their genetic condition.					
Grade 10/11	2.28	(2.09,2.46)	2.25	(2.06,2.44)	0.778

I understand what it can be like to live with a genetic condition.					
Grade 5/6	2.55	(2.31,2.79)	2.60	(2.34,2.85)	0.714
Grade 8	2.55	(2.00,3.10)	2.86	(2.17,3.55)	0.488
Grade 10/11	2.02	(1.68,2.36)	2.34	(2.00,2.68)	0.027*
I think that living with a genetic condition can make someone resilient.					
Grade 5/6	3.09	(2.91,3.26)	3.06	(2.88,3.24)	0.705
Grade 8	3.27	(2.85,3.69)	3.14	(2.62,3.67)	0.705
Grade 10/11	3.36	(3.20,3.52)	3.27	(3.11,3.43)	0.360
I feel confident in recognising when someone with a genetic condition might need help					
Grade 5/6	3.11	(2.93,3.29)	3.15	(2.95,3.34)	0.744
Grade 8	3.36	(2.94,3.79)	3.12	(2.60,3.64)	0.413
Grade 10/11	2.77	(2.57,2.97)	2.87	(2.67,3.08)	0.332

Note. Scale values range from 1 to 4, with higher values representing stronger agreement. N = 56 (grade 5 and 6 students), N = 11 (grade 8), N = 47 (grade 10/11). *Statistically significant at $p < 0.05$. Grade 8 students received only 1 lesson.

Discussion

This study aimed to evaluate the Science Within Us (SWU) program, a novel community-led genetics program, by exploring the impact of SWU on genetic knowledge and attitudes towards individuals with genetic conditions. Results provided early evidence that a curriculum-aligned, person-focused genetics program can be successfully used to scaffold genetics knowledge and support empathetic attitudes towards peers with genetic conditions.

Despite challenges with implementing the program within a full curriculum, SWU was piloted across three of the eight schools that were approached. Although the program was not comprehensively trialled within the participating year eight class; in other year levels the findings demonstrated that the program was easily implemented within the classroom context, including with younger students who had not been previously exposed to genetic concepts at school. Teacher findings highlighted the adaptability of the resource, with the use of modular standalone components with multiple learning modalities, such as visual, narrative, discussion-based, and reflective activities. This enabled teachers to adapt the sequencing of the content according to their classroom context, student needs, and curriculum timing. Previous research has indicated that the conceptual complexity of genetics and genomic concepts can act as a barrier to educators implementing genetics education with confidence within the classroom

(McKnight et al., 2021). However, these findings suggest that the SWU program's practical usability enabled teachers to feel confident and supported while teaching this content, thereby lowering barriers to implementation.

Knowledge Gains

Results indicated that students demonstrated increased understanding of core genetic concepts following participation in SWU. Statistically significant improvements in conceptual knowledge were observed for some items among students in grades 5/6 and 10/11. Given most primary-aged students indicated no prior classroom exposure to genetics, these results suggest that foundational genetic concepts can be effectively introduced before Years 7/8 as currently reflected in the Australian curriculum (Australian Curriculum Assessment and Reporting Authority (ACARA), 2020; Elmesky, 2013). Students' self-reported understanding of genomic concepts significantly increased following implementation across all year levels. Furthermore, despite the presence of social and ethical considerations of genetics within the senior school curriculum, secondary-school teachers reported that the use of lived-experience case studies generated novel knowledge gains that they had not observed previously.

Critical thinking and application of knowledge

The findings highlighted the role of SWU in creating science experiences that are useful in real-life settings, by supporting students to connect abstract genetic concepts to human experiences in their families, communities, and broader society. Teachers reported that the real-world examples and videos of young people living with genetic conditions enabled students to emotionally engage with the material, move beyond abstract concepts and recognise how genetics can apply to socially meaningful contexts, including their lives, and others in their communities. This is consistent with socio-scientific and context-based approaches to science education (Bennett et al., 2007; Dawson, 2024). Story and case-based approaches have been used in school genetics, largely as hypothetical or public case scenarios to support argumentation and decision-making (Dawson & Venville, 2010) however, evaluations of real stories of young people living with genetic conditions as the organising thread of a school genetics program are lacking.

The findings also suggested that the program's use of narrative-based videos and case studies supported students to think critically about genetic variation, human difference, and how genetic conditions can impact individuals' quality of life. Within SWU, the use of personal stories and inclusive examples appeared to support students in engaging with genetic concepts with a socio-scientific lens, where genetic knowledge was considered alongside social, ethical, and lived experience contexts (Chowning et al., 2012; Pulimeno et al., 2020). Importantly, these shifts were achieved without compromising scientific rigour, demonstrating in alignment with Dawson's assertion (2024) that socio-scientific issues are not an optional add-on but a necessary framework for connecting scientific understanding with ethical reasoning, citizenship, and real-world decision-making in secondary science education.

