Creating Accessible, Patient-Centered Education Materials for Fetal Blood Sampling and Intrauterine Transfusion

by
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Abstract

Fetal anemia, caused by conditions such as hemolytic disease of the fetus and newborn (HDFN) or parvovirus B19 infection, can lead to severe complications, including hydrops fetalis and fetal death. The most common treatment for fetal anemia is intrauterine transfusion (IUT), a lifesaving but historically risky intervention with limited patient-friendly educational resources. Existing materials often lack visual aids, are text-heavy, or contain outdated information, contributing to patient anxiety and knowledge gaps.

This study aimed to create and evaluate an animated educational video to improve patient understanding of IUT, reduce anxiety, and promote self-advocacy. The animation was designed using evidence-based multimedia learning principles and assessed for educational value and emotional impact. The animation was developed with iterative feedback from clinicians, patient stakeholders, and the Patient Education Material Assessment Tool for Audiovisual Material (PEMAT-A/V). A 5-minute animation depicting an overview of a typical IUT procedure at a high-volume fetal therapy center was produced. A study was conducted with 11 participants, including IUT-experienced and inexperienced individuals, to evaluate the video's understandability (via the PEMAT-A/V) and emotional impact (via Likert scales and open-response feedback).

The animation scored 97.5% on the PEMAT-A/V, exceeding the 70% threshold required for effective educational materials. Participants rated it 4.5/5 stars and reported overall positive emotions (e.g. calmness, confidence) despite some anxiety-related responses. Key strengths included clear visuals of needle placement and explanations of medical terms.

Feedback highlighted opportunities to expand content (e.g. complications, support resources) and adjust tonal elements (e.g. voiceover style).

This animation serves as an accessible patient education tool that improves understanding of IUT while reducing anxiety. It also demonstrates how patient-centered multimedia resources can bridge critical information gaps for rare medical procedures, ultimately empowering patients, improving informed consent, and setting a model for similar fetal therapy education initiatives. Future directions include increasing survey sample size, iterating further based on survey feedback, and eventually hosting the animation on the Johns Hopkins Center for Fetal Therapy website and YouTube channel for increased accessibility and credibility.

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Introduction

Overview of Fetal Anemia and IUT

During pregnancy, certain genetic or viral complications can result in fetal anemia, which can cause significant morbidity and mortality. The two most common causes of fetal anemia in the United States are hemolytic disease of the fetus and newborn (HDFN) and human parvovirus B19 infections (Prefumo et al., 2019). HDFN, which affects 3 to 8 out of 100,000 patients annually, occurs when mother and fetus have incompatible blood types, such as a mother being O- while her fetus is B+, resulting in maternal alloimmunization wherein the mother's antibodies attack the fetus's antigens (Myle & Al-Khattabi, 2021). Parvovirus B19 causes severe fetal anemia by attacking red blood cell progenitors and can be passed from mother to fetus if an infection occurs during pregnancy. In 2024, the proportion of people with parvovirus B19 infections in the U.S. increased by more than 300%, indicating that the need for fetal anemia treatment is likely to increase (CDC Health Alert Network, 2024).

Prolonged fetal anemia has an array of deleterious effects on the fetus. Bilirubin released during continual hemolysis builds up and causes hyperbilirubinemia, which in 25% of cases results in severe jaundice and kernicterus, a form of brain damage (Watchko, 2018). Additionally, the low blood cell count taxes the fetus's heart and, left untreated, the fetus may develop immune hydrops fetalis, a condition with a mortality rate between 82% and 93% (Bukowski & Saade, 2000).

Since its introduction in 1981, the most common treatment method for both fetal anemia and immune hydrops is intrauterine transfusion (IUT) with percutaneous umbilical cord sampling (PUBS), also known as fetal blood sampling or cordocentesis, often performed simultaneously to analyze the fetus's hematocrit during the procedure. These procedures are invasive and historically risky, carrying the possibility of severe complications such as membrane rupture, infection, or fetal death. That said, modern PUBS/IUT procedures are significantly safer than their historical counterparts. When performed by an experienced team, IUT has been reported to result in fetal survival as high as 97% for fetuses with HDFN, a marked increase from the pre-2001 survival rate of 89% (Crowe et al., 2023). PUBS has a similar success rate (Bigelow et al., 2016). Procedure-related complications have also dropped significantly since 2001 with the introduction of specialized, high-volume treatment centers (Zwiers et al., 2017).

Perhaps due to the rarity of the procedure or the rapid changes it has undergone since its conception in 1963, there are currently no published recommendations for best practices for IUT. How and when the procedure is performed varies widely from center to center, relying on expert opinions and historical precedents to determine important details such as location of the procedure and use of maternal anesthesia (Donepudi et al., 2022). These expert opinions can be scarce, as most centers in the U.S. perform less than 10 IUTs per year (Sobhani et al., 2022) and performing at least 10 procedures per year is considered necessary to maintain the appropriate level of skill required for such a delicate procedure (Lindenburg et al., 2011). With this dearth of consistency and potential lack of provider experience, it is important that IUT patients of all health literacy levels know enough to self-advocate.

Existing Resources for IUT Patients

Fetal anemia can develop acutely and urgent referral to a specialized center is typical. Thus, patient education and counseling about the procedure and its associated risks happen once the patient is evaluated at the fetal center. Patients usually have fewer than 72 hours between a fetal anemia diagnosis and their first IUT appointment, so it is necessary that any patient education material be easy to find, verify, and digest within that period (Miller, 2024). The need to be able to quickly interpret education material is especially vital if the patient only receives that material immediately prior to the procedure.

Currently, patient-friendly visual information describing PUBS and IUT are lacking. The Johns Hopkins Fetal Therapy Center, a high-volume center that performs an average of 60-70 IUT per year (*Hopkins Fetal Therapy*, 2024), has no readily available patient counseling resource detailing how PUBS/IUT is performed at their center besides brief webpage descriptions (**Figs. 1, 2**), instead relying on verbal communication upon arrival. Additionally, the first six hospital websites listed on a web search for "intrauterine transfusion" contain longer written descriptions of PUBS and IUT but lack any visual accompaniment.

Fetal Blood Sampling

Fetal blood sampling is a procedure used to diagnose, treat or monitor various fetal problems. Using a very small needle, specialists in Maternal-Fetal Medicine are able to remove a tiny amount of blood from the fetus during pregnancy.

This procedure is performed to:

- Determine blood type
- Diagnose genetic or chromosome abnormalities
- Diagnose possible fetal infections
- Identify possible fetal anemia (low red blood cell count)
- Identify possible low platelet count

How is this procedure performed?

1. This procedure is performed using continuous ultrasound guidance to place a needle through the maternal abdomen into a tiny fetal blood vessel.
2. A sample of fetal blood can then be sent for testing.

Will I need to have a full bladder?

Sometimes but usually not.

When will I get the results?

Your physician can advise you regarding when to expect the results, as result times do vary depending on the kind of test.

Fig. 1: The Center for Fetal Therapy's webpage on fetal blood sampling.

Intrauterine Transfusion

This procedure is done using ultrasound guidance to place a small needle through the mother's abdomen into a small fetal blood vessel. Blood, platelets or medications can be administered to the fetus through this technique.

Fig. 2: The only description of IUT on the Center for Fetal Therapy's website.

Besides hospital websites, many initial web search results for "intrauterine transfusion" or "fetal blood sampling" link to journal articles aimed at a medically trained, high-literacy audience. These resources, though factually correct, may be beyond the accessibility and needs of a patient audience, especially those in such short supply of time.

Online images of IUT and PUBS consist of text-heavy slides, fuzzy ultrasound images, or depictions of similar but unrelated fetal therapy procedures (**Figs. 3, 4**). The few accurate, though often very simple, illustrations of either procedure link to non-hospital websites, making them difficult for the average viewer to verify as correct. A search on YouTube yields personal interest news stories and short, medical definitions of the procedures that lack details on what the patient will actually experience.

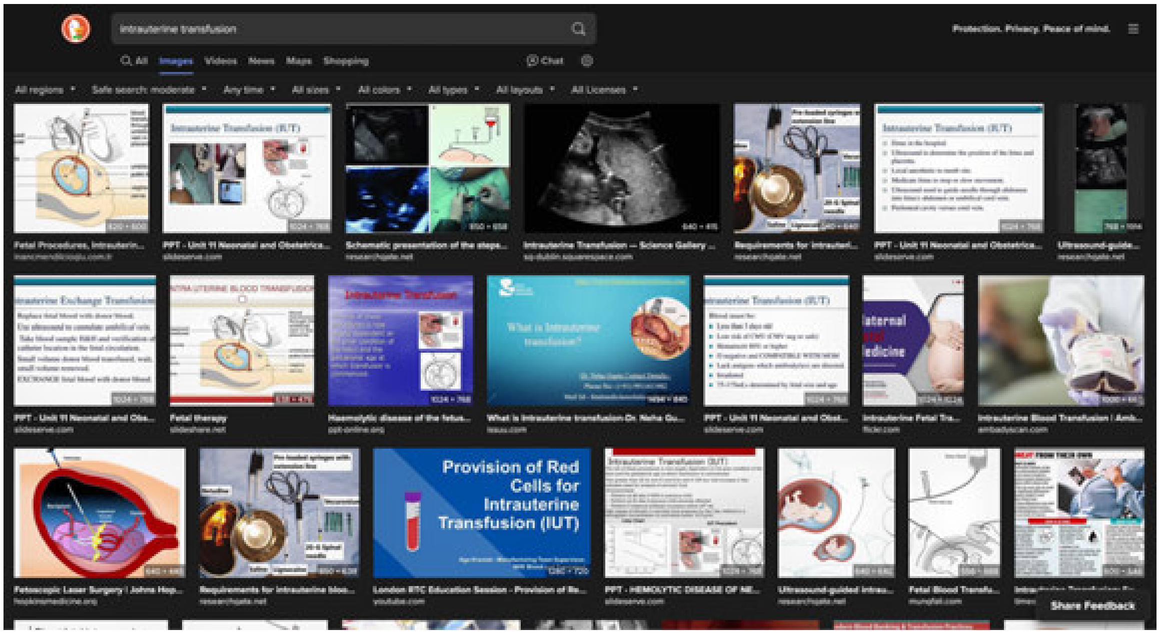


Fig. 3: Search results for "intrauterine transfusion." Text not intended to be read.

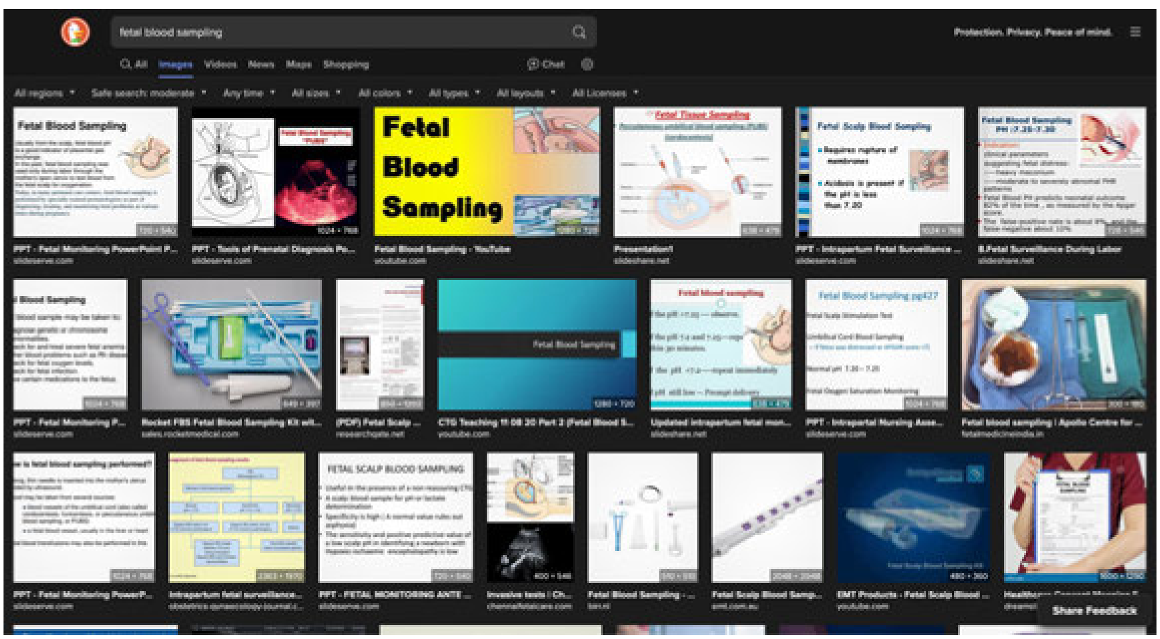


Fig. 4: Search results for "fetal blood sampling." Text not intended to be read.

Wikipedia, a website that often appears in the initial results of any web search, has pages for both IUT and PUBS. The IUT page contains information that was generally accurate, though at least one typo ("HFDN … affects 3 … to 80 out of 100,000 patients per year" instead of "3 to 8") was observed at the time of writing. There are also no visuals on the page. Wikipedia's PUBS page contains diagrammatic visuals depicting needle placement, though the angle of the needle is incorrect (**Fig. 5**). Notably, the page also describes PUBS as "carr[ying] a significant risk of complication and [being] typically reserved for pregnancies determined to be at high risk for genetic defect" according to a source that no longer exists. Information that is inaccurate or outdated can create misunderstandings and increase anxiety, especially given the relatively recent increase in safety of PUBS/IUT procedures.

