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PATIENT STORIES:
ANIMATION AND VISUAL STORYTELLING FOR THE COMMUNICATION OF COMPLEX GENOMIC CONCEPTS TO REDUCE CULTURAL AND LANGUAGE BARRIERS

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Abstract

Medical animations are widely used in patient education; however, their didactic presentation can limit effective engagement and memory retention. Illustrated patient stories, such as comics and video games, have been proven effective in evoking empathy and fostering greater understanding for patients suffering from diseases. Therefore, animated patient stories could be a valuable tool for clinicians to enhance the quality of care and deepen their understanding of a disease from the patient's perspective.

Despite the importance of cultural representation in medical communication, patient education resources tailored to culturally specific communities remain limited. This paper will explore opportunities to integrate diverse cultural aspects into such animations. The research team, composed of animators and clinicians, will discuss a multidisciplinary project that explores how animation can transcend the boundaries of entertainment in communicating genetics and hereditary cancer predisposition syndromes to specific target audiences. The aim is to investigate and prototype a process to design animation narratives for this audience. Additionally, the paper will discuss how visual storytelling choices could improve individuals' decision-making regarding their and their family's increased risk of cancer.

We hypothesise that sharing these animations with non-carriers can raise public awareness of genetic conditions and enhance genetic literacy, correcting myths and misconceptions about genetic predisposition that are prevalent in popular media.

Through an iterative process, two culturally tailored animations were developed: one with a linear narrative that illustrates the story in chronological order and another with a dramatic narrative structure featuring a non-linear ordering of story events. After viewing the animations, a pre-post, mixed-method survey of 260 participants revealed increased interest and knowledge of genetics. Notably, 61.2% preferred the dramatic narrative for its emotional impact, and 98.9% were open to receiving genetic education through animations featuring characters of diverse ethnicities.

This study advances research on culturally sensitive visual storytelling in an Asian population, demonstrating its potential to create accessible, educational, and engaging resources that empower diverse audiences to navigate their genetic health journey.

Keywords: Animation, Visual Storytelling, Genetic Cancer Predisposition, Patient Education, Medical Animation

Introduction

The 2020 COVID-19 outbreak demonstrated the critical role of health communication in mitigating the devastating impact of a pandemic and how effective health communication has been vital in disseminating accurate information and dispelling misinformation. Using creative and visual storytelling in medical education could reduce uncertainty, address fears, and promote adherence to behavioural changes like social distancing (Finset et al., 2020). The ability of animation to transcend cultural and verbal boundaries can hardly be overstated; this argument becomes even more compelling when we consider how animation has become omnipresent in many STEM disciplines, not just medicine. This paper presents the research team's multidisciplinary approach to creating visual storytelling and dramatised animated patient stories to raise public awareness of cancer caused by a genetic predisposition. The paper briefly introduces how animation has been used as a supplement and support in STEM disciplines, and it presents the concept of medical animations in patient education. It then highlights the importance of patient stories. It examines the research supporting their role in health education, detailing how animated patient stories can be designed, conceived, and tested within this framework. Animated patient stories can enhance medical animations to optimise patient education by targeting cognitive and affective aspects. As the team operated in a particular geographical setting, the research also proposes tailoring the animation content to address a targeted community's specific needs and cultural background.

Animation Other than Entertainment

Since its early onset, animation has proven to be an excellent medium not only for entertainment but also for disseminating ideas and bridging complex concepts through visual narratives. It works alongside disciplines not typically associated with entertainment, including military training, medicine, engineering, and astrophysics. Whether accompanied by sound or presented in silence, animation can convey emotions in a manner that is often more accessible than text (Williamson & Abraham, 1995).

Animation has the potential to contextualise and disseminate ideas and abstract knowledge, presenting complicated topics in more understandable ways. Both aspects have been well documented by scholarly research. As Annabelle Honess Roe describes in her in-depth study *Animated Documentary* (2013), "the use of animation as a representational strategy in documentary audiovisual works illustrates the various ways individuals see and understand their world" (Roe, 2013, p.2). Roe states, "factual information is communicated more efficiently via animation than through spoken word," and "animated segments are still used in a non-fictional context to clarify, explain, illustrate, and emphasise" (Roe, 2013, p.1).

From scientific to medical films, numerous examples can be highlighted with varying objectives, ranging from educational to propaganda to training, incorporating information within pseudo storytelling to data-driven infomercials where the content is dry and lacks any narrative or entertainment value. In the 1965 essay, Computer *Animation: A New Scientific and Educational Tool*, Zajac argued that educational material produced with animation could "build into a library for subsequent uses of sorts" (Zajac, 1965, p.1006). By utilising animation, scientists and scholars could communicate directly through the "film medium" in their "natural language of mathematics" (Zajac, 1965, p.1006).

As a scientific communicative tool, Zajac noted that animation has "great potential" for scientists to communicate with one another and other non-specialists. Animation can help individuals "absorb vast amounts of data"; thus, the audience can "see" the study results instead of perusing complicated papers (Zajac, 1965, p.1006). Similarly, in the educational

animated film *Force, Mass and Motion* (1968), the mathematician F. W. Sinden explains Newton's law of motion in two dimensions, demonstrating how animation can help to produce results that enable researchers, scientists, or engineers to communicate to different audiences directly.

The training type of films is another example of established practice where animation can aggregate information for a specific audience. A well-known instance is the movie produced by Walt Disney Studios and Schlesinger Studios during World War II for the U.S. government. These animations featured "military training materials" that included "schematic explanations on how to use the Boy MK-1 Anti-Tank rifle, covering loading, reloading, aiming, unloading, and cleaning" (Ceccarelli, 2012, p.119).

