Diagnosis Day

A collaborative storytelling project about rare genetic conditions

Melbourne Genomics Health Alliance

gsnv Genetic Support Network Victoria

August 2023

CON-TENTS

"Your child is not the sum of their diagnosis or not just what you read about in a medical journal – your child is capable of so much more."

Beth and Josh (Diagnosis Day, Ep.5)

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Diagnosis Day

PURPOSE

This report shares insights from the evaluation of a collaborative storytelling project, Diagnosis Day

We hope it is useful to advocates and communicators who:

- use storytelling to draw attention to health and social issues
- work with subject matter experts to create public content
- support people in vulnerable circumstances to tell their stories

WHAT IS DIAGNOSIS DAY?

Diagnosis Day is the story of six Australians with rare genetic conditions.

The seven-episode video series follows individuals and families as they search for answers, find community, and plan for the future. Episodes run for around five minutes and are collected on the website **DiagnosisDay.org.au**.

The series is a collaboration between the Melbourne Genomics Health Alliance and the Genetic Support Network of Victoria (GSNV).

WHY DID WE MAKE IT?

Rare disease is not as rare as people think. Approximately 8% of Australians live with one of more than 10,000 known rare diseases – more than those who live with diabetes.[1]

Many rare diseases have a genetic origin and can be diagnosed through genomic testing: a process that sequences a patient's entire genome (all of their DNA) and analyses it for gene variants that can cause disease. Genomics is not yet offered widely in clinical care.

Melbourne Genomics saw Diagnosis Day as an opportunity to demonstrate the value of a genetic diagnosis: its impact on people's healthcare, wellbeing and capacity to plan for the future. The series is a learning tool for clinicians who use genomics in their practice.

GSNV saw Diagnosis Day as a way for people with lived experience to tell their own stories, in their own words. We wanted health professionals to understand the importance of communicating a diagnosis with care and sensitivity, and recognise that ongoing support is essential.

1. Elliott, E & Zurynski, Y. (2015) 'Rare diseases are a 'common' problem for clinicians. Australian Family Physician. https://www.racgp.org.au/afp/2015/september/rare-diseases-are-a-common-problem-for-clinicians

MEET THE FAMILIES

PATRICK

Patrick is nine going on ten and is an avid student of the martial arts. His tight-knit, food-loving family consists of parents Kathy and Rocky and his baby brother. Patrick was born with Phenylketonuria (PKU), a condition that prevents the normal breakdown of proteins found in many foods.

AMELIA

Amelia is nine years old and is Robbin and Georgia's only child. She enjoys swimming, dancing and playing the guitar. Both Robbin and Georgia have a variant of Thalassaemia, a blood condition that inhibits the body's ability to produce haemoglobin. Amelia was born with Thalassaemia Major and needs regular blood transfusions.

Diagnosis Day follows six Australians as they seek answers and find community.

JOSH

Josh is a master of comedic timing and the eldest of four. His family is made up of parents Beth and Anthony and siblings Dominic, Sophie and Louisa, as well as two dogs, a black cat, a turtle, a snake, and many chickens. When he was 16 years old, Josh was diagnosed with Pitt-Hopkins Syndrome, a neurological disorder.

NOAH

Noah is five years old and has just started school this year. His family consists of parents Deanna and Andrew, and Henry the dog. Noah has Niemann-Pick Type C, an ultra-rare condition that prohibits his body's ability to process fats and cholesterol.

SCOTT

Scott is a 35-year-old engineer with a penchant for all things tech. At age 13, Scott began developing kidney stones regularly. Genomic testing revealed he has a rare condition known as Primary Hyperoxaluria, which causes a build-up of a substance known as oxalate in the body.

YUSUF

Yusuf is five years old and is described by parents Selima and Kasum as 'very cheeky'. He has a very rare condition known as Pitt-Hopkins Syndrome, which was fortunately detected when he was a baby.

EPISODE GUIDE

EP 1. MEET THE FAMILIES
Meet six Aussie families who live with rare genetic conditions. This micro-series follows their search for answers, options and community.