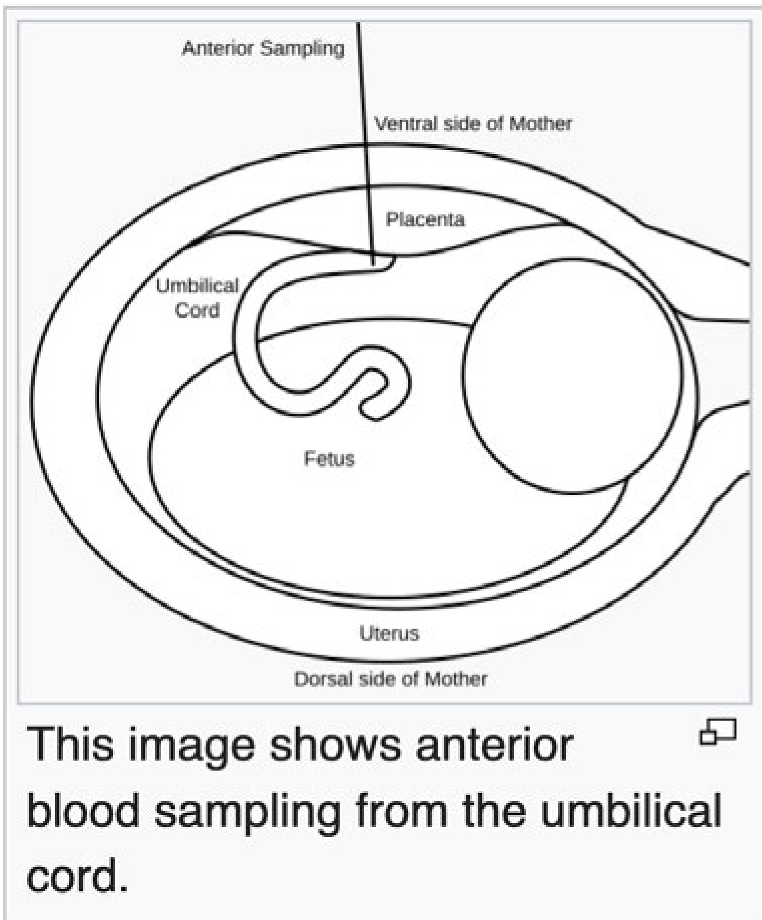


Fig. 5: An image from Wikipedia's PUBS page that depicts the needle entering the umbilical cord from a perpendicular angle; the needle should be at the same angle as the cord's insertion into the placenta.

Few publicly available resources exist for patients to learn about IUT and among them conflicting information is presented. To rectify this gap in patient information and to demonstrate how IUT is performed by an experienced team, we designed an animation for the Johns Hopkins Center for Fetal Therapy based on feedback from both clinician experts and patient stakeholders to determine content needs.

Evidence-based Recommendations for Patient Education

Access to online information about treatment has been shown to impact patients' decision-making (Chang et al., 2020), and educational videos given to patients before a procedure decrease patient anxiety regardless of patient age or gender (Bondy et al., 1999). That said, the quality of medical resources online can be poor, with high readability levels that lead to misinterpretation of information (Alshaikh et al., 2021). Additionally, it has been found that while simpler patient education materials increase knowledge and reduce patient anxiety before an appointment, more complex materials only increase knowledge and do not lessen anxiety (Marteau et al., 1996). By giving a simple but thorough overview of the entire IUT procedure in video format, we hope to fill an important gap in online IUT education material, reduce patient anxiety, and increase patient knowledge with the goal of encouraging self-advocacy.

We decided on the animated video format of this project after researching how patients might best learn information in a limited time frame. The Cognitive Theory of Multimedia Learning states, firstly, that people learn more from the combination of words and pictures than just from words alone and, secondly, that it is necessary to not overload learners with non-essential information (Mayer, 2008). The Dual Coding Theory similarly states that information processed through two systems, audio and visual, leads to more gains in knowledge than information processed through a single system (Clark & Paivio, 1991). Audio aids, in particular, improve patient understanding of medical procedures significantly more than visuals with no audio aids (Kraft et al., 2017). These theories are supported by research indicating that short animations significantly improve viewers' understanding of health and clinical procedures across age, sex, and levels of health literacy (Feeley et al., 2023). We designed our animation with these findings in mind: non-essential IUT information is minimized, the video is narrated throughout, the visuals reinforce the narration, and the video itself is under 5 minutes long.

Educational Value as Defined by the PEMAT

The Patient Education Material Assessment Tool (PEMAT) is a validated, numerically scored questionnaire developed by the Agency for Healthcare Research and Quality that evaluates patient education materials in two domains: understandability and actionability. Understandability in the PEMAT is defined as when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages, while actionability is when those consumers can identify what to do based on the information presented. A higher score on the PEMAT, even when the survey taker has not been trained before taking it, is positively correlated with better patient understanding of health materials (Shoemaker et al., 2014). Importantly, the PEMAT allows its user to test educational material with no additional information needed by the user, making the test widely accessible. Versions of the PEMAT exist for both printable materials (PEMAT-P) and audiovisual materials (PEMAT-A/V).

By modeling our animation based on the tenets outlined by the PEMAT-A/V, specifically the Understandability domain, we aim to enhance the project's value as a patient education material for viewers of various health literacy levels in a manner that is proven and easy to test. The structure of the animation, for example, was crafted to begin with a short overview, then present each topic in its own "chunk," before ending with a summary in accordance with the PEMAT-A/V. Clear narration, the use of active voice, and uncluttered illustrations are also among the items the PEMAT-A/V asks for. Combining the PEMAT-A/V with expert-approved information on IUT should, in theory, result in IUT patient education material that is accurate and easy to understand across varying levels of health literacy.

Objectives

- **Create** an animation that will educate patients of different health literacy levels about IUT and what to expect during and after the procedure.
- **Iteratively develop** content with user-centered design to produce materials that best suit our audience's needs and interests.
- **Assess** the animation's educational value using the PEMAT-A/V and patients' emotional response to the material using open response questions.

Intended Audience

The primary intended audience for this project is people who might require IUT at some point during a pregnancy, particularly people who have never received IUT before. The secondary audience includes friends and family of the patient who want to learn more about the patient's experience to better support the patient. Students or physicians who may refer to this project for a general outline of how a high-volume center performs an IUT make up the tertiary audience.

Significance

IUT is an underrepresented fetal therapy procedure regarding online patient content. This project serves as authoritative web content for a topic with little information for patients. By using patient-friendly language and imagery to describe how a high-volume, experienced fetal therapy center performs IUT, we provide an easily searchable "standard" procedure that patients, families, and physicians can use to educate themselves. Patients will be able to self-advocate, and doctors will have a resource to help with anticipatory guidance and informed consent. Sharing the project on YouTube will help improve engagement, accessibility, and searchability, allowing more people to utilize information on the procedure. Our project can also serve as an example for other Hopkins web content by incorporating patient needs and feedback into the design process.

Materials and Methods

I. Animation Creation

Initial research and observation

The final content of the animation was influenced by a combination of existing literature, direct observation, and conversations with patients and experts. Because there are currently no published best practices for IUT procedures, extensive research was performed before production to accurately portray an average IUT procedure. We performed a literature review to understand current trends in IUT procedures both in the U.S. and globally. Dr. Jena Miller, a clinician at the Johns Hopkins Center for Fetal Therapy and the preceptor for this thesis, provided expert feedback and resources in the form of pre-prints, recent statistics from the Center, and her own academic conference presentation PowerPoints on IUTs. Dr. Miller also helped create a basic overview of the IUT procedure as performed at Hopkins that could be broken down into distinct stages in the animation. A one-hour Ultrasound Education Conference on the topic of fetal anemia presented by Dr. Ahmet Baschat, the Director of the Center for Fetal Therapy, was attended online. This presentation described recent case studies from the Center and indicators, outcomes, and treatment recommendations for fetal anemia. Finally, an IUT procedure performed at the Center was observed. A team meeting to discuss the known details of the case and planning the procedure was attended before entering the triage room where the patient was waiting. Fetal blood sampling, an IUT procedure, and a fetal partial exchange transfusion were observed and recorded (**Fig. 6**).

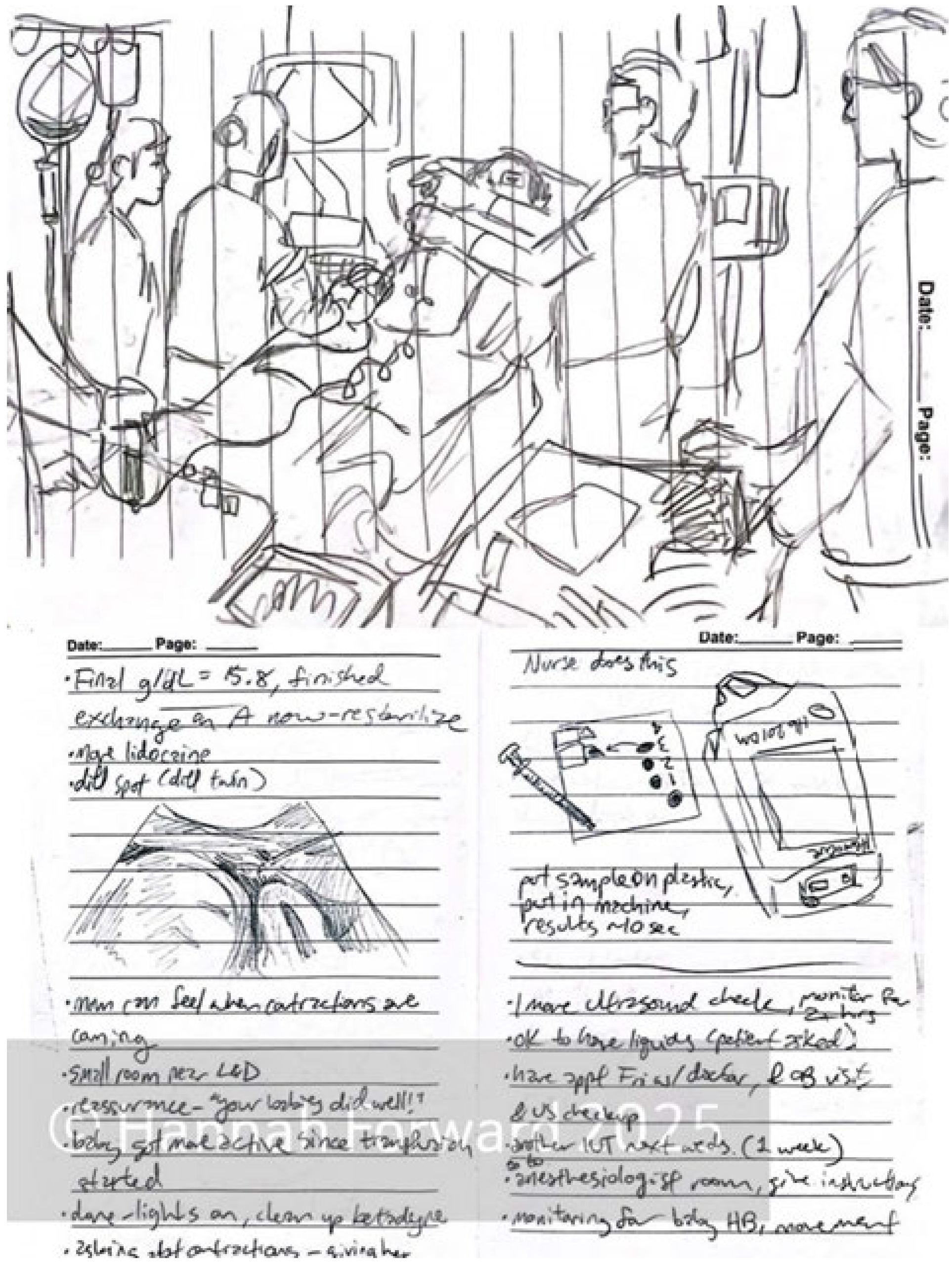


Fig. 6: Drawings and notes taken of the environment, ultrasound, and fetal blood sampling instruments. Text not intended to be read.

Next, gaps in patient resources for IUTs were identified. A web search for patient education materials about IUTs and the closely associated fetal blood sampling procedure was conducted using combinations of key words such as: intrauterine transfusion, IUT, fetal blood sampling, percutaneous umbilical blood sampling, PUBS, PUBS/IUT, fetal anemia, intervention, procedure, patient education, and patient information. The Johns Hopkins Center for Fetal Therapy website pages “Fetal Blood Sampling” and “Fetal Surgery and Procedures” (in lieu of a dedicated IUT page) were reviewed, followed by other hospital pages on IUT. Discussions with Dr. Miller helped to clarify how patients at the Center currently receive information before treatment, describe the patient timeline from diagnosis to treatment to birth, and identify clinician needs for improving communication with patients.