These films are part of a larger discourse in the broader field or ongoing conversation regarding the role of animation in educational, instructional, or training contexts.

For example, in a 2009 study, Riaza Rias notes that animation is part of a broader multimedia learning aid that "enables individuals to memorise concepts, leading to increased clarity" (Senthil Kumar, 2016, p.392). In 2017, Chris McGillion led a team of animators from Charles Sturt University in Australia to create an animated video to help disseminate agricultural knowledge to subsistence labourers in Timor-Leste. McGillion (2017) argued that, due to the low literacy rate among subsistence farmers in Timor-Leste, textual resources and similar knowledge may not be the most efficient way to inform them about high-yielding agricultural practices. In 2022, Yildiz and Cavkaytar explored the integration of animations into an educational programme designed for individuals with mild to moderate intellectual disabilities to equip them with independent living skills. Yildiz and Cavkaytar (2022) demonstrated that individuals who participated in the educational programme significantly improved their independent living skills compared to those who did not, highlighting animation's effectiveness in education and training for individuals with intellectual disabilities.

The examples above rely heavily on views and practices to produce an animation that contextualises and presents abstract ideas and critical information to audiences of both specialists and non-specialists.

The visual and narrative aspects of animation help break down barriers to understanding, especially in fields that are heavy in theory or involve intricate processes like medical visualisation and simulations.

Inclusivity is one of animation's greatest strengths, as it can lessen cognitive demands (Sanchez & Weber, 2019). The medium's versatility enables it to tell stories that resonate with a global audience, breaking down language and cultural barriers. In other words, animation can address specific audiences with cultural sensitivity while remaining accessible to the broader public. Its content and visuals can be designed to transcend boundaries, appealing universally while maintaining cultural appropriateness.

Medical Animation and Patient Education

Medical animations play a specific and unique role in patient education, a systematic process of teaching and learning designed for patients in clinical settings to encourage the adoption of behaviours or beliefs that promote health. These animations illustrate various medical concepts, processes, or conditions, aiming to clarify complex medical and biological phenomena in a visually engaging and accessible way. They can address a wide range of topics, from anatomy and physiology to disease mechanisms and surgical procedures. As a valuable tool for patient education, animations help bridge the knowledge gap for individuals with a limited understanding of medical terminology and practices. Research by Bankoff

and Sandberg (2012) has shown that retention of medically related information presented solely through verbal communication during consultations is particularly deficient among elderly patients. Medical animations can thus enhance memory retention and learning, as supported by various cognitive psychological theories.

The cognitive load theory posits that the cognitive capacity of working memory is limited, and an excess of information can lead to cognitive overload (Mayer, 2003), thus impeding cognitive processing. In a short film, information can be distributed over time; hence, reducing the amount of information presented at any given moment can alleviate cognitive overload. Additionally, the narrative nature of medical animations enables the chunking of information, further decreasing cognitive load. In a study by Meuschke in 2022, a seven-stage template for the narrative structure of medical visualisation was proposed to educate individuals about diseases, including symptoms, diagnosis, and treatment. Such narrative structures reduce cognitive load and provide an organised framework. Simultaneously, the multimedia learning theory suggests that utilising multiple modalities for information presentation enhances the mental representation of information compared to text or illustrations alone. This, in turn, facilitates encoding and retrieval of information from long-term memory (Mayer, 2003). Unlike static illustrations, animations often incorporate narration, audio, and textual elements alongside the visual component. In a study conducted in 2016, multimedia features, such as animated images, arrows, and sound effects, have been found to guide attention to specific information and enhance comprehension, especially in children, more effectively than static images (Takacs & Bus, 2016).

In the study by Li et al. (2019), an animation education programme was developed to promote active respiratory rehabilitation in postsurgical lung cancer patients. Compared to the control group, patients who underwent the programme exhibited increased exercise compliance and decreased postoperative pulmonary complications. Similarly, Yayla and Menevşe (2022) adopted an animation education programme for gastrectomy patients to educate them on breathing techniques to improve sleep quality and alleviate pain. Their randomised controlled trial demonstrated improved sleep quality and reduced pain ratings due to increased compliance with breathing techniques. Lipsey (2020) argues that while medical animations undoubtedly enhance treatment compliance and patient outcomes, the didactic presentation of information often limits affective engagement, making it less likely to influence or change patients' attitudes and behaviours. Emotional stimuli can evoke interest and curiosity in viewers, motivating them to explore further and priming their cognitive processes to receive and assimilate new information (Oudeyer et al., 2016). Moreover, Seli (2016) reiterates that emotionally salient stimuli have been associated with superior memory retention and learning compared to neutral stimuli, as they garner more attention and are more likely to be encoded and stored in long-term memory. Therefore, incorporating elements that elicit an emotional response from the audience in medical animations holds the potential to enhance patient education.

Unfortunately, until a few years ago, animation in medical education was primarily limited to visualising complex concepts and scientific data. Only recently have animation and visual storytelling started to be understood as crucial components in health education. Parker et al. (2013, p.141) discussed the importance of patient narratives, which could help "build trust between healthcare practitioners and the people they serve," and the use of storytelling to communicate "human experiences and emotions across disciplines, ages, and cultures".

Similarly, Adam et al. (2020, p.1) emphasised that health communication "must capture the public's attention" to convey reliable messages that are accessible "across languages, ages, cultural affiliations, and education levels". However, the message should not be packaged didactically, relying mainly

on the technical presentation of information, running the risk of missing the target audiences, where "framing health messages as informational arguments have proven to be less effective for changing behaviours" (Adam et al., 2020, p.1).