EP 2. NOT KNOWING
Beth's fears for Josh are dismissed. Scott's teenage years are full of hospital visits. Selima's first moment with her baby is shattered by unsettling news.

EP 3. HEARING THE NEWS
Beth has a good day. Selima makes a shock discovery. The world slows down for Deanna and Andrew.

EP 4. THE AFTERMATH
They tell you not to – but everyone does. Deanna and Kathy turn to Google as they struggle to make sense of ultra-rare, complex conditions.

EP 5: FINDING SUPPORT
Beth gets an odd request on Facebook. Kathy learns to cook for someone who can't digest protein. Robbin wants Amelia to face her future without fear.

EP 6: IMPACT OF DIAGNOSIS
What changed after a diagnosis? Deanna reflects on acceptance while new doors open for Josh. Scott takes back some control, and Selima turns playtime into therapy.

EP 7: WHAT WE KNOW NOW
The series ends but the journey continues. Scott encourages people to seek support while Kasum explains what makes him proud. Selima and Deanna help their kids to chart their own path. And Robbin and Georgia have a little romantic moment.

PRO-DUCING DIAGNOSIS DAY

FORMING THE COLLABORATION

Dec 2021 – Feb 2022

- Initial meetings to understand each collaborator's objectives and strengths
- Identification of shared goals and products/deliverables
- Collaboration agreement to document roles, responsibilities and budget

DESIGNING THE PROJECT

Feb-Mar 2022

- Video producer (Aspire Pictures) sourced through a competitive process
- Subject matter experts invited to advise on themes, questions, formats and participant experience
- Project plan with timelines, risks and mitigations

Diagnosis Day

RECRUITING AND BRIEFING PARTICIPANTS

Feb-Aug 2022

- Recruitment via rare disease support groups, clinicians and social media advertising
- Pre-interviews to understand participants' stories and ensure informed consent
- Interview guides and informed consent materials

FILMING

Jun-Aug 2022

- Video and photo shoots with participants in locations of their choice

POST-PRODUCTION

Aug-Oct 2022

- Transcripts analysed for common themes and shared experiences
- Product and distribution plans revised based on available content
- Script writing and review with participants and subject matter experts
- Production and review of first and second cuts of videos
- Final edits for content, narrative and timing

PREMIERE

17 Oct 2022

- Participants, advisors and collaborators invited to a premiere screening of the series
- Participants invited to request any changes to their stories

DISSEMINATION

Oct-Nov 2022

- Microsite **DiagnosisDay.org.au** created to house videos
- 60-second trailer created and shared
- Email promotions to health services, peak bodies and rare disease support groups
- Episodes released weekly on LinkedIn and YouTube, with additional promotion on Twitter and Facebook
- Content developed for use in clinician education events

EVALUATION

Feb-Mar 2023

- Surveys with participants and advisors; interviews with project collaborators
- Analysis of engagement data on the videos

EVAL-UATING DIAGNOSIS DAY

Diagnosis Day was evaluated by skilled evaluators from the Melbourne Genomics program team, who were not directly involved in the project.

The evaluation sought to answer three questions:

1. How effective was the engagement between the project collaborators?
2. How well were participants and advisors engaged in the project?
3. How have the stories been used?