An interview was also conducted with patient stakeholders from the Allo Hope Foundation, an organization that offers resources and support to alloimmunized women and patients with Hemolytic Disease of the Fetus and Newborn (HFDN), who often undergo IUTs as part of their treatment. Our goal was to understand patients’ mindsets before, during, and after undergoing IUT and what patients desired to see in educational materials on IUT. The patient stakeholders shared additional patient-facing resources on IUT procedures such as relevant episodes from The Allo Podcast and their website allohopefoundation.org.

Animation Development

Our goal was to create a short overview video to inform patient of the IUT procedure prior to undergoing an IUT that would 1. reduce patient stress by improving patient understanding of IUT and 2. improve communication between patient and doctor by giving the patient a basis from which to ask more informed questions.

Scripting

A script describing a typical IUT procedure sequentially from referral to discharge was written. Iterative edits were made by the thesis preceptor, patient stakeholders, and the faculty advisor to ensure that the script accurately outlined the procedure, used the correct terminology, and maintained an empathetic, conversational tone. The script was written to suit a five-minute animation and comply with the principles outlined for audiovisual materials in the PEMAT-AV. Content for the animation was divided into six sections (**Table 1**). The full script is available in **Appendix A**.

Section Title	Content
Overview	Introduction Description of fetal anemia
Your IUT Team	Roles of care team members in room during IUT
Preparing for the IUT	Goal of IUT State of patient Pain management Use of ultrasound Possible locations for needle insertion
Taking the Sample	Description of fetal blood sampling Administration of fetal paralytic
Transfusing the Blood	Description of transfusion Post-procedure monitoring & discharge
Summary	One-sentence summaries of prior sections Assurance of support for patient and baby

Table 1: Description of content in each section of the animation.

Storyboarding

Storyboards were created iteratively with reviews by the thesis preceptor and advisor on the accuracy of the visuals and portrayal of the patient experience. A preliminary version was shared with patient stakeholders from the Allo Hope Foundation to receive feedback on patient-friendly language and imagery and then revised with that feedback in mind. The final storyboard sequence can be viewed in **Appendix B**. Storyboards were drawn in the Storyboarder app at the intended final resolution 1920x1080 and refined in Photoshop via Storyboarder's "edit in Photoshop" feature. Line drawings with limited spot color to describe movement were used.

Asset Creation

We chose a hand-drawn, textured illustrative style with bright, flat colors to create friendly, inviting visuals. Backgrounds were kept simple to keep viewers' focus on the actions being performed by the characters. The characters, though stylized, were drawn with realistic proportions as patient stakeholders stated that overly cartoonish styles may feel condescending toward the adult viewer. We aimed to illustrate characters with diversity to resonate with a wide public audience, and **Fig. 7** shows some of the different facial features, hair styles and colors, skin tones, and body shapes that were assigned to different characters. Diversity is important because representation of historically marginalized populations in health communication materials may help reduce health inequities in those populations (Myers et al., 2019). Final assets were created in Photoshop at a resolution of 350 DPI.

Fig. 7: Final versions of characters used in the "Your IUT Team" scene.

Flat color with minimal additional rendering allowed for a seamless blend of separate assets; for example, the fetus body, thigh, and leg can all be rotated without revealing an obvious seam. To ensure viewers could easily follow the story and characters across multiple scenes, local color was used in Photoshop and later adjusted per scene in After Effects with Overlay layers, allowing characters and items to maintain similar relative palettes throughout the animation.

After the illustrations were reviewed for accuracy by the preceptor, asset files were duplicated, resized to 1920x1080 px, and lowered to 150 DPI resolution to reduce the file size for import into After Effects. Assets that were intended to be dramatically zoomed in on were kept appropriately large to avoid pixelated edges. Folders in Photoshop translate into pre-compositions in After Effects when imported, so care was taken to organize folders in a way that would allow for associated assets to be animated together. Shapes that were to be animated separately, such as limbs or instruments, were kept on separate layers, while other shapes were flattened into a single layer to further reduce file size.

Animation

Adobe After Effects was used for animation. Several plug-ins helped to streamline the animation process including Animation Composer 3, which provides preset animations and transitions, and Duik Ángela, which rigs and animates characters.

Character Rigging

We used two methods of character rigging depending on the movement required. First, for characters who needed more complex articulation, Duik's autorigging feature was used. Anchor points of each limb segment layer were moved to the center of the intended joint. Next, each more distal segment of the limb was made a child of the more proximal segment. Finally, relevant layers were selected and autorigged, creating controllers for the limb segments that could be keyframed (**Fig. 8**).

Fig. 8: An arm controller that moves the entire arm based on the position of the hand.

Second, because Duik Ángela relies on the extensive separation of layers, the puppet pin feature was used to rig aspects of characters which resided in the same layer or precomposition such as an umbilical cord, head and neck, or facial features. Unlike Duik's autorig feature which generated a rig that moved different layers relative to each other's anchor points but otherwise left those layers unaltered, the placement of a puppet pin generated a triangular mesh within a layer (**Fig. 9**). Each puppet pin placed on the mesh served to "pin down" the point it was placed on. When a puppet pin's position was altered, the mesh around that pin warped the layer except for where it was stuck in place by other pins. The resultant squash/stretch warping was ideal for smaller, naturalistic movement.

Fig. 9: A character with a puppet pin mesh covering his head and neck. The puppet pin (solid yellow circle) on the head allows him to nod while the puppet pins on his neck (hollow yellow circles) keep that region from moving along with the head.

Expressions

Many of the animations were created or modified using expressions, which run on the JavaScript engine. Dan Ebberts's Keyframe Overshoot expression (Ebberts, 2012) (**Fig. 10**), which calculates keyframe value based on an exponentially decaying sin wave, was frequently added to objects entering a scene to make movement feel less robotically smooth. The frequency (freq) value determined the number of times the final value was overshot and the decay value determined how far it was overshot. This expression only worked on keyframes that had not been easy-eased, as the easy-ease value curve overwrote the sin wave value curve.

```
freq = 1;
decay = 7;

n = 0;
if (numKeys > 0){
  n = nearestKey(time).index;
  if (key(n).time > time) n--;
}
if (n > 0){
  t = time - key(n).time;
  amp = velocityAtTime(key(n).time - .001);
  w = freq*Math.PI*2;
  value + amp*(Math.sin(t*w)/Math.exp(decay*t)/w);
}else
  value
```

Table 2: A keyframe overshoot expression with the frequency value set to 1 and the decay value set to 7.

To create random, ambient movement in a scene, the Wiggle expression was applied to select object position or rotation properties. The Wiggle expression relies on two values: frequency of value change per second and amplitude (or breadth) of that change. This expression functions independently of keyframes, allowing for position or rotation keyframes to be added without interrupting the random movement, but also then requiring some modification to the expression to keyframe the Wiggle values themselves. To overcome this limitation, a Slider Control was added to the object being animated. The Slider Control contains a value slider that can be inserted into the Wiggle expression and then keyframed (**Fig. 10**).

Fig. 10: An object with a Slider Control renamed "Amplitude Slider" and a Position field containing a modified Wiggle expression linked to the slider in the amplitude place.

Camera Movement

Camera movement was simulated using null objects to create visual interest during otherwise still scenes. To imitate handheld camera movement in scenes like the Your IUT Team scene, a null object was created and given the modified Wiggle expression in its Position field as outlined in the previous section. The characters and objects in the scene were then made children of the null object, making them move as a group while still allowing for individualized keyframing. This basic setup served as the foundation for more complex camera movements. In the Overview scene, a parallax effect was achieved by making the entire scene a precomposition and then using the null object to scale the scene up and keyframe a pan from right to left. Within the precomposition, the background's position was keyframed to slightly move from left to right at the same time the null object moves, creating the illusion that the characters and the background exist on different planes.

Crash zoom transitions, such as the zoom into the ultrasound monitor in the Preparing for the IUT scene, were created by using a null object to simulate a dramatic camera zoom from one scene into another. First, both scenes (as precompositions) were placed in their own composition with the ultrasound scene at full size. The fetus scene was scaled down, rotated, and moved until the fetus in that scene roughly aligned with the fetus in the ultrasound monitor (**Fig. 11**). A null object was created and moved so that its anchor point sat in the middle of the fetus scene, and then both scenes were parented to the null. Using the null object, both scenes could then be zoomed into and positioned so that the fetus scene filled the screen, with the fetus scene's opacity flipping from 0 to 100 in a single frame in the middle of the zoom. This effect was enhanced by turning on motion blur for the objects, going into Composition Settings > Advanced and turning the shutter speed to 200, opening the Graph Editor and heightening the null object's position and zoom speed curves (**Fig. 12**), and using the Motion Tile effect on the fetus scene to hide any remaining sharp edges during the zoom.

Fig. 11: Fetus scene at 50% opacity to demonstrate pre-zoom scene alignment.

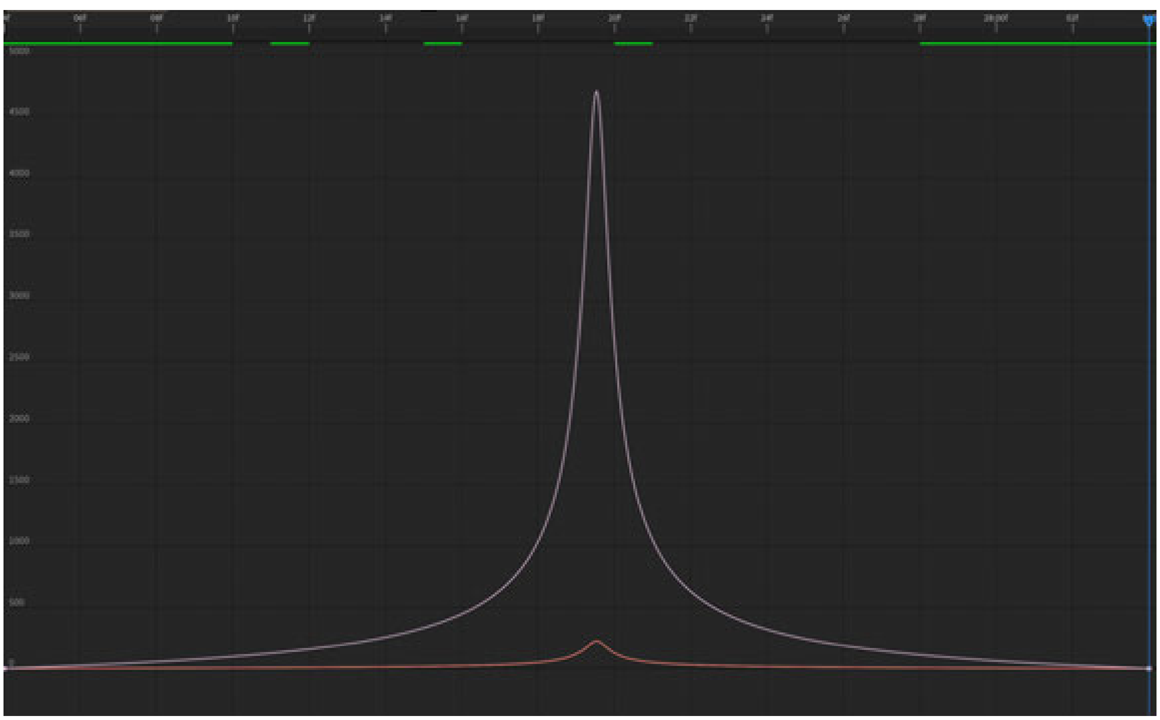


Fig. 12: The null object's position curve (pink) peaks at 4750 px/sec while the scale curve (red) peaks at 225 px/sec. The whole transition takes 30 frames, or one second. Text not intended to be read.

Additional Stylization

Rim light effect

CC Light Sweep was used to create a rim light effect on assets in certain scenes by turning the Sweep Intensity value to 0 and setting the Edge Thickness value to a value between 4 and 10, depending on the size of the asset (**Fig. 13**).

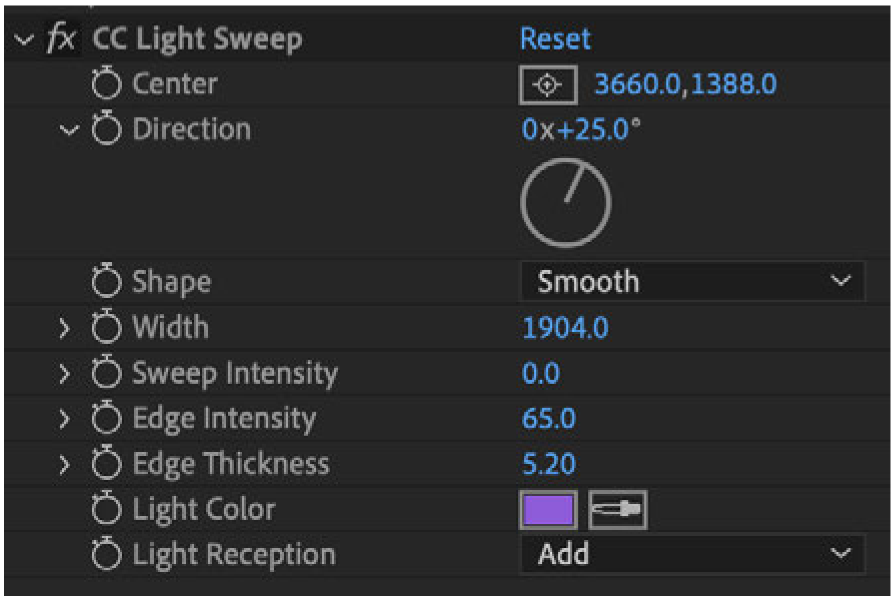


Fig. 13: An example of a typical CC Light Sweep setup.