Specifically, within the field of genomics, information is often complex and rare, posing informational challenges for the afflicted (Boycott & Ardigó, 2018). A cohort of individuals diagnosed with cancer predisposition syndromes are usually faced with the task of communicating their genetic test results and diagnosis to at-risk relatives. Those relatives are recommended to consider their genetic testing to clarify their at-risk status.

In 2011, the National Human Genome Research Institute at the National Institutes of Health held a workshop in Rockville, MD, USA; the workshop focused on genomic literacy, defined as "the working knowledge of genomic science and its role in society, including personal decision making… In addition, the need to research storytelling, or the use of personal stories to illustrate the relevancy of genomics concepts to real people, was frequently mentioned as possibly helping the public understand how this information could be of value for future health care and family decisions" (Hurle et al., 2013, p.661).

Since then, the medical research community has worked on several projects to engage the public with genomics and genetic health issues using animation. The two short films, *My Genome Sequence* (Lewis et al., 2020) and *Whole Genome Sequencing and You* (Sanderson et al., 2016), are worth mentioning. The short animations were created as part of a study to verify the effectiveness of animation in clarifying the importance of genomic sequencing. Both studies conducted surveys and rigorous evaluations, revealing how the awareness and understanding of the words *genome* and *genome sequencing* increased significantly after watching the animation.

However, neither film featured specific patient narratives, studied viewers' emotional engagement, or considered how the information could be more personal or relatable to patients and relatives.

One example of popular media where film and animation deliver stories related to genetic disorders is the live-action film *The Elephant Man* (1980) by David Lynch and the short film *The Animals* by Mark Wee (2014). The live-action movie dramatises the real story of Joseph Merrick, a man afflicted by a rare genetic disorder in 19th-century England. It is based on the writings of Dr Frederick Treves, a Victorian surgeon who tended to Merrick in the Royal London Hospital. The movie uses black and white and is artistically remarkable but does little to inform us about the condition from a scientific point of view. The animated film *The Animals* explores the same story using stop motion and visually referencing the classical expressionist film *The Cabinet of Dr Caligari* (Wiene, 1920). Created in black and white, it reverses the narrative point of view by revealing ordinary people as animal monsters and fully realises the visual storytelling potential of animation. As emotionally engaging and artistic as these films are, they would not find a place in a medical journal or a qualitative study project.

The dichotomy of entertainment values as the dominant driver versus delivering information persists when examining popular media. Examples abound where medical or scientific information is presented to prioritise entertainment over accuracy; one prominent instance is the movie *Jurassic Park* by Steven Spielberg (1993). The brief animation featuring Mr. DNA quickly and efficiently conveys a complex narrative to a broad audience. The style and visual storytelling choices reflect the need to communicate with an audience that varies in age, ethnicity, and cultural background. The animation provides the essential clue that renders the movie engaging and offers a plausible response to the *What if* question. The original book by Michael Crichton details the

genetic science behind dinosaur creation, making the impossible seem plausible and helping to elevate genetic technology to a mainstream topic in the 1990s. The book and the film inspired literature that debunks and elucidates the science behind the popular franchise, guiding readers in theoretical recreations, yet impossible, recreation of dinosaurs through real-life genetic engineering (Coletti, 2019). Other mainstream examples of the intersection of medical science and entertainment include the hybrid movie *Osmosis Jones* (2001), which narrates the adventure of a white blood cell depicted as a policeman protecting its host from a deadly infectious disease and the 2D French educational television series, a series of 26 episodes, *Il était une fois... la Vie* by Albert Barillé was dedicated to the functioning of the human body. Aimed primarily at a young audience, it used animated characters to illustrate the structure and functions of the human body, utilising anthropomorphic figures to represent its microscopic components, from white blood cells to vitamins to the components of DNA.

The distinction between the use of animation in popular media and animation and its use in fields beyond entertainment lays a foundation for organised research, especially as we seek to integrate narrative content within patient stories and medical animation. Here, elements of more advanced visual storytelling, character design, and animated narratives can be utilised to deliver information and engage viewers less instructively, employing strategies sourced from domains outside Medical Science or Cognitive Science.

Patient Stories

Patient stories are integral to patient decision aids, and research underscores their potential to enhance empathy and informed decision-making in medical discourse. This suggests narrative-based approaches and animation's complementary role in fostering patient education and engagement. Over the past decade, research into the utility of animated patient stories has evolved from a nascent field to a growing area of study (Bekker et al., 2013).

Patient stories, also known as patient narratives, are personal accounts of individuals detailing their experiences with illness, medical treatments, or healthcare encounters. These stories provide a unique perspective on patients' experiences and offer insights into their healthcare journeys' emotional, physical, and social aspects. Patient stories are valued in medical research, education, and practice; first, patient stories humanise the healthcare experience by focusing on individuals and their unique circumstances, shedding light on the impact of illness on patients' lives, including their struggles, challenges, triumphs, and how their healthcare interactions shape their overall well-being. Patients' stories contribute to a deeper understanding of the patient experience, helping students and healthcare professionals to connect with patients on a deeper level, develop empathy, and understand the impact of illness beyond its medical aspects, enhancing communication, promoting cultural competency, and fostering patient-centred approaches to care.

Furthermore, as Shaffer (2018) and Lipsey (2020) declare, patient stories have demonstrated efficacy in public health education. The narrative nature of patient stories possesses a heightened persuasive power compared to didactic information, making them more likely to elicit attitudinal, judgemental, and behavioural changes.