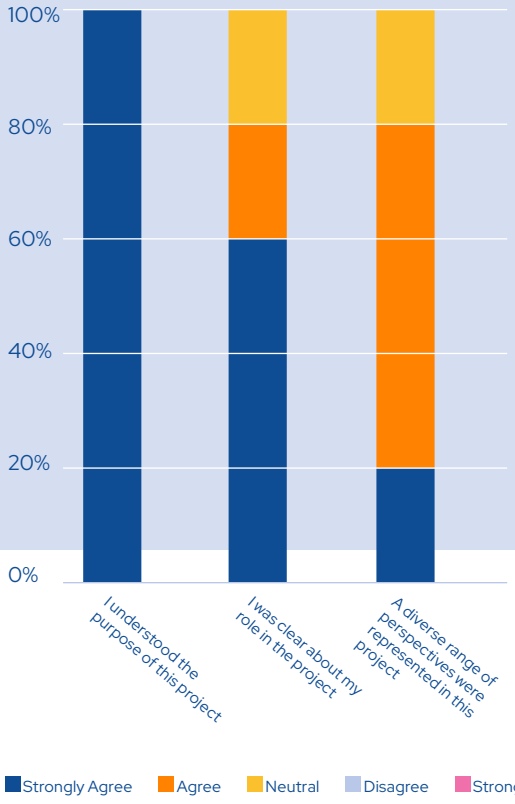
COLLABORATORS

Collaborators were the key project staff from Melbourne Genomics and GSNV, as well as the videographer from Aspire Pictures. They completed anonymous surveys and by in-depth interviews to capture insights and lessons learnt.

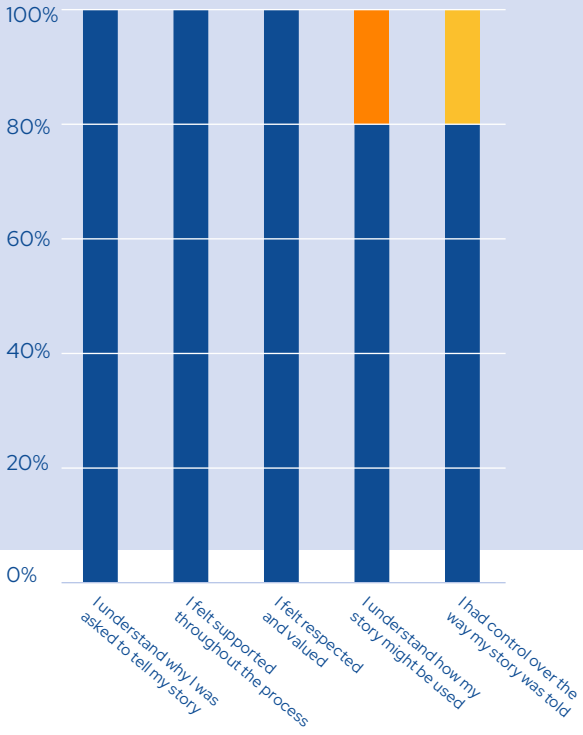
PARTICIPANTS

The individuals and families filmed for Diagnosis Day were sent anonymous surveys – one per household – inviting them to rate their experience and provide additional comments. Five out of six surveys were returned.

Collaborator perspectives (n=5)



Participant perspectives (n=5)



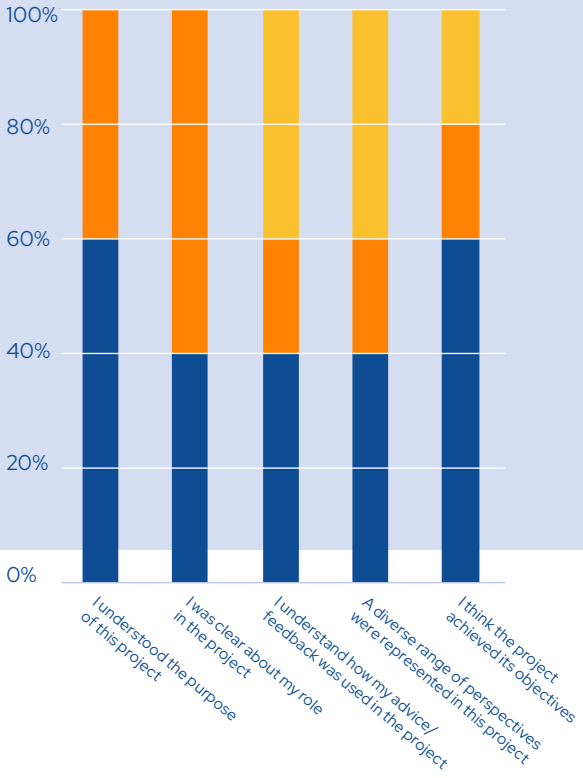
Diagnosis Day

> "We really enjoyed being a part of the whole process. We went from being somewhat hesitant in sharing our story to becoming quite proud and confident in doing so. We hope our story can help others." — Participant