Hand-drawn effect

If an asset was created directly in After Effects instead of Photoshop, the hand-drawn rough-line look could be mimicked by using the Turbulent Displace effect (**Fig. 14**).

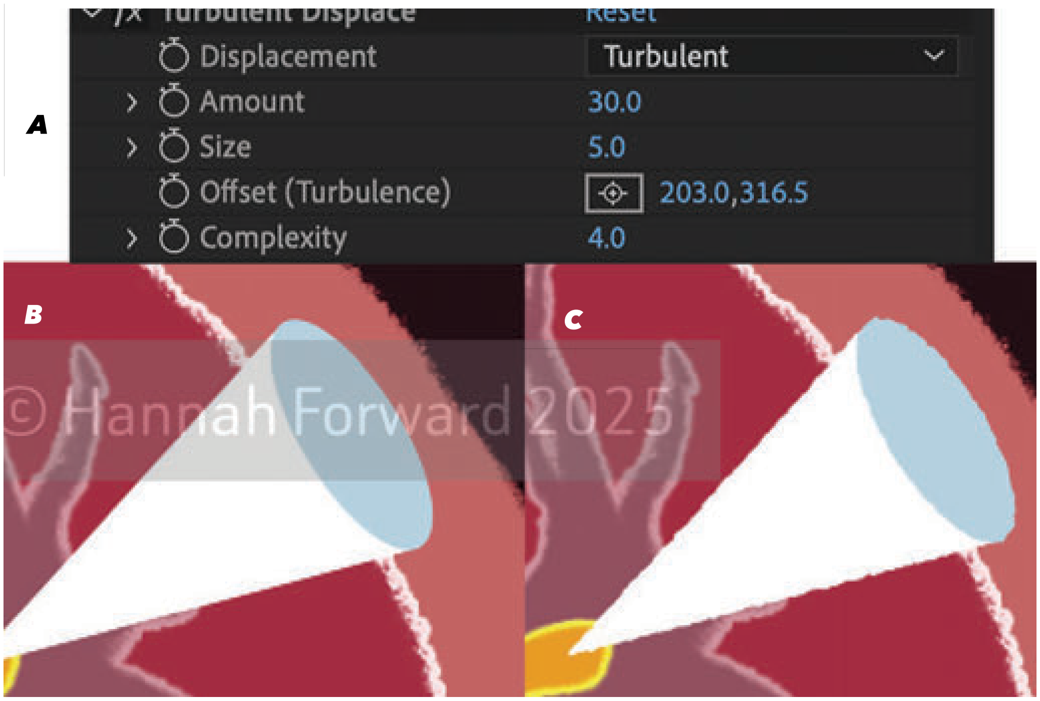


Fig. 14: A) Turbulent Displace effect settings. B) Item without the effect. C) Item with Turbulent Displace.

Accessibility

Text in the animation was adjusted to meet accessibility standards set by the Web Content Accessibility Guidelines (WCAG 2.2). All text complies with the AA standard contrast ratio of 4.5:1. Additionally, an audio description of all important information in the video is provided by the voiceover.

II. Study Design

A quality improvement study was performed with previous or potential IUT patients to test the efficacy of and response to the animation. The study was approved by the Johns Hopkins Medicine Institutional Review Board (IRB00470589).

Recruitment

The study was distributed to the Allo Hope Foundation's Patient Advisory Council, which consisted of 9 people, at their quarterly meeting. Participants were given 15 minutes during the meeting to complete the survey with the option of pausing and finishing it anytime in the following week. The study was also distributed to acquaintances who had young (<8 years old) children. The recruitment email can be found in **Appendix C**.

Procedure

An online survey was conducted through Qualtrics, which participants could access through their smartphones, tablets, or computers. The survey consisted of a demographic collection section, viewing our animation, questions from the PEMAT Tool for Audiovisual Materials (PEMAT-A/V), and an open response feedback section (**Fig. 15**). The demographic collection section determined how familiar the participant was with IUT procedures; the PEMAT-A/V section measured the material's value as an educational device; and the feedback section collected participants' attitudes toward the material. The survey was estimated to take about 15 minutes to complete. The full survey can be found in **Appendix D**. The PEMAT-A/V can be found in **Appendix E**.

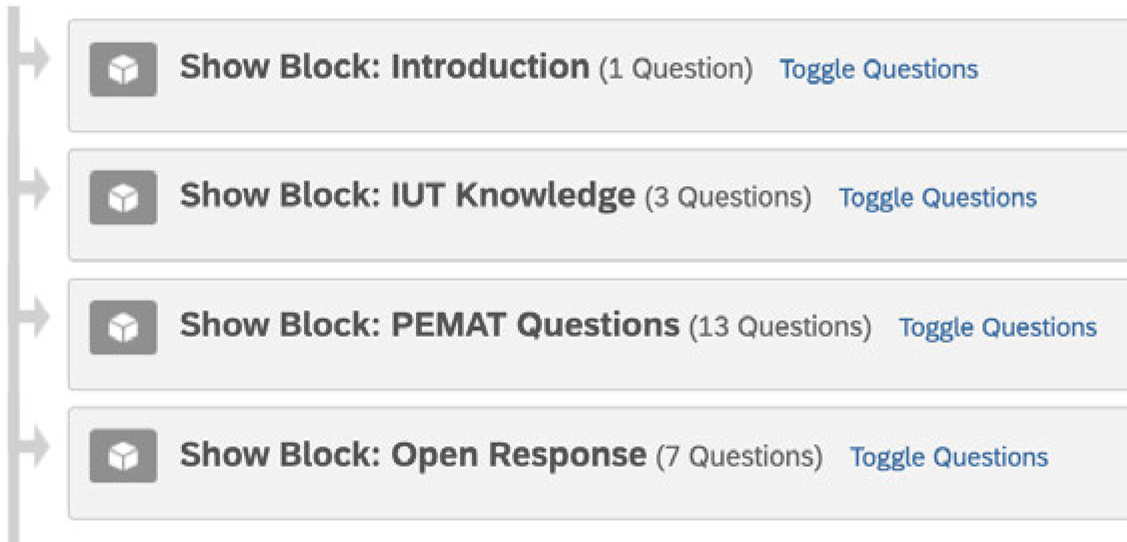


Fig. 15: Qualtrics survey flow.

PEMAT-A/V Section Design

We adapted the PEMAT-A/V to create a more streamlined experience for participants, preventing the need to click off the survey page. According to the PEMAT User's Guide, PEMAT users should read through the User's Guide and instrument to familiarize themselves with the items. This step was adapted by listing the Guide's item rating instructions at the beginning of the section and then providing each item's explanatory text beneath the corresponding survey question (**Fig. 16**).

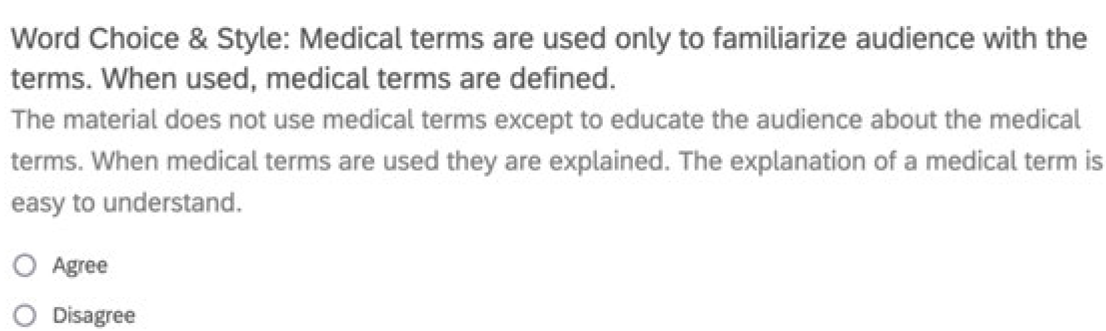


Fig. 16: An example of a PEMAT-A/V item with its corresponding explanation in the survey.

Certain items may be marked as Not Applicable (N/A) in the original PEMAT. To reduce the length of the survey, items determined to be N/A by our team were excluded from the survey altogether. Item #13, “Text on the screen is easy to read,” was determined to be N/A with the exclusion criteria "all text is narrated." Item #19, “The material uses simple tables with short and clear row and column headings,” was also determined to be N/A by the exclusion criteria “no tables.” Because the animation was created to be purely informative, the four items in the “Actionability” domain were similarly excluded. The final version of the PEMAT-A/V given to participants consisted of 11 total possible points.

Data Analysis

Each participant’s PEMAT-AV point total was divided by the total possible points to determine their score of the material’s understandability (as outlined by the User’s Guide), and these scores were then averaged to find the mean understandability score. Our hypothesis was that the material would score 100%; a score of >70% on the PEMAT is considered passing. Open response feedback was examined qualitatively for themes.

Results

Animation

We created a patient education animation (**Fig. 17**) that was assessed in our study. The animation, titled "What to Expect During an Intrauterine Transfusion Procedure," is 5 minutes long.

Fig. 17: Screenshots of four scenes in the animation describing the IUT team, possible needle insertion locations, the transfusion, and post-procedure monitoring.

Study Results

Survey Population

Our Qualtrics survey was conducted over 8 days from February 27th to March 7th. The survey was sent to 9 members of the Allo Hope Foundation's Patient Advisory Council as well as several acquaintances with children under 8 years of age. 13 responses were recorded with 2 excluded because the survey was incomplete, resulting in 11 quality responses for analysis.

All 11 participants had previously experienced a pregnancy; 6 of those 11 participants had undergone IUT. Participants were asked to rank their familiarity with IUT using a 5-point Likert scale prior to watching the animation, with the majority of participants stating that they were already very or extremely familiar with IUT (**Fig. 18**).

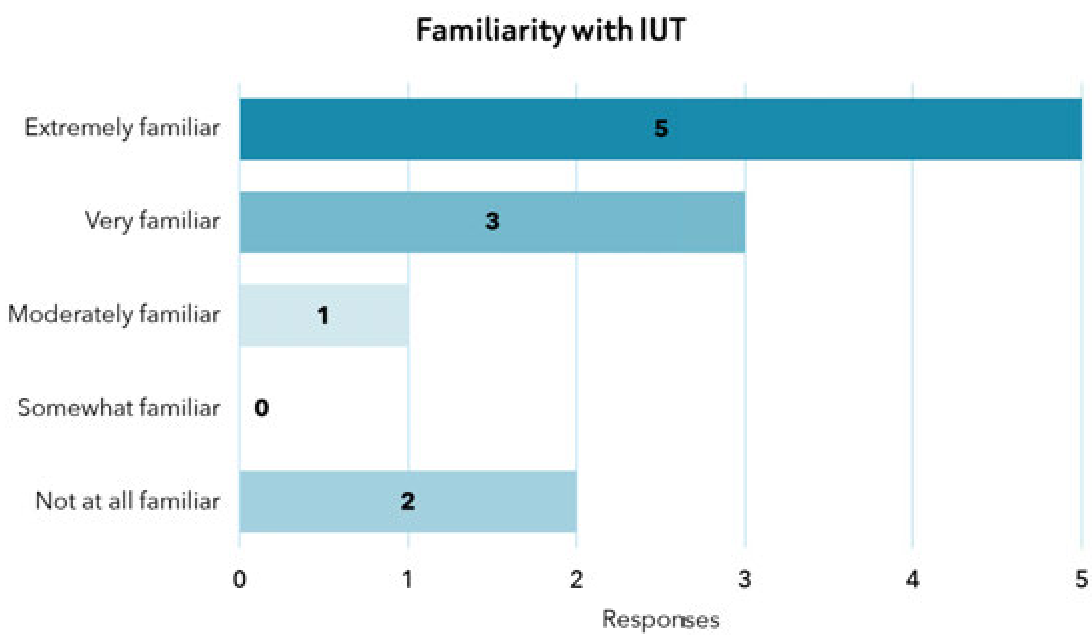


Fig. 18: Responses to the question "How familiar are you with intrauterine transfusion (IUT)?" Participants ranked statements on a 5-point Likert scale, ranging from Not at all familiar (1) to Extremely familiar (5).

PEMAT-A/V Results

The PEMAT-A/V was scored out of 11 points, with each "agree" response adding 1 point to the participant's overall score, and then calculated as a percentage. All items were weighted evenly. The average score was 97.5%, or 10.7/11 points (**Fig. 19**).