Through patient stories, listeners can effectively witness how others have coped with specific situations and observe their actions' positive or negative consequences. Patient stories have been successfully utilised in the context of cancer treatment and awareness. For instance, a study (Hinyard & Kreuter, 2007) found that patients exposed to patient stories exhibited greater exercise compliance and experienced fewer postoperative complications than the control group. Similarly,

women who watched videos featuring patient stories of breast cancer patients demonstrated increased attentiveness and better recall than those who watched informational videos (Bollinger & Kreuter, 2012).

In the case of cancer predisposition syndromes, existing literature on carrier perspectives has revealed the value of patient stories and narratives in acclimatising carriers and family members to the knowledge of genetic diagnoses (Campbell-Salome & Rauscher, 2020). Carriers request other patients' experiences as they see value in understanding how other families coped, their perceptions of risk, and how they made medical decisions to manage those risks – information not provided during their genetic counselling sessions (Yuen et al., 2020).

Several studies have already explored the use of animated patient stories. For instance, a survey conducted in 2019 at the Sanjay Gandhi Postgraduate Institute of Medical Sciences in Lucknow, India, examined the educational application of storytelling and animation to inform euthyroid patients about thyroid surgery (Sabaretnam & Bothra, 2019). Their animated video featured a first-person narrative of a fictional character named Sona, who undergoes diagnosis and treatment for thyroid disease. A survey conducted among 59 euthyroid patients revealed an increased interest in thyroid diseases following the viewing of the animation.

First-person storytelling or patient stories can be particularly compelling for addressing racial/ethnic minority groups. Moreover, the impact of storytelling is significantly amplified when the narratives include characters or scenarios that reflect the patient's racial or ethnic background. Such representation enhances the empathetic connection, making the experiences more relatable and impactful (Avenanti et al., 2010). Thus, incorporating diverse and culturally relevant stories in medical communication can significantly enhance patient education and engagement effectiveness, underscoring the importance of creating a more inclusive and empathetic healthcare environment where patients see their own experiences and backgrounds reflected in the stories they are told (Lian, 2016). However, limited animated patient stories specific to certain minority groups are available.

Cultural representation is crucial in healthcare for several reasons. It refers to acknowledging, recognising, and including diverse cultural backgrounds, beliefs, values, and practices within the healthcare system. It involves understanding and respecting the cultural contexts of individuals and communities and ensuring that healthcare services are sensitive to their cultural needs and preferences (Kreuter & McClure, 2004). It can promote equity and access to healthcare and help providers develop interventions, treatment plans, and preventive measures sensitive to cultural practices, preferences, and beliefs. Thus, this improves patient engagement, adherence to treatment, overall health outcomes, and patient satisfaction (Thomas et al., 2004). Culturally appropriate delivery can also improve health literacy by tailoring health information according to cultural norms, language preferences and literacy levels. Overall, this can enhance the patient's ability to make informed decisions about their health, follow treatment plans, and engage in preventive measures.

Culture-sensitive patient education is the "deliberate and evidence-informed adaptation of health communication to the recipients' cultural background to increase knowledge and improve preparation for medical decision making and to enhance the persuasiveness of messages in health promotion" (Betsch et al., 2016, p. 813-814). Cultural sensitivity can be achieved through various approaches, including language adaptation, cultural beliefs and practices, and appropriate communication styles using storytelling, metaphors, or visual presentations.

One aspect that could be better discussed is how animation can transcend the confines of a specific individual's story

and how it can be used to communicate effectively with a bigger audience. It can convey information creatively in ways unique to the medium, differing from live-action footage that might use a more documentary-like approach to presenting the same material.

A knowledge gap emerges once you look at how patient stories are used in patient education worldwide. One element deficient in most analyses is how integrating multicultural elements into these narratives could significantly enhance the effectiveness of patient engagement and decision-making processes. This absence of empirical support highlights a domain ripe for future research endeavours, suggesting a need for focused scholarly attention on the effects of culturally diverse storytelling within the medical sphere. In a multicultural and ethnically diverse society like Singapore, this element of culturally sensitive storytelling is relevant and is carefully examined and integrated into all the phases of the study's development and evaluation.

Animation can be a powerful tool for celebrating and representing diverse cultures, providing opportunities for authentic storytelling, and promoting cross-cultural understanding. However, animation can also be a medium through which cultural appropriation occurs. This happens when elements of a culture are taken out of context, misrepresented, or exploited for commercial gain without proper acknowledgement or understanding of their significance. This can lead to stereotypes, misinterpretations, and the perpetuation of harmful narratives about specific cultures. While animation can promote cultural appreciation and understanding, it also carries the risk of cultural appropriation if not approached with sensitivity, respect, and a deep understanding of the depicted cultures. As creators in a Southeast Asian context where our research took place, this aspect was carefully considered as the research team engaged in consultation and collaboration to ensure authentic and respectful portrayal.

Within the multicultural milieu of Singapore, the respect accorded to populations of varying ethnicities is reflected across the spectrum of societal dimensions (Lian, 2015). Singapore also mirrors this inclusive approach in its various facets of life (Lian, 2015). The nation has made commendable efforts to acknowledge and respect its diverse ethnic groups across multiple domains, such as public signage, food and catering services, and entertainment venues. In Singapore, recognising different ethnic communities and the intention to provide equitable resources through those categorisations proved successful in creating a nation tolerant of diversity (Kathiravelu, 2019). This inclusive strategy is not just about representation; it is a more profound commitment to fostering a sense of belonging and respect among all its citizens, irrespective of their ethnic background. Singapore's cultural diversity justifies the creation of innovative, ethnically-tailored patient story animations. These custom narratives, designed to align with the nuances of the Singaporean healthcare system, aim to improve patients' understanding of various medical conditions and the strategies adopted by individuals facing similar health challenges.