ADVISORS

Advisors were subject matter experts engaged in various aspects of the project. They included people with lived experience of genetic conditions (including members of the Melbourne Genomics Community Advisory Group) as well as genetic counsellors, and members of the Melbourne Genomics education team. Advisors were sent anonymous surveys, which had a 71% completion rate.

Advisor perspectives (n=5)



REACH AND ENGAGEMENT

Diagnosis Day videos had over **79,166 views** on LinkedIn, Twitter and YouTube.

The series had an average engagement rate of **5%**. (Engagement above 2% on LinkedIn is considered great.[2])

Diagnosis Day had a global reach, with meaningful viewership analytics in Australia, the United States, New Zealand, the United Kingdom, India and Canada.

DiagnosisDay.org.au had 936 page views. Visitors spent an average of four minutes on the site.

Engagement data was collected from October 2022 to January 2023.

Diagnosis Day has been used in online education modules for paediatricians and as course content for the University of Melbourne's Master of Genomics and Health.

2. Aamplify Marketing: What is a good LinkedIn engagement rate? https://www.aamplify.marketing/blog/what-is-a-good-linkedin-engagement-rate#, Viewed 12 July 2023

IN-SIGHTS FOR FUTURE STORY-TELLING PROJECTS

Interviews and survey comments yielded rich insights that can help storytellers strengthen planning, production and distribution.

WORKING COLLABORATIVELY

Co-define your objectives and expectations. Revisit them regularly.

The collaboration worked well overall to achieve the project objectives. While purpose, roles and responsibilities were defined at the start, collaborators felt it would have been worthwhile to revisit them periodically, to ensure the project was on track and decision-making remained transparent.

We developed a collaboration checklist (p14) to guide future projects.

Identify the different kinds of expertise required.

Diagnosis Day needed expertise in genetic counselling, rare disease and supporting families with genetic conditions, as well as video production, photography, scriptwriting and social media.

The collaborators first mapped our own strengths. Then we reached out to subject matter experts (e.g. genetic counsellors, lived experience experts and digital marketers) for advice at each step: from identifying interview questions to planning video shoots, to reviewing draft scripts and first cuts of the videos. We hired a video producer with demonstrated expertise in telling respectful, strength-based stories.

Consider setting up a project advisory group.

Subject matter experts were engaged as advisors on an ad hoc basis, for example a meeting to discuss interview questions, or an email with scripts to review. Their connection to the project may have been strengthened if they had been part of a formal group that met at regular intervals, to see how their advice was shaping the project.

FINDING DIVERSE STORIES AND PARTICIPANTS

Leave ample time to find people willing to tell their stories.

Finding participants took far longer than anticipated. We recommend using multiple strategies: ask support groups, talk with doctors, seek out relevant community networks, and use social media to cast the widest net possible.

Don't rely on usual channels to find diverse participants.

Almost all participants were recruited from rare disease support groups. People from culturally and linguistically diverse backgrounds were not well represented in the groups we approached, so their valuable experience and insights were missing from the final product.

We were also unable to identify Aboriginal and Torres Strait Islander families who had experience of genetic testing for rare conditions, within the project timeframe.

Building relationships with relevant service providers is a crucial first step in identifying participants for future storytelling projects. Respectful relationships take time and trust to build; this should be factored into the project.

Video may not be the right medium for some people's stories.

We found three people from refugee backgrounds with powerful stories to share. Although they consented to discuss their experience through interpreters, none were willing to appear on video – due to visa conditions or the fear of being stigmatised. To capture these stories in the future, we recommend de-identified options such as podcasts or animation.

PARTICIPANT EXPERIENCE

Find out why people want to share their stories.