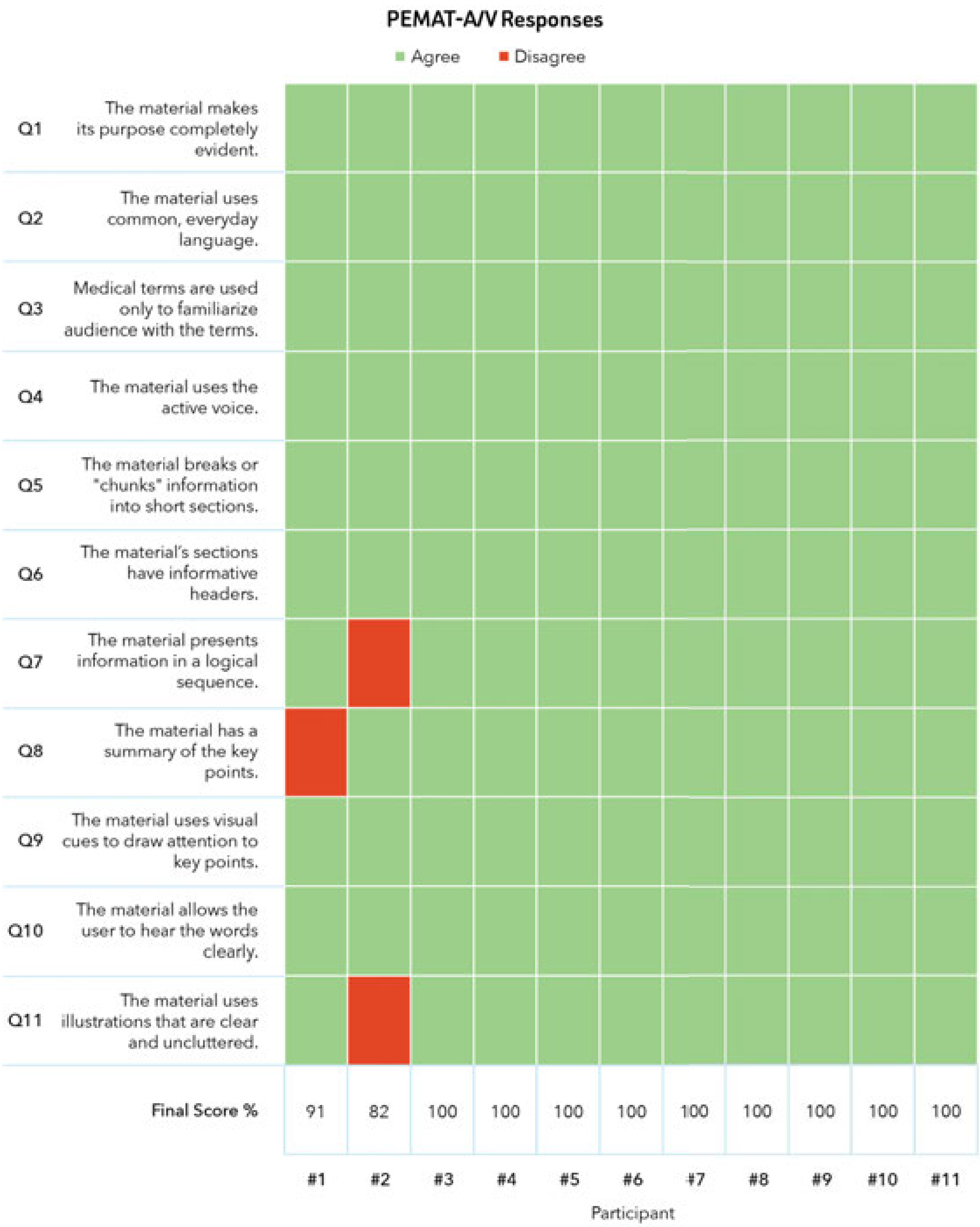


Fig. 19: PEMAT-A/V question results and final scores from 11 participants. Participants chose to agree or disagree on each item. The sum of "agree" answers was then divided by the total number of items for the final score.

Open Response Results

We used a combination of Likert scale, star rating, and free-response questions to assess participants' responses to the video. The Likert scale question and the star rating question were both ranked out of 5 points, with 5 being the highest rating. A full list of the written responses we received is available in **Appendix F**.

Participants were asked, on a scale of very unlikely (1) to very likely (5), "How likely would you be to recommend this video to someone about to undergo an IUT procedure?" The average score was 4.4 out of 5 (see **Fig. 20**). The question "What is your overall star rating of the animation, with five stars being the best rating?" had nearly identical results, with only one participant giving a higher score than their likelihood to recommend rating, resulting in an average score of 4.5 out of 5 stars.

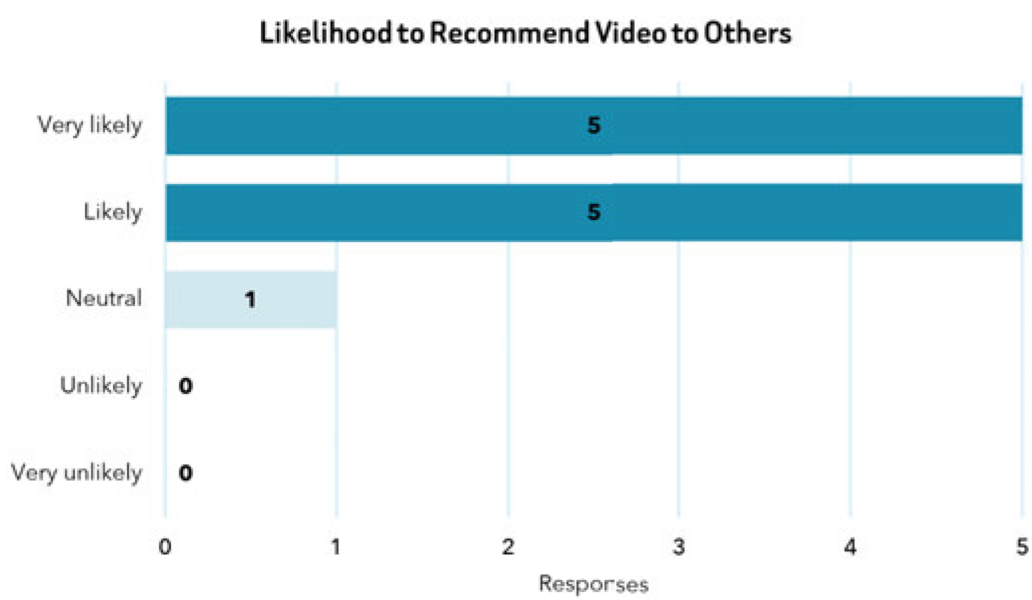


Fig. 20: Responses to the question "How likely would you be to recommend this video to someone about to undergo an IUT procedure?" Participants ranked statements on a 5-point Likert scale, ranging from Very unlikely (1) to Very likely (5).

Free-response questions were analyzed qualitatively, searching for common themes among responses. Question C asked "What was most helpful or educational about the video?" (**Fig. 21**) Five of the eleven participants mentioned seeing the location of the IUT needle in their responses. Other common responses included the video's explanations and definitions, the visuals of the procedure, and seeing the whole IUT process from start to finish. Two participants said the video helped set expectations for IUT procedures and two participants mentioned the video's clarity in depicting IUT.

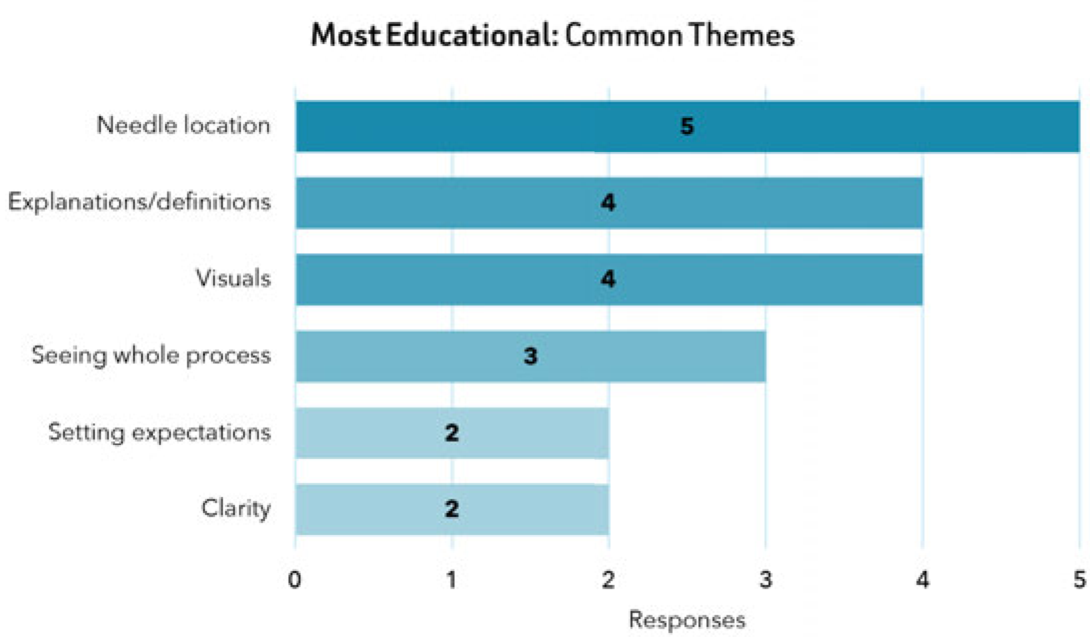


Fig. 21: Common themes found in participants' responses to Question C, "What was most helpful or educational about the video?"

Question D asked participants "What emotion(s) do you associate with the video?" Responses were analyzed and divided into positive and negative emotions (**Fig. 22**). Participants were allowed to list more than one emotion, with each emotion listed counting as a unique response. 70.5% (12/17) of the emotions listed were considered positive. Responses were then sorted by specific emotion (**Fig. 23**). The most common responses, listed 4 times each, were "calm/peace" and "confidence/decisiveness." The next most common response, and also the most common negative emotion, listed 3 times, was "anxiety/nervousness." Two participants listed "security/safety/trust." Other responses included "supportive," "hopeful," "fear," and "nausea." Four participants listed exclusively positive emotions; five listed at least one positive and one negative emotion; and two participants listed exclusively negative emotions.

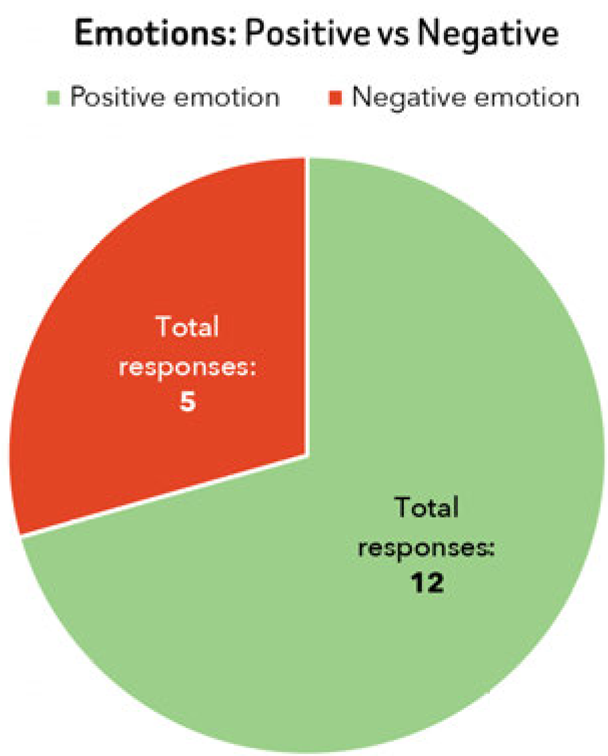


Fig. 22: Summary of responses to the question "What emotion(s) do you associate with the video?" sorted by positive and negative.

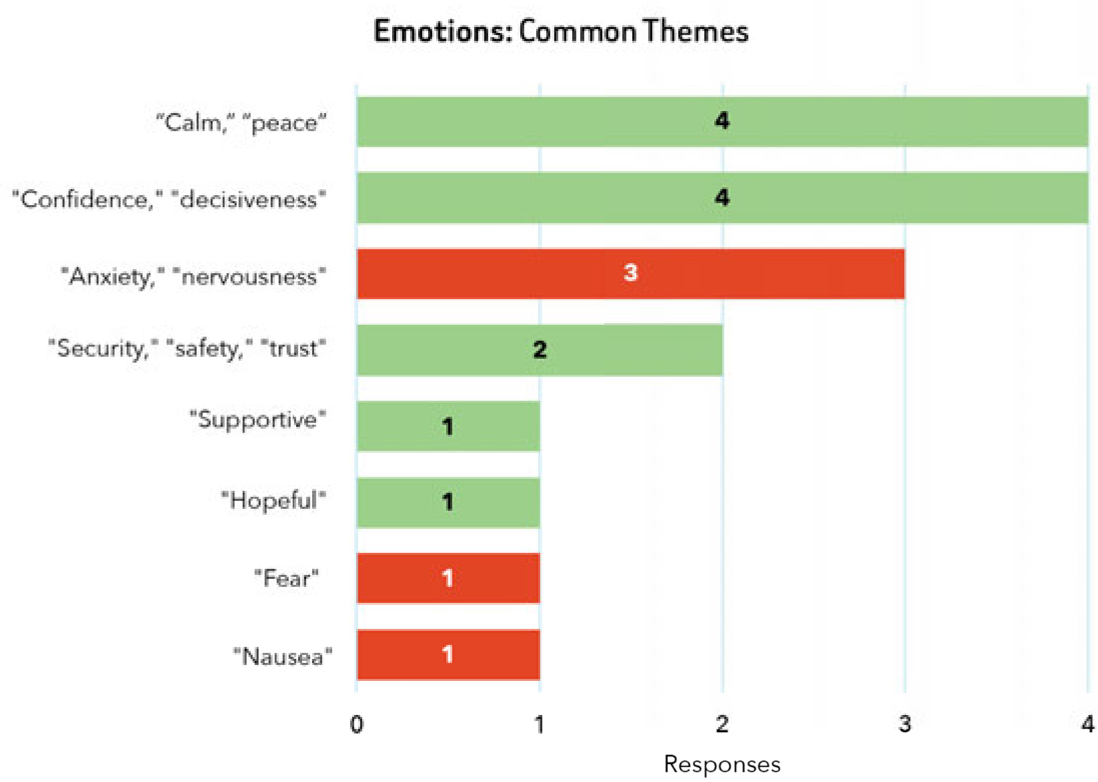


Fig. 23: Common themes found in participants' responses to the question "What emotion(s) do you associate with the video?" Positive emotions are depicted in green and negative emotions are depicted in red.