Patient Stories Meet Animation

In the above discussion, we have illustrated how the conventional association of animation solely with entertainment is a false assumption and demonstrated how contemporary research underscores its broader applicability. Building upon the foundation laid by past studies, which have emphasised the potency of integrating visual elements, compelling narratives, and elements of entertainment education into health communication strategies (Adam et al., 2019), contemporary research continues to shed light on the efficacy of leveraging animation as a powerful medium for disseminating health-related information.

Previous research has recognised the potential of multimedia resources, particularly animations, in enhancing patients' knowledge and has delved into how these resources can impact individuals before undergoing medical procedures (Hammond, 2021). Furthermore, we have argued that animated patient stories represent a novel way to engage and inform patients, families, and the public in the field of genomic literacy, where information and education are essential.

Once the relationship between animation, medicine and culturally appropriate patient stories is understood, we can establish a theoretical framework to illustrate the case study detailing the creation of the animated narratives and how the animation was evaluated to understand the potentially profound impact of personalised narratives in effectively conveying health-related information.

The framework mentioned above allows us to formalise the main research questions, which can be summarised as follows:

1) What is the best design process for using animation to overcome cultural and literacy barriers to communicating complex genomic concepts to patients and their at-risk relatives?
2) How can an animation's artistic quality and visual storytelling be applied to deliver information to a diverse, multicultural audience using real patient stories?
3) Would the same approach work in a multicultural society like Singapore, or would a transcultural approach be more effective in addressing patient groups in an Asian context?

Participants were selected to kick-start the production process; their experiences were references for scripting the animations. The stories were identified through a review of available patient stories within the patient cohort at the National Cancer Genetics Service in Singapore and selected based on a review of existing patient stories by the clinical team with discussion with the animation team.

Carriers were selected from the Cancer Genetics Service in Singapore and had to abide by the following selection criteria:

- Individuals aged 21
- Asian ethnicity, namely Chinese, Indian, or Malay
- Carriers who have been diagnosed with a cancer predisposition syndrome (i.e., known to have a pathogenic variant in a cancer predisposition gene)
- Had the capacity to give informed consent to feature their experience and story in the animation

Carriers were asked to share their journeys in navigating their healthcare decisions and considerations related to communication with their at-risk family members. Based on their shared narratives, the prototype scripts were created.

Each short narrative was designed to feature a distinct carrier's story. In an early iteration of the project, the research team proposed the creation of three short films that will have the following common elements:

1) The story is designed to feature a specific racial group but can also resonate with a broad audience.
2) A Singaporean localised narrative with a lighter tone designed for younger audiences.
3) Stories should convey a positive and empowering message, encouraging carriers to seek testing and treatment.

Once the framework was established and the base for the narrative content was obtained, the medical and animation teams worked together to create and execute the animation. It was later used for evaluation to determine its acceptability and appropriateness. To ensure the validity and accuracy of the animated films, the initial work in progress of the short films in the form of animatics was extensively discussed with healthcare professionals. The medical team served as an

expert audience, as they commented on the clarity of visual storytelling and the accuracy of medical information. It was recommended that the animation convey an accurate and positive message.

Furthermore, the teams of doctors provided the necessary revisions to the character's dialogue and the voice-over of the speaker. They encouraged using simple graphics and cartoony solutions versus medical diagrams and real photographs of the condition's symptoms and presentations. Several sessions were conducted over the space of a year and a half, during which the animation team progressively incorporated these insights, editing the film's visuals and pacing to improve the overall effectiveness of the visual storytelling.

This iterative and collaborative approach helped enhance the educational materials' relevance.

In the early preliminary discussions, three conditions were chosen to be represented by different ethnic groups in Singapore: FAP (Familial Adenomatous Polyposis), featuring the story of a young Malay girl who learns about her condition; Lynch syndrome, a story involving an Indian individual who discovers a possible inherited genetic condition through his relatives; and NF1 Neurofibromatosis Type1, the story of a young Chinese man who learns about his condition and understands how to cope with its symptoms and the self-confidence issues caused by the specific nature of his illness.

All three proposed conditions share common traits but exhibit different symptoms and presentations that vary from person to person. They can affect carriers at various life stages, necessitating genetic testing for accurate diagnosis and targeted intervention.

After discussion and re-evaluation of the scope and aim of the project, it was collegially decided for the benefit of the study design to focus only on two conditions, FAP and NF1.

With this approach, the research team aimed to create two distinct stories that utilised different storytelling methodologies: linear storytelling and a more whimsical style. This decision aligned with one of the research questions, which sought to determine which narrative style could effectively communicate medical information.

The research team had to mediate between delivering accurate information and pushing the visual and narrative style as much as possible within the parameters established by our premise. The first film to enter production was the one that explored Familial Adenomatous Polyposis (FAP), which is one of the genetic diseases associated with hereditary colorectal cancer. The current treatment for this genetic condition requires patients to undergo surgery at a relatively young age to avoid the development of colon cancer, as carriers of the condition have a higher chance of developing colon cancer than non-carriers (Monahan et al., 2020). The narrative design of the story centres around the idea that young patients can be impressionable, and the delivery of information needs to be carried out tactfully and using appropriate terms to encourage young patients to undergo genetic testing at the earliest opportunity.