Attitudinal shifts

This greater understanding was also illustrated by the majority of primary and secondary students (50% and 81%, respectively) reporting that the program helped them understand genetic conditions that may affect others and the significant improvements observed in their responses to several social inclusion items. These observed attitudinal shifts align with previous research (Dole et al., 2025) indicating that exposure to disability representation and narrative approaches can challenge deficit-based assumptions and contribute to reducing stigmatising attitudes. Differences in how students engaged with the social and ethical dimensions of genetics were evident across the grade levels. Rather than age-related patterns, these differences may reflect variation in students' exposure to the social inclusion framework within the Australian curriculum. If this explanation holds, the impact of genetics education on inclusive attitudes may depend on how explicitly it is connected to students' existing inclusion learning. Students in focus groups described existing understanding of bodily variation within social inclusion topics prior to SWU, and teachers noted that inclusion messages were a strong focus in their schools. This suggests that in primary school settings, genetic variation could be positioned as a context for identity and respectful relationships learning, as in SWU's Years 5–6 module, which is aligned to Health and Physical Education. In secondary science, where the social dimensions of genetics are framed through ethics and genetic technologies, lived-experience perspectives could be integrated alongside this content.

The responses of primary-aged students and primary teachers highlighted significant familiarity with social inclusion messaging prior to the SWU module but less pre-existing understanding of the physical, medical and practical impacts that disabilities and health conditions can involve. In Victoria, primary students receive structured social and emotional learning through the Resilience, Rights and Respectful Relationships materials (Cahill et al., 2018), a program available to schools nationally; however, we were unable to identify evaluations of their effect on students' understanding of disability. SWU therefore provided an opportunity for learning about genetic conditions in a new context, complementing students' existing familiarity with social inclusion messaging with a new scientific understanding of the biological basis of bodily variation. The case studies provided a mechanism for students to link their existing familiarity with the importance of social inclusion with newer understandings of genetic variations as a factor producing levels of disability.

SWU appears to have played a different role in each stage of teaching. For primary students, SWU appeared to integrate scientific learning into an established understanding of diversity and community. In contrast, secondary students in this cohort have received less exposure to structured material about social inclusion, as their primary schooling pre-dates the mandatory implementation of *Resilience, Rights and Respectful Relationships* (RRRR) curriculum (Cahill et al., 2024) and encountered the program's ethical and social components as a core part of the senior science curriculum, with a stronger emphasis on ethics and genetic technologies rather than social inclusion. These patterns suggest that age-appropriate scaffolding and curriculum sequencing play a critical role in shaping how students interpret and apply genetic knowledge and that flexible, developmentally responsive implementation is essential in community genetics education.

Limitations

Limitations of this study included implementation difficulties related to lesson and research timetabling and the variability in delivery arising from the program's adaptable design, a common limitation in school-based intervention research (Lovett et al., 2024). Further evaluation in larger more diverse samples is required to examine implementation in varied classroom settings and how to best support student engagement and impact, while maintaining the program's flexibility and accessibility. The sample was small and drawn from three metropolitan schools with high socio-educational advantage, which limits generalisability. The study had no control group, so changes cannot be attributed to the program alone. The interval between program completion and follow-up varied from one day to two months. The grade 8 sample was small and received one lesson only, and focus groups could not be held with secondary students.

Conclusion

In conclusion, SWU was implemented in participating classrooms and demonstrated initial impacts on students' genetic knowledge and attitudes towards people living with genetic conditions. Teachers reported increased confidence teaching genetics content, an important finding given that this has previously been identified as a key barrier to implementing genetics education in schools. Importantly, these outcomes were achieved through a community-led development model, in collaboration with individuals living with, or caring for, someone with a genetic condition. The findings provide promising evidence that a narrative-based approach featuring authentic voices and experiences can create meaningful connections between scientific concepts and everyday life. This simultaneously supports knowledge gains and attitudinal shifts. The findings also illustrated that developmentally sequenced genetic concepts can be introduced earlier than the Australian curriculum currently reflects and can be integrated with personal narratives and real-world contexts to support gains in students' conceptual understanding and generate engagement with socio-scientific issues.

Declarations

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Competing interests

HRF was employed by Genetic Support Network Victoria, which developed The Science Within Us program. The remaining authors have no relevant financial or non-financial interests to disclose.

Ethics approval

This study was approved by the Human Research Ethics Committee of The Royal Children's Hospital, Melbourne (HREC 105245). Approval to conduct research in Victorian Government schools was granted by the Victorian Department of Education through the Research in Schools and Early Childhood Settings (RISEC) process (24-02-263). The study was conducted in accordance with the National Statement on Ethical Conduct in Human Research (2023).

Consent to participate

Informed consent was obtained from all teacher participants. For student participants, informed consent was obtained from a parent or guardian, and students gave their assent.

Consent for publication

Participants consented to publication of de-identified data, including quotations.

Consent for publication

Participants consented to publication of de-identified data, including quotations. Written consent for the use of identifiable images in any media was obtained from all individuals appearing in the videos provided as Online Resources 1–3, including from parents or guardians on behalf of participants under 18 years of age.

Data availability

The data are not publicly available to protect participant privacy. De-identified data may be available from the corresponding author on reasonable request, subject to approval by the Human Research Ethics Committee of The Royal Children's Hospital.

Author contributions

HRF: conceptualisation, funding acquisition, investigation, methodology, resources, supervision, visualisation, writing (original draft), writing (review and editing).

KA: data curation, methodology, project administration, writing (original draft), writing (review and editing).

SG: conceptualisation, investigation, methodology, writing (review and editing).

LAP: formal analysis, writing (review and editing).

RS: conceptualisation, methodology, supervision, writing (review and editing).

SH: data curation, formal analysis, methodology, writing (original draft), writing (review and editing).

BNT: conceptualisation, methodology, supervision, writing (review and editing).

SJD: conceptualisation, funding acquisition, methodology, supervision, writing (review and editing).

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