Diagnosis Day participants wanted to share their stories to support other families living with genetic conditions; to help them feel less alone, and to make them aware of support services.

Use a robust screening and consent process.

A detailed phone screening guide helped us capture stories and ensure a range of conditions and experiences were represented. People could make informed decisions about whether to participate – knowing how, where and for how long their images would be used.

Seek advice from people with lived experience.

This helped us identify what questions to ask, how to prepare families for interviews (for example, checking whether parents were comfortable discussing their child's medical history with the child present), and what post-interview support might be needed.

Ask about the person, not just their condition.

Two questions that yielded the richest content were 'Tell me about your family' and 'Looking back, what makes you proud?'.

Make filming safe and comfortable for participants.

All participants said they felt supported and respected through the process, and most said they had control over how their story was told. This was done by:

- empowering people to choose where they were filmed and what activities to film
- asking people what aspects of their story they wanted others to know

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IN-SIGHTS

- building rapport with all family members before the cameras came out
- asking families to decide who should be interviewed
- ensuring people could decline questions they didn't want to answer
- sharing draft scripts and videos and inviting people to make changes
- regular follow-up to let participants know how the project was progressing

A premiere screening is a good way to recognise participants.

We invited participants and advisors to a premiere screening of the series. Families were able to meet each other and see their stories in full, and senior leaders from Melbourne Genomics and GSNV were able to thank them in person. Several participants felt the premiere was a highlight of the project.

PRODUCING STORIES

Create content with a specific platform in mind.

We originally planned to make three separate videos, each 8-10 minutes long. These would be housed on a webpage, with previews shared on social media. Once we chose LinkedIn as a primary channel, we opted instead to make an episodic series, with each episode short enough to play on LinkedIn in its entirety.

Keep your film crew small and functional.

Everyone at a video shoot needs a purpose: whether to operate the camera, do interviews, or provide support to participants. Having additional people 'observing' the shoot sometimes made participants more self-conscious in front of the camera.

Clear review processes make it easier to get quality feedback.

The review team – which included collaborators and advisors – was asked specific questions about each script (What works and doesn't work? How easy is it to follow the story? What can we cut?). Reviewers watched first cuts of the videos as a group and agreed on changes.

Repurpose the content for different audiences.

In addition to the seven episodes, we cut a one-minute trailer for the series. We also cut two-minute videos on each family, used as content for Rare Disease Day and other occasions. Each family was given their own video to share as they wanted. Footage was also used in education events for doctors who needed to discuss genomic testing with patients.

Finally, getting a set of professionally-shot still images at each video shoot enabled us to create high-quality print and online materials.

"Thank you for allowing us to be involved in this amazing project. We are so proud of our little family. We'd love for other families to feel that way too."

— Participant

DISTRIBUTION

LinkedIn offers targeted ways to reach professional audiences.

LinkedIn was the key channel for Diagnosis Day. Several advertisements were created for the series, targeting specific professions (e.g. paediatricians and genetic counsellors) and organisations (e.g. hospitals, rare disease support groups). In this way, we not only reached new audiences but increased our visibility among current followers.

Invite people to create their own posts with your content.

We shared the videos from our personal accounts and asked colleagues to do the same.

Secure media or government partnerships at the outset.

The Victorian state election disrupted plans to launch the event with government. For future projects, we recommend involving government advisors early in planning. We would also consider collaborating with a media outlet (e.g. ABC or SBS) to shoot content, which would then have a wider distribution.

Keep stories short and engaging.

Episodes were released on a weekly basis, with supplementary LinkedIn articles on topics such as genetic counselling. While posts with videos received high engagement rates, articles did not. Although LinkedIn allows higher character counts than other social channels, these results suggest that short, rapidly-consumed content still performs best.

"After we got the diagnosis? Everything changed. The way we converse with our family, the way I viewed my friends and their problems, the way I viewed work, absolutely everything changed."