Optional question E asked participants for suggestions for improving the video, and optional question D asked if participants had any additional feedback or comments on the video. Responses to both questions were combined and analyzed for common themes (**Fig. 24**). The most common response, given by five participants, was that the participants wanted more information on various aspects of the IUT procedure. Areas of desired information included diagnosis of fetal anemia, resources and support groups for patients, fetal movement after the procedure, alternative terms for fetal blood sampling, possible complications, medications given to the patient, and what the patient might feel during the procedure. Two participants said that their own experience with IUT was different than depicted in the video, with both stating that a support person was not allowed in the room during IUT. Other responses mentioned the voice sounding too robotic (2) and the patient in the video looking too happy (1).

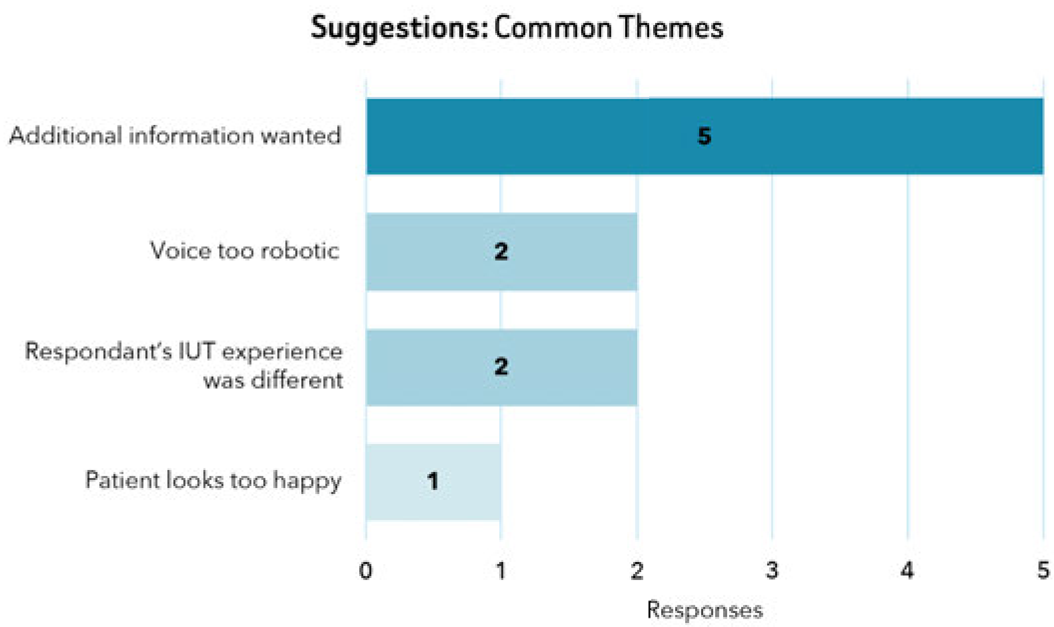


Fig. 24: Common themes found in participants' responses to the question "Do you have any suggestions for how to improve this video?

Access to Assets Resulting from this Thesis

The animation produced from this thesis project can be found at forwardmedart.com or by contacting the artist at hannah4ward@gmail.com. The video is hosted on Vimeo (https://vimeo.com/1069334000). The author of this project can be reached through the Johns Hopkins University School of Medicine Department of Art as Applied to Medicine at the following website: https://medicalart.johnshopkins.edu/.

Discussion

We created an animation and assessed its efficacy as an educational tool for IUT patients. The goal of the animation was to give patients a general overview of how a high-volume specialty center performs IUT procedures to help patients inform themselves and set expectations before undergoing IUT. Because there is no published best practice for IUT, and because the procedure's safety ratings have significantly improved over the last 20 years, there is little current patient-centered educational material online, and even less that visually portrays the procedure accurately. For our project, we used principles from the PEMAT-A/V to inform the creation of a concise, sensitive, but effective patient education animation. Results from this study may provide a template for integrating patient-centered audiovisual content into patient consultation plans.

Educational Value

A goal for this project was to create learning material for prospective IUT patients that is educational and quickly and easily digestible given the short window of time between referral and procedure. Our study showed that the educational material we created was effective according to the standards outlined by the PEMAT-A/V. The average score of 97.5% is well beyond the 70% passing grade for effective material, and nine out of eleven participants with various levels of experience and familiarity with IUT gave the material a 100% score. That said, we did create the material with the PEMAT-A/V in mind and aimed to achieve an average score of 100%.

Two participants gave the material less-than-perfect scores of 91% (10/11 points) and 82% (9/11 points), respectively. Both participants had previously undergone IUT and were familiar with the procedure. The first participant disagreed with the item "The material has a summary of the key points." The second participant disagreed with the items "The material presents information in a logical sequence" and "The material uses illustrations that are clear and uncluttered." These results are likely due to differences in opinion on what makes up a summary and what counts as sufficiently "logical" or "uncluttered," but the participants' reasoning is unclear. Future studies could provide further clarification and examples from the PEMAT User's Guide for each item or ask for participants to explain their reasoning when they choose to disagree with an item. Due to the small sample size, it is unclear whether a lower PEMAT score correlates with a lesser likelihood of recommending the video to others or to a more negative emotional response.

Participants were asked in an open response question what they found most helpful or educational about the video and responses were analyzed qualitatively for patterns in feedback. The most common answer was seeing where the needle may be placed in relation to the patient and the fetus, which suggests that this is a visual explanation of IUT that participants may not have previously encountered but found easy to interpret. One of the next most common responses, the animation's visuals, suggests that participants found it helpful to receive visual explanations that support the video's oral explanations. This is supported by another common answer, which was that participants found the explanations and definitions given in the video helpful. A goal of this project was to enhance learning by presenting the material in an audiovisual format. These results suggest that participants appreciated that format for an educational tool. The video was also described as helpful for depicting the entire process and setting expectations for IUT, which was another goal of this project.

Emotional Response

Our survey showed an overall positive response to the content and presentation of the animation. Participants ranked the animation 4.5 out of 5 stars, indicating they were generally satisfied with the material presented. When asked how likely they would be to recommend the video to someone about to undergo an IUT, most participants stated they would be likely or very likely to, resulting in an average rating of 4.4 out of 5 points. The close correlation between these scores suggests that participants would not share the animation with others if they were not personally satisfied with it and reinforces the high star rating.

When asked to list emotions they associated with the video, participants responded with mostly positive emotions (70.5%) and some negative emotions (29.5%). Negative emotions such as anxiety (3 responses), fear (1 response), and nausea (1 response; likely intended to indicate anxiety or fear) are expected when discussing pregnancy complications and needles, both of which are known to result in increased anxiety and fear, especially among women (Abrar et al., 2020; McLenon & Rogers, 2019). However, the fact that these emotions comprise the minority of responses to a material that depicts both of these issues, combined with the high star rating and likelihood to recommend, is promising for our goal of reducing patient anxiety around IUT. This idea is supported by one of the most common positive emotions listed being "calm/peace." The other most common positive response, "confidence/decisiveness," suggests that the animation gave participants the impression of having authority on the subject of IUT. Other associated emotions were “security/safety/trust” and “supportive,” which suggests that the animation reassured participants and made them feel they could trust it as a resource on IUT. Overall, the responses to these questions affirm our goal of creating a resource that reduces patient anxiety and increases patient confidence on the subject of IUT, though additional refinement may further reduce negative emotional responses.

Feedback and Suggestions

Participants were invited to leave feedback and suggestions to improve the animation. The most common suggestion provided was that the animation should include more information, with participants each listing different aspects of IUT they think should be clarified. This indicates that the information in the animation may be oversimplified, which could reduce its efficacy as a tool for self-advocacy. However, because the majority of survey participants were already familiar with IUT, they may have been inclined to feel the information was oversimplified. It is necessary to determine the level of information a first-time IUT patient might find suitable. In the future, we are interested in further testing this animation with a larger sample size of people unfamiliar with IUT.

Other feedback included that in the personal experience of the participants, unlike in the video, a support person was not allowed in the room during the IUT procedure. It is true that IUT procedures are performed with many variations like this one across centers, and including what may be interpreted by a patient as false information would reduce trust in the video. We intend to revise the language used in the video to account for this variability.

The voiceover was described as too robotic, suggesting that participants might prefer a more conversational tone. The patient in the video was also described as looking too happy; a calmer, confident look for the animated patient may be appreciated by viewers.

Study Participants

Our Qualtrics survey was primarily distributed through the Allo Hope Foundation at their quarterly Patient Advisory Council meeting. Some participants were also recruited through acquaintances, but in all cases the survey was distributed by second parties to participants unknown to the authors of this paper. By utilizing this impersonal distribution method, we aimed to mitigate survey responses that were overly complimentary due to reasons other than the content of the animation.

IUT is a rare, stressful medical procedure that very few patients will ever undergo, making experienced patients a scarcity. However, because the majority of the 11 participants were likely recruited through the Allo Hope Foundation, most participants were already familiar with IUT and over half had undergone IUT previously. This experienced patient population was vital for our survey as they were able to offer us insight into the applicability of our animation across variable IUT practices (e.g. the presence of a support person, the speed of fetal blood sampling), as well as give quality feedback on the educational novelties of our animation (e.g. visualizing different needle placements, representing a diverse population). The participants' high likelihood to recommend the video to others undergoing IUT is especially meaningful when stated by a population of patients well-versed in existing IUT patient materials.

That said, our conservative distribution method was not without its limitations. The small sample size limits detailed analysis of possible trends in responses, particularly in differences in feedback between participants with and without IUT experience. Additionally, though the survey did not ask about participants' education levels, it is likely that the survey participants do not represent a significant range of literacy levels given the educated recruitment pool and the overall high quality of the written open response answers.

Patient Stakeholder Collaboration

Patient stakeholders from the Allo Hope Foundation were recruited at the beginning of this project to co-develop the animation's content. These patients were not only extremely familiar with IUT, but also with educating and connecting other patients to resources on IUT, making their insight particularly informed. During key iterative design phases, stakeholders helped us assess the needs of the IUT patient population, gave feedback on accuracy and tone for storyboards and scripts, and reviewed the final animation. The initial interview conducted with patient stakeholders asked for elements they felt were missing from current IUT patient materials. Feedback at this stage resulted in the inclusion of an anatomically correct view of how the needle enters a patient as well as a focus on the patient experience versus a purely medical explanation of IUT. The script review led to the inclusion of patient-centered, empathetic lines such as, "We know that this procedure can be overwhelming, but your team is here to ensure the safety and comfort of both you and your baby every step of the way."

The value of our patient stakeholders' feedback was confirmed by the survey. The visualization of the needle placement was remarked upon as the most educational aspect of the animation by almost half of survey participants, and the generally positive emotional reactions indicate that the patient-focused, empathetic approach was similarly impactful. Gathering patient stakeholder feedback was limited by time and availability but given the success of the feedback items that were incorporated, future development should aim to maximize stakeholder involvement. Additional meetings to continue to refine the content, tone, and visuals of the animation would be beneficial.

Future Directions

In the future, a longer survey period may allow us to recruit more participants of varying IUT knowledge, experience levels, and backgrounds. While the experienced, highly educated population we recruited for this study was important to survey, as they provided insight on the animation's educational value based on prior knowledge of the procedure, additional insight can be gained by comparing their survey responses to those of people unfamiliar with IUT and of lower literacy levels. We also aim to distribute the survey to patients at the Johns Hopkins Center for Fetal Therapy, who may have more recent experiences with IUT than our sample population. The addition of a pre- and post-test as well as a comparison to other material formats, such as written or verbal, will further confirm the educational value of the material.

Our study team will continue to refine the animation with patient stakeholder and participant feedback in mind. Because our objective is for this animation to serve as an easily discoverable, recognizably trustworthy resource on IUT, we will host the video on the Johns Hopkins Medicine YouTube channel and create a webpage on the Johns Hopkins Center for

Fetal Therapy's website where the video will be embedded. The associated webpage will also allow for the future inclusion of the additional information survey participants requested, while the animation will serve as a more general introduction to IUT. We will use illustrated assets from the animation to create a printable handout that will help doctors counsel patients before their appointments in a more personalized manner.

Conclusion

Intrauterine transfusion, or IUT, is the most common treatment for fetal anemia, a potentially life-threatening condition for the developing fetus. Few publicly available resources exist for patients to learn about PUBS/IUT and among them conflicting or outdated information is presented. There is a need for accurate, trustworthy, patient-centered material about IUT to reduce patient stress before appointments and allow for more informed decisions about treatment.