The initial scenario involving the young Malay girl, whom the team named Fatira, was fairly conventional. It depicted a visit to the doctor when she was eight years old, during which she first learned about her condition and the necessity of understanding a procedure that would require her to have her colon removed, typically around 18 years old, to reduce her chances of developing colorectal cancer. The story concludes with the girl, now an adult, accepting and managing her condition with the support of doctors and a support group. As previously mentioned, the didactic nature of this narrative is suitable but could be enhanced. One element that was not fully explored in this initial version was the stress that a young person might experience upon learning of their condition and realising that treatment would involve invasive surgery.

This aspect presented narrative opportunities that the team decided to exploit, seeking a more nuanced approach to the story and one that could fully utilise animation visual storytelling. While delivering an empowering message and accurate information remained paramount and central to the project, it was balanced with artistic and filmic considerations.

The animated film commences with a depiction set at Tanah Merah MRT Station, a recognisable landmark within the local Singaporean context. A family unit comprising a father, mother, and a young girl is observed boarding the train, with their dialogue revealing their intended destination as a medical facility. Upon arrival at the hospital, the medical practitioner elucidates the family's condition and delineates the requisite steps for a favourable prognosis. However, the girl, Fatira, becomes increasingly terrified as she hears the information and learns of the need to undergo surgery. Leveraging the premise that young individuals may engage in imaginative elaboration, the animation transits into a nightmarish portrayal wherein grotesque manifestations of the colon and stomach pursue the young girl. In her state of fear, she encounters two personified entities: Doc (doctor marked by a cross on his chest for easy recognition) and Gen (genetics marked by the symbol of a strand of DNA). The two entities initiate an exorcism intervention to dispel the menacing entities. It is worth highlighting that this surreal sequence reverently nods to Disney's *Dumbo Pink Elephants on Parade* (1941), notably evoking specific chromatic selections, exaggerated animations, and narrative motifs (Benzon, 2012). The referenced sequence and the sequence in our film both have a nightmarish, surreal quality and represent a deliberate stylistic choice that breaks from the so-called reality of the piece. The doctor is depicted here holding a chainsaw to vanquish the malignant tumours. Efforts were made to inject humour, exemplified by the comical collision between the monstrous Colon and Stomach, scared and dazed by the performed exorcism. Following this sequence, the narrative returns to reality, introducing an inconsolable Fatira who begins to cry, her imagination overcoming her.

The primary objective of this initial segment of the film is to engage the audience through a locally resonant narrative while presenting a fresh perspective on recounting a patient's story. As deliberated with the medical team, the film also conveys information about the disease. Additionally, as the design principle states, the video must conclude positively. Consequently, the story seamlessly transitions into its second phase, where Fatira steps into the forefront of the frame to deliver a self-introduction. Fatira recounts her challenges by adopting a first-person narrative, reflecting a realistic portrayal of a child grappling with complex terminology. Notably, the elongated lens duration on certain words strategically underscores their significance, enhancing memorability. Fatira proceeds to delve into the genetic underpinnings of the disease, conveying intricate details through a combination of illustrations and simple schematic visuals rendered in a childlike style, which she might have created. Employing this dual approach, as filmmakers, we endeavour to augment the video's appeal, aiming to captivate the audience and enhance retention of the information presented.

The video reaches its crescendo as it delves into Fatira's decision-making process. As the narrative unfolds, we witness Fatira's evolution from a young child to a teenager, navigating the complexities of her genetic predisposition to colon cancer. Determined to take control of her health, Fatira commits to a regimen of regular body screenings and ultimately opts for preventative surgical measures. This strategic approach, rooted in foresight and proactive action, serves as a reminder of the importance of making informed health decisions to mitigate genetic risks and prevent potential health complications.

Embedded within the fabric of the short film is a commitment to attention to detail and ethical representation. Fatira and her

mother are depicted wearing headscarves, or "coverchiefs", honouring their Muslim identity (Reece, 1996). This attire holds profound cultural significance in Singapore (Suratman & Esa, 2017), where approximately 15.6% of the population identifies as Islamic Malay (Singapore Department of Statistics, 2020), with nearly half being female. By incorporating this detail, the video not only acknowledges the rich tapestry of cultural diversity inherent in Singapore but also ensures a portrayal that is both respectful and authentic. Other visual clues also root the piece geographically: the MRT train station mentioned above or an HDB public housing building familiar to every Singaporean household (Fig.1).

The second film to be produced focused on exploring Neurofibromatosis type 1 (NF1), also known as von Recklinghausen disease, a condition that, given the visible manifestation on the body, presents physical challenges and has psychological implications. According to research by Dr Domon-Archambault et al. (2018), compared to unaffected children and adolescents in the general population, paediatric patients with NF1 face an increased risk of social difficulties, mental health disorders, behavioural and emotional problems, as well as diminished quality of life. Consequently, there is a need to develop and assess psychosocial interventions for patients with NF1; thus, the narrative of the second story centred around the idea that patients can adopt a positive outlook to confront challenging situations.