— Deanna (Diagnosis Day, Ep.6)

COLLABORATION CHECKLIST

SETTING UP THE COLLABORATION

Explore with all collaborators:

- ☐ Why each individual or organisation wants to participate
- ☐ What each collaborator sees as a good outcome for the project
- ☐ Each collaborator's strengths and the skills, knowledge or resources each can bring

Establish and document a common understanding of:

- ☐ The shared purpose and objectives
- ☐ Roles and responsibilities of each collaborator
- ☐ How decisions about the project will be made
- ☐ How feedback will be sought, given and actioned
- ☐ How issues and assumptions will be addressed

Consider who else should be involved in the project.

- ☐ What gaps exist (e.g. areas of knowledge, resources or connections)?
- ☐ Who might be able to provide these?
- ☐ How can they be best engaged?
- ☐ Is a formal advisory or reference group needed?

DURING THE COLLABORATION

Set up regular checkpoints during the project lifecycle.

- ☐ Reflect on progress against the agreed purpose and objectives.
- ☐ Consider whether any expectations need to be reviewed or revised.
- ☐ Identify barriers and make a plan to address them.
- ☐ Review and revise the project timeline if necessary.

AFTER THE COLLABORATION

Allocate time to evaluate and reflect upon the collaboration. Consider:

- ☐ What worked well?
- ☐ What might be improved?
- ☐ What can we learn to improve future projects and collaborations?

Make it easy and safe for people to participate in evaluation.

- ☐ Give people options for how to participate (e.g. surveys, phone interviews).
- ☐ Enable anonymous responses to protect privacy and enable frank feedback.
- ☐ Bring people together to reflect on core evaluation findings.

Celebrate the completion of the project or collaboration.

- ☐ Consider an in-person or virtual event to recognise and thank collaborators.

"Once you have the diagnosis, it's not the end of the world. It's just opening you to a different view of the world."

— Kasum (Diagnosis Day, Ep.6)

Melbourne Genomics and GSNV are grateful to everyone who brought Diagnosis Day to life.

The participants

Scott; Patrick, Cathy, Rocky and Tony; Josh, Beth, Anthony, Dom, Sophia, and Louisa; Noah, Deanna and Andrew; Yusuf, Selima and Kasum; Amelia, Robbin and Georgia ...

Thank you for inviting us into your homes. For sharing your stories with grace, courage and humour. For all you have done to help other families feel more connected and less alone.

It was a privilege to share your stories.

Collaborators

Melbourne Genomics Health Alliance

Zayne D'Crus, Amelia Rahardja, Clara Gaff

Genetic Support Network of Victoria

Monica Ferrie, Hollie Feller, Isaac Hockey

Aspire Pictures

Rodney Dekker

Advisors

Melbourne Genomics Community Advisory Group

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And...

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Amy Nisselle, Melbourne Genomics Health Alliance
Fran Maher, Melbourne Genomics Health Alliance

Evaluation team

Melbourne Genomics Health Alliance

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Melbourne Genomics
Health Alliance

Melbourne Genomics is an alliance of leading hospitals, research and academic institutions, working to make genomic medicine a reality for all Victorians who need it.

The Alliance comprises The Royal Melbourne Hospital, The Royal Children's Hospital, The University of Melbourne, WEHI, Murdoch Children's Research Institute, CSIRO, AGRF, The Peter MacCallum Cancer Centre, Austin Health and Monash Health.

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gsnv
Genetic Support Network Victoria

The Genetic Support Network of Victoria (GSNV) was established in 1997 in response to a changing complex environment; in recognition of the importance of a broad consumer voice in genetic health; acknowledgement of a gap in existing support for many rare, undiagnosed and genetic conditions and to increase awareness of the challenges faced by people with genetic conditions and those who support them.

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We acknowledge the Wurundjeri people of the Kulin Nation, on whose lands we work, and all Aboriginal and Torres Strait Islander peoples across Australia. We pay respect to their Elders, past and present.

We also acknowledge the First Nations health professionals, researchers and leaders who are shaping the future of genomic medicine.