To address this need, we iteratively developed an educational animation to give potential IUT patients an overview of the procedure. The animation's look and structure were informed by interviews with patient stakeholders from the Allo Hope Foundation and clinicians from the Johns Hopkins Center for Fetal Therapy, as well as by the educational values outlined in the Patient Education Materials Assessment Tool (PEMAT). We distributed a Qualtrics survey to previous and potential IUT patients which assessed the educational value and emotional impact of the animation. The high PEMAT score, overall positive emotions associated with the animation, and generally positive feedback from participants indicated the animation was an effective patient education material. Feedback highlighted the effectiveness of visual explanations, particularly in clarifying needle placement and procedural steps, while also identifying opportunities for refinement, such as expanding on complications and support resources. Insights gathered from this study will be used to further develop the animation and an associated webpage.

Moving forward, we aim to host the animation on trusted hospital platforms such as the Johns Hopkins Center for Fetal Therapy website and the Johns Hopkins Medicine YouTube channel to ensure accessibility and discoverability. Future research should include a larger, more diverse participant pool to validate its impact across different literacy levels and patient backgrounds. This project underscores the importance of patient-centered multimedia tools in improving education for rare, high-stakes medical procedures. By providing an understandable, trustworthy resource, we empower patients to make informed decisions, foster better clinician-patient communication, and reduce procedural anxiety, setting a precedent for similar initiatives in fetal and maternal healthcare.

Appendix A: Script

What to expect during an intrauterine transfusion procedure

Overview

This video will help you understand how fetal blood sampling & intrauterine transfusion, or IUT, diagnose and treat fetal anemia.

Fetal anemia is a condition where the developing baby has an unusually low amount of red blood cells and hemoglobin, which the baby needs to carry oxygen to the tissues. If the pregnant patient's maternal fetal medicine doctor suspects that the baby has fetal anemia, they may refer their patient to a specialized care center for evaluation and possible treatment.

Your IUT Team

Your team will walk you through each step of the IUT procedure and you will have the opportunity to ask any questions to ensure you're comfortable with the process.

Many skilled caretakers take part in the procedure to make sure it goes smoothly. Teams usually include a sonographer, who specializes in ultrasound scanning; a doctor in charge of the procedure; and nurses that test any samples, assist with giving the baby blood, and record the procedure. If the patient is in an operating room, an anesthesiologist may also be present. The patient can also bring along a support person who will stay in the room the whole time.

Preparing for the IUT

The goal of an IUT is to first take a blood sample then give the baby new blood.

During an IUT, the patient is usually awake, lying down, and kept warm and comfortable with blankets. Local anesthesia helps numb the skin and the area all the way down to the uterus. Additional pain medication can be given at any time to help with discomfort.

Before the procedure starts, an ultrasound checks the baby's position and informs where the needle should be placed.

Most often the doctor targets the umbilical vein, which brings blood and nutrients from the placenta to the baby. The needle can enter the umbilical vein in the part attached to the placenta, the part in the umbilical cord, or the part in the baby's liver. If none of these areas work, or if the vein is too small, the doctor can also give blood directly into the baby's abdomen, where it is absorbed into the baby's circulation. The location of the needle placement depends on how the baby is positioned, and where the placenta is attached to the uterine wall.

Taking the Sample

Before giving the baby any blood, fetal blood sampling measures the baby's hemoglobin to determine if the baby is anemic. Guided by ultrasound, a needle enters the umbilical vein and draws a small amount of the baby's blood. While the results are calculated, the doctor gives the baby medicine to temporarily slow their movement. A small machine measures the blood sample's hemoglobin levels and delivers its result in less than a minute. The result tells the team if a blood transfusion is needed and how much blood they need to give.

Transfusing the Blood

If the blood sample confirms the baby has anemia, the team performs an intrauterine transfusion to give blood to the baby. Without removing the needle from the umbilical vein, specially prepared blood is given. The team checks the baby's blood level again, and if it is okay, the needle is removed.

The patient and their baby stay at the hospital for a couple hours for monitoring, and once their care team clears them, they are good to go until their next appointment.

Summary

Fetal blood sampling diagnoses fetal anemia, and intrauterine transfusion, or IUT, treats it.

A sonographer, doctors, nurses, and the patient's support person make up the care team.

The preferred place to give or take blood is through the umbilical vein connecting the baby to the placenta.

Based on the reason for fetal anemia and gestational age at the first IUT, the procedure may need to be repeated during the pregnancy.

We understand that this procedure can be overwhelming, but your team is here to ensure the safety and comfort of both you and your baby every step of the way.