This video adopts a linear narrative style, recounting the story of a Chinese patient and his struggle during his National Service, which every Singaporean male must enlist in once they reach the age of 18. Visual clues are integrated into the design of the backgrounds and the characters' attire to enhance the localised scenario. For example, all characters except the doctor speak Chinese, and our protagonist wears typical military attire and sports a crew cut, which is a common sight for Singaporean army boys. The loose narrative premise revolves around how this condition causes the patient to feel inadequate, shy, and uncomfortable with his self-image, as it leads to bumps and benign tumours in various parts of the body. The genetic condition is not curable but can be effectively managed once the patients are identified. The patient who shared his story and inspired our narrative found a way to cope by covering some of his scars with tattoos. Tattoos can carry negative connotations in Southeast Asia, often associated with crime syndicates, and are not well-received by the more traditional Chinese communities. To maintain a positive message, the short film traces the protagonist, "Alan", from a young age when he paints himself as his favourite superhero. We see him interacting with

Fig. 1 A (left) - Screenshot of MRT station as illustrated in the short animation. B (right) - Screenshot of HDB Building as seen in the short animation. Art by research assistant Yap Wei Ying

his Ah-ma (grandmother) at home, transitioning from a free, youthful kid to a concerned, self-conscious young adult. The narrative resolves with the grandmother's understanding of the struggle and encourages Alan to pursue his desire to get a cool tattoo, which gives him the confidence to be around his peers (Fig. 2).

As previously stated, the team adopted a linear storytelling approach for this film. Like the earlier illustrated film, the need to deliver a positive message was achieved through the empowerment of the main character by family support and understanding. Additionally, this video had to convey educational information. To align with the research aim of creating engaging content that enhances retention, the creative team utilised cartoonish characters shaped like hands in the segment intended to explain the condition's causes and symptoms, loosely referencing the flat colour art style of Disney's 1953 Oscar-winning short film directed by Ward Kimball, *Toot, Whistle, Plunk and Boom.*

Evaluating Animated Patient Stories in Patient Education

Once the films were produced, the research moved to evaluate the effectiveness of the animated patient narratives in communicating genetic concepts to a culturally diverse audience. The study employed a mixed-methods survey to assess cognitive and affective responses to the animations, focusing on the acceptability of animation as a health education tool. The survey design, participant recruitment, study procedures and analytical approach were carefully structured to ensure robust and meaningful insights.

Survey Design and Measures

The survey was designed to assess both the cognitive and emotional impact of the animations, guided by the Theoretical Framework of Acceptability developed by Sekhon et al. (2017). This framework, widely used in health intervention research, provided a structured approach for evaluating the animations' effectiveness, perceived value, and ethical considerations as an educational tool.

The survey was structured into three key sections—a pre-screening questionnaire, the animation viewing stage, and a post-screening questionnaire. The pre-post study design allows intra-individual comparisons, thus giving insight into the effect of the animations on participants' knowledge and attitudes. Participants' perceived level of understanding and interest in genetics and genetic testing were measured

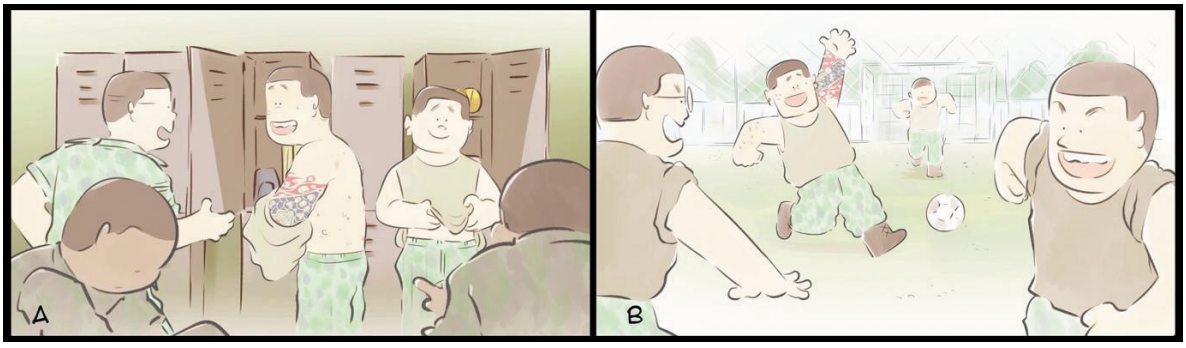

Fig. 2 A-B Screenshots of "Alan" interacting with his National Service peers showing off his tattoos. Art by research assistant Yap Wei Ying.

on a five-point Likert scale, ranging from "None" to "Very high". Additionally, participants' willingness to undergo genetic testing— "Yes", "No", or "Unsure" — were measured before and after watching the animation, assessing the animations' effectiveness in shifting health decision-making behaviour.

In the post-screening questionnaire, participants were also asked to reflect on their preferred medium for receiving genetic information. They were presented with various options, including animated short films, booklets, online sources, patient stories, genetic counsellors, and doctors. By identifying their preferred mode of information delivery, this measure provided insight into how animated patient narratives compare to more traditional methods of science communication. Furthermore, participants were asked to evaluate each animation on a seven-point rating scale, assessing key attributes such as informativeness, narrative pace, visual appeal, engagement, and simplicity. This allowed for a comparative analysis of how effectively each animation conveyed genetic concepts and how well it resonated with the audience.

Participants could express their thoughts in an open-ended section to complement these structured responses, explaining their animation preferences and the reasoning behind their choices. This qualitative component enriched the analysis by capturing subjective reflections on the strengths and limitations of each animation, providing a deeper understanding of audience engagement and perception.

Survey Development and Procedure

The survey was conducted on FormSG, a platform Singaporean government agencies use to ensure high data security. To minimise data loss, built-in constraints required participants to answer all questions before submission. Additionally, video controls such as skipping, fast-forwarding, and pausing were disabled to ensure full engagement with the animations. Access to the post-screening questionnaire was restricted via a password provided once participants viewed both animations. To reduce the influence of viewing order on participant preference, animation sequences were randomised using a pre-generated list in Microsoft Excel. The survey was designed to be completed in one sitting, with the entire process taking approximately 20 minutes.

Two hundred and sixty participants were recruited in the National Cancer Centre, Singapore (NCCS). The sample consisted of patients and their caregivers waiting for their appointments, ensuring a broad representation of perspectives. Recruitment occurred in NCCS waiting rooms during clinic hours, where participants were approached using a convenient sampling method. Those who expressed interest in participating in the study were given a detailed explanation of its purpose before providing informed consent. Once consent was obtained, participants accessed the online survey via a QR code. They were advised to watch the animations using their headphones or aloud, depending on their preference. For participants who were not confident using a digital survey due to limited technological familiarity, the researcher assisted by filling in their responses on an iPad. This ensured that all participants, regardless of digital literacy, could engage fully with the study and have their perspectives accurately recorded.

Data Analysis

The data collected from the survey were analysed using both quantitative and qualitative methods.

To evaluate how the animations impacted participants' knowledge and interest in genetics and genetic testing, pre- and post-screening measures were compared using a two-tailed Wilcoxon signed-rank test, a non-parametric test appropriate for ordinal data. The same test was utilised to

compare participants' ratings of the two animations, ensuring a thorough evaluation of their relative effectiveness. Additionally, the McNemar-Bowker test was employed to assess whether participants' willingness to pursue genetic testing changed after interacting with the animations. This test was chosen for its suitability in analysing categorical paired data, making it well-suited for evaluating shifts in decision-making behaviour.

The qualitative data were analysed using thematic coding, guided by predefined categories derived from the Theoretical Framework of Acceptability (Sekhon et al., 2017). Two researchers independently coded the responses, resolving discrepancies through discussion and consensus. Responses were classified according to key acceptability dimensions, including affective attitude, perceived effectiveness, burden and ethicality, as Sekhon et al. (2017) described. In addition, the open-ended responses were categorised into four distinct groups based on participants' preferred animation. Responses were classified as expressing a preference for the NF1 animation, a preference for the FAP animation, an equal preference for both, or a critical stance towards both animations. The frequency of responses within each category was then tabulated to identify recurring themes and key factors influencing participants' preferences. These findings offer valuable insights into design considerations for creating compelling animated patient stories in the context of patient education.

Another methodological consideration in the study design involved selecting the most appropriate approach for evaluating the effectiveness and acceptability of the animated patient stories. Initially, the research team had considered using focus group discussions (FGDs) to assess the efficacy and acceptability of the animated patient stories. However, they ultimately opted for a survey-based approach. While FGDs are typically employed when discussing highly sensitive or emotionally charged topics, the evaluation in this study did not address particularly sensitive subject matter. Consequently, using a survey allowed for faster data collection from a larger, more representative sample, thereby ensuring broader insights into participants' perceptions of the animations.

Discussion of Findings and Conclusion

Through exposure to the videos, participating individuals stood to gain a heightened understanding of the importance of genetic testing and general knowledge of genomics and genetic health issues. Beyond the individual participants, the outcomes of this study have broader implications. The findings can benefit the public, the medical community, and future patients by providing insights into the efficacy of animated patient stories as educational tools for conveying information on genomics and genetic health issues. This study contributes to the ongoing exploration of innovative and engaging methods to enhance public understanding of genetics.

The study recruited participants across diverse ethnicities, incomes and education levels, ensuring a sufficiently broad range of perspectives. Our study found increased perceived knowledge and interest in genetics after watching the animation. Furthermore, 61.2% of participants preferred the FAP animation, rating it as more engaging and informative compared to the NF1 animation. These results suggest that audiences are more engaged with genomics and genetic health topics when presented through a dramatised and localised narrative style rather than a straightforward, generalised approach.

Moreover, our study showed that 98.9% of participants were receptive to learning genetic information from animations featuring characters of different ethnicities. This finding indicates that embedding cultural and local visual elements in

animated patient stories is relevant when designing visual health education tools.

Compelling healthcare storytelling is best achieved through a culturally sensitive animated narrative. This approach enables exploration of how artistic choices presented in animated video form can significantly influence healthcare decisions, particularly regarding understanding a genetic diagnosis. Moreover, within an Asian context, this method is apt for addressing concerns regarding discrimination and marginalisation. The visual and narrative elements of animation offer a unique platform for engaging audiences and fostering understanding and empathy when discussing sensitive healthcare topics.

The potential impact of sharing these animations with non-carriers on raising awareness of genetic conditions can be significant. Enhancing genetic literacy among the public is crucial in dispelling myths and correcting misconceptions about genetic predisposition. This increased awareness can foster a more informed and supportive community regarding genetic health.

Additionally, the main goal of creating accessible and educational resources is crucial for empowering carriers to make informed choices about managing genetic diseases. This project is particularly relevant to the local Asian community, where cultural nuances can influence perspectives on health and genetics. The aim of customising educational content to suit a specific context is to provide carriers with the tools and knowledge needed to navigate their genetic health journey more confidently and effectively.

Regarding the study's limitations, a potential avenue for further research could involve evaluating how the animation might be modified to better integrate into a genetic counselling scenario. However, the current research team did not explore this aspect because it fell outside the study's scope. To conduct such research effectively, a subset of patients must be invited to participate in semi-structured interviews. These interviews could explore their perspectives on the appropriateness and acceptability of the animations within the context of genetic counselling. Adopting this comprehensive approach, which combines quantitative data with qualitative insights, could facilitate a thorough examination of the impact and reception of the animations in a real-world setting. The findings from this phase could yield valuable insights into the effectiveness and acceptance of integrating animations into the process, potentially guiding future research directions.

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