Appendix B: Storyboards

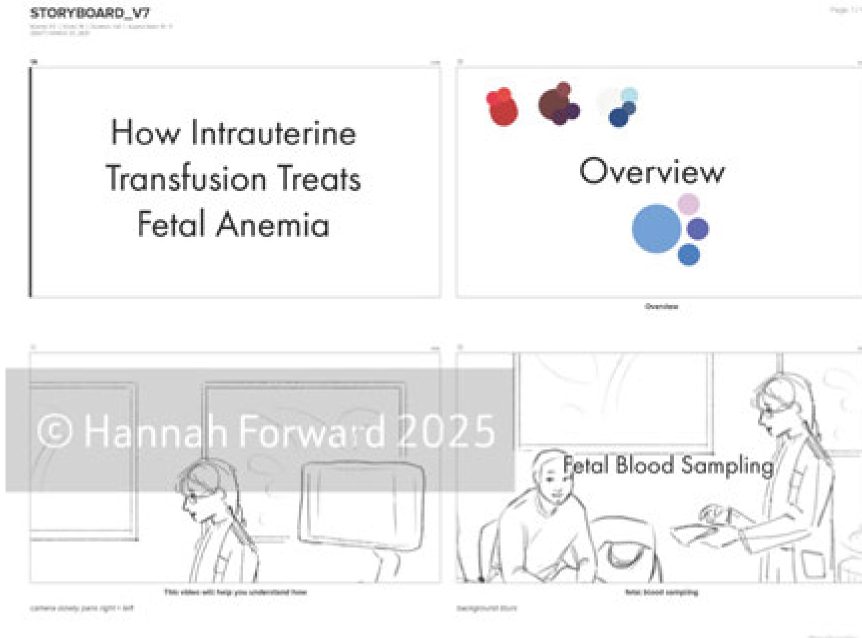


Fig. 25: Storyboard page 1

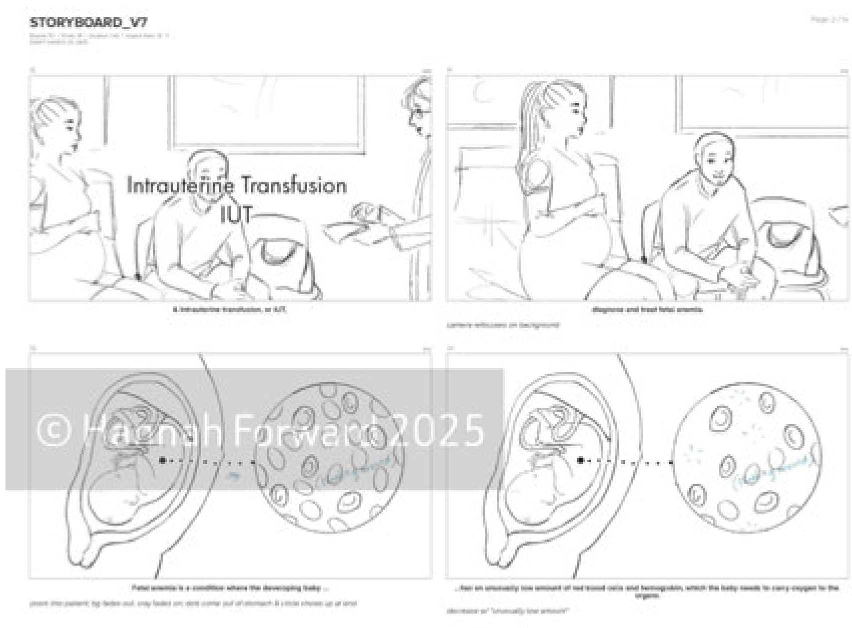


Fig. 26: Storyboard page 2

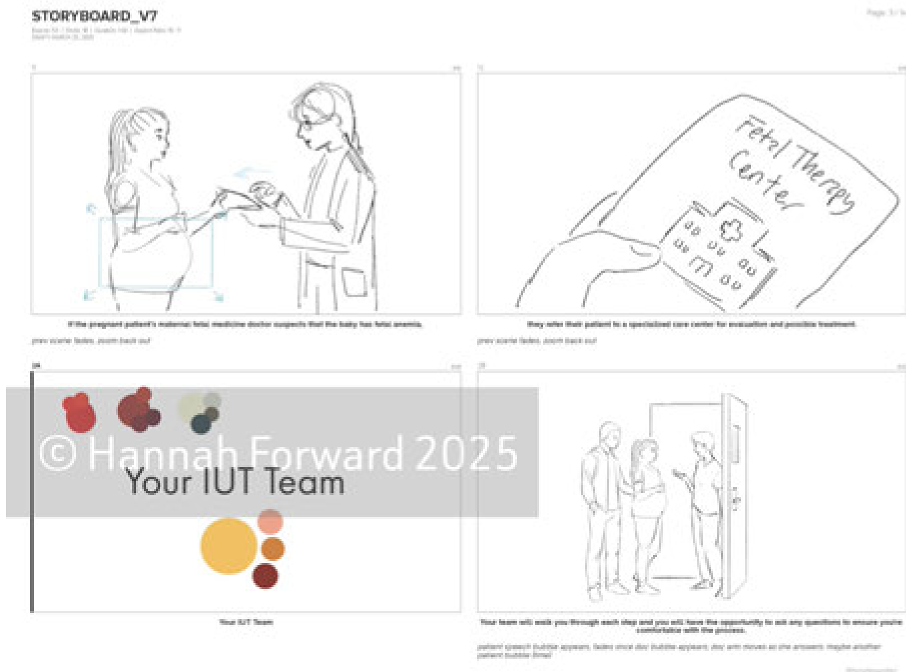


Fig. 27: Storyboard page 3

Fig. 28: Storyboard page 4

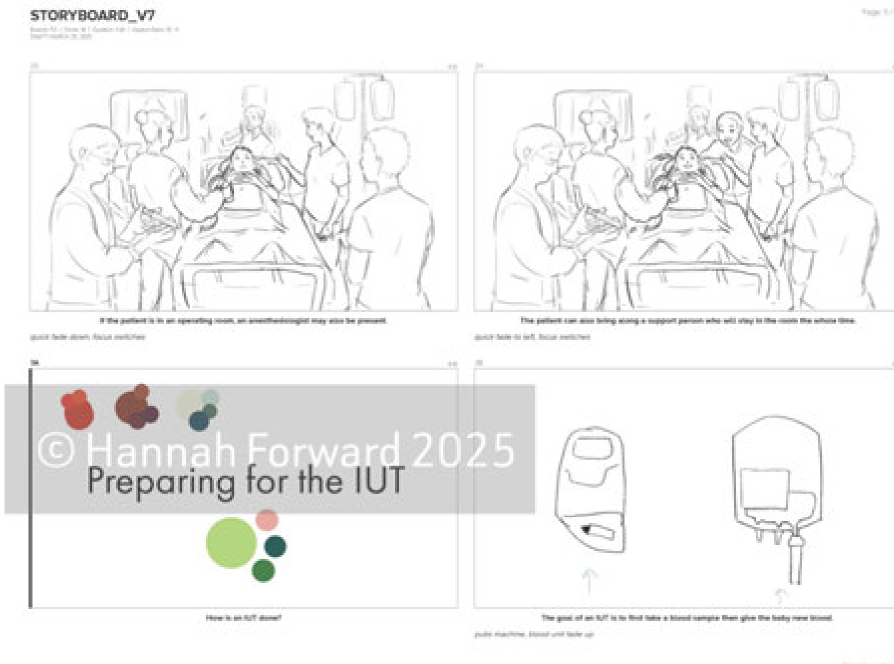


Fig. 29: Storyboard page 5

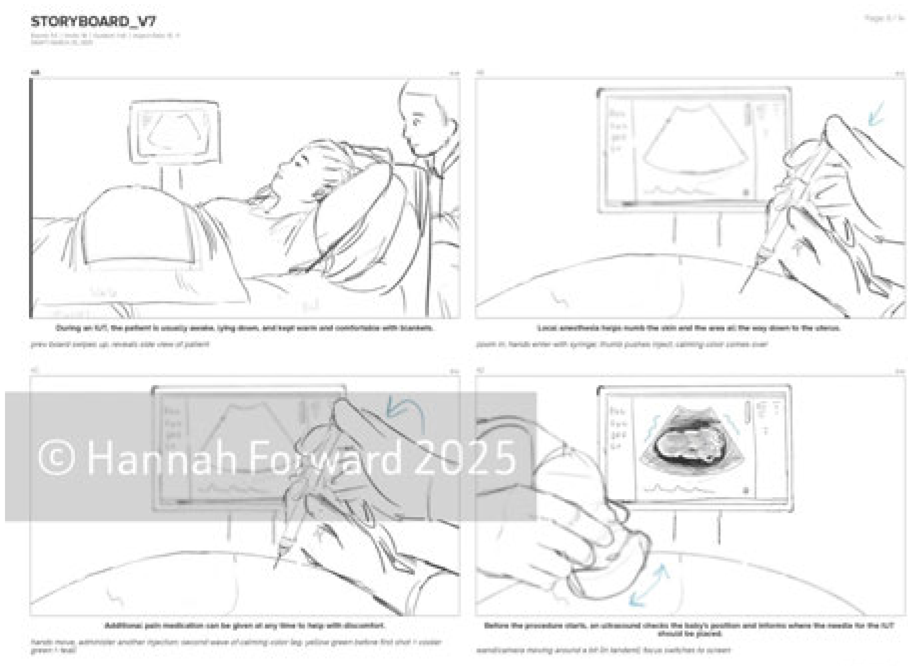


Fig. 30: Storyboard page 6

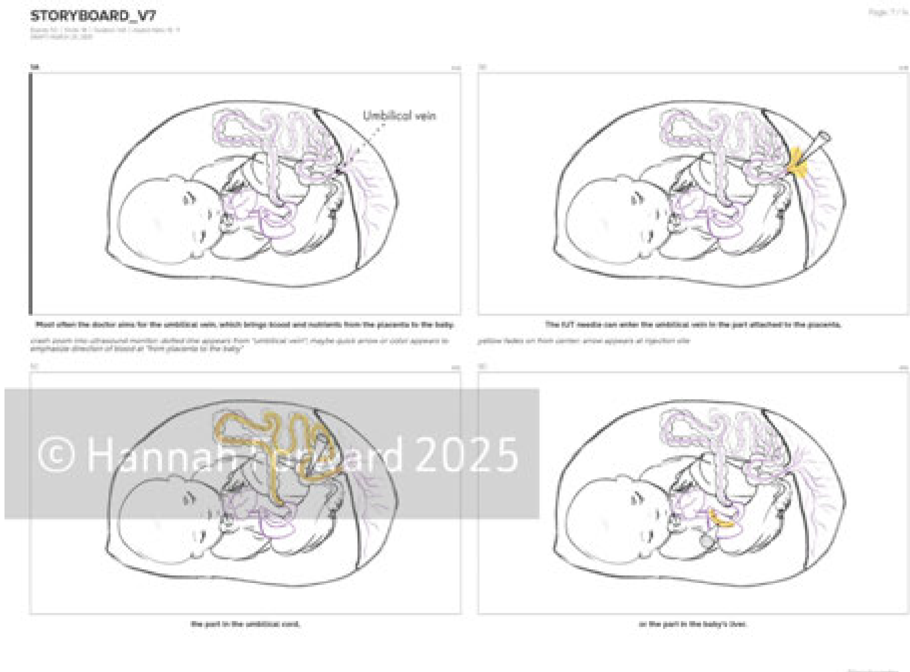


Fig. 31: Storyboard page 7

Fig. 32: Storyboard page 8

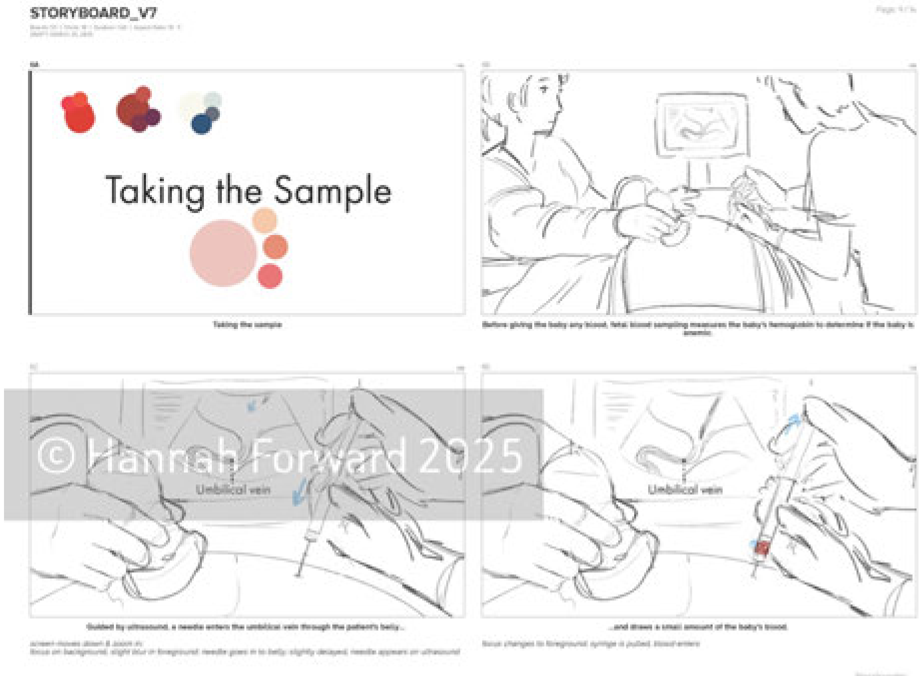


Fig. 33: Storyboard page 9

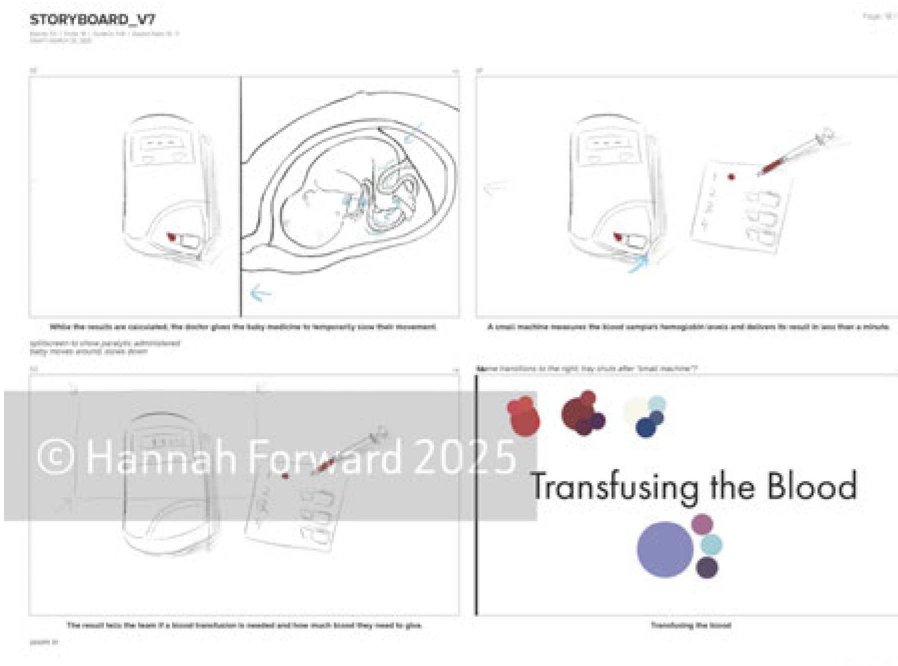


Fig. 34: Storyboard page 10

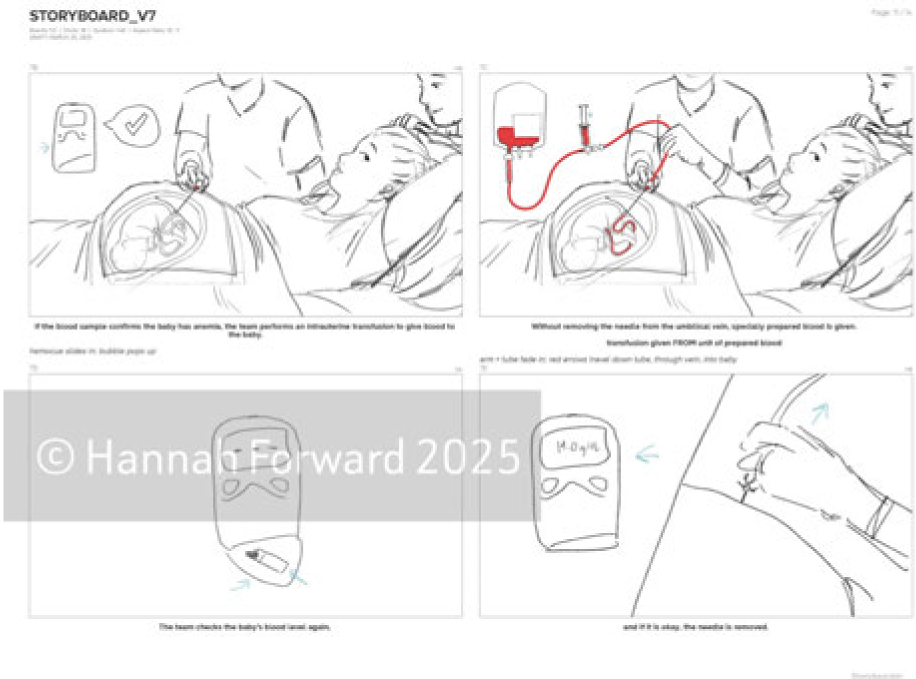


Fig. 35: Storyboard page 11

Fig. 36: Storyboard page 12

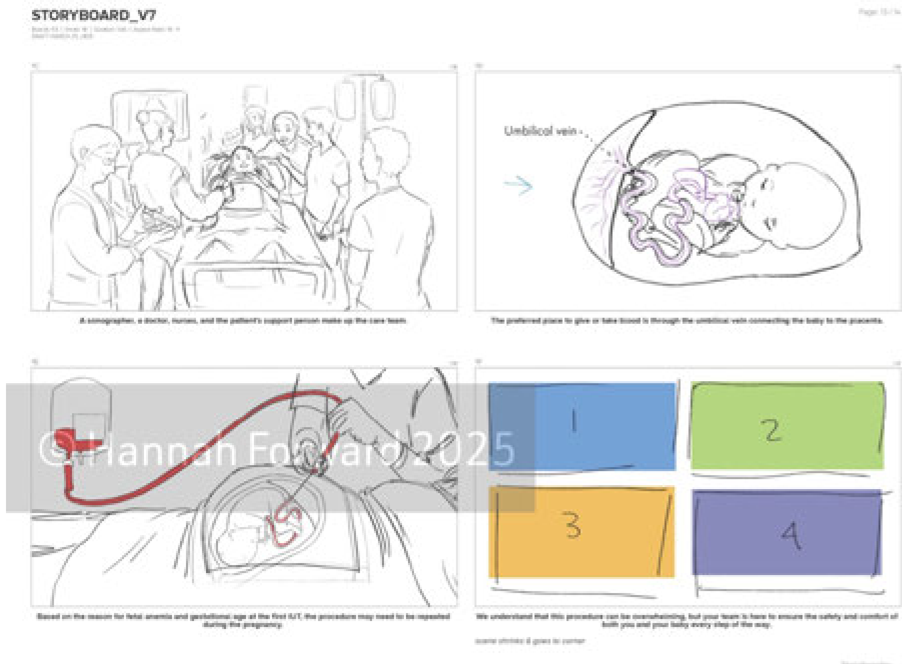


Fig. 37: Storyboard page 13

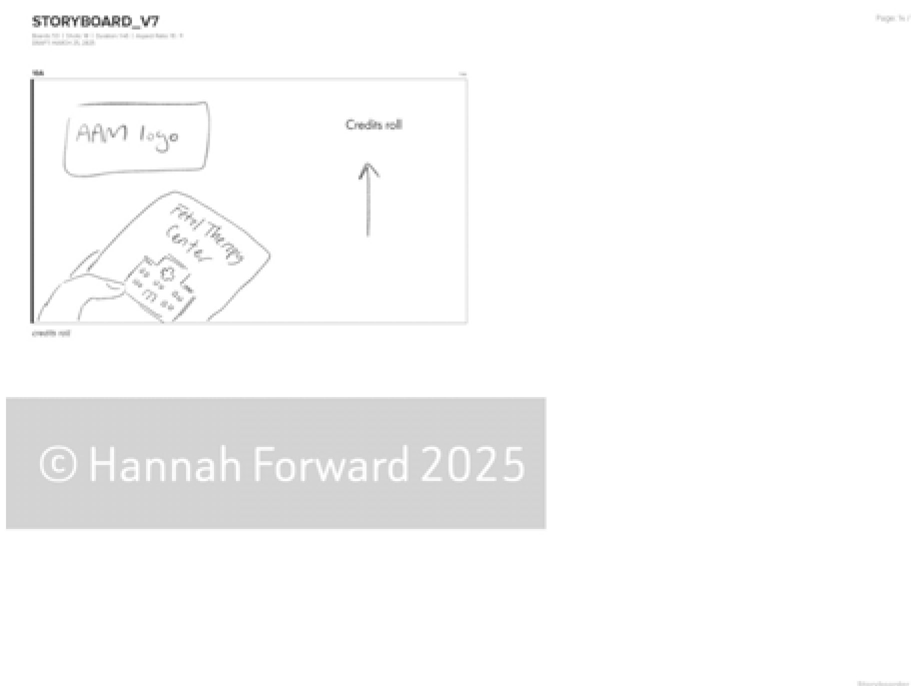


Fig. 38: Storyboard page 14

Appendix C: Recruitment Email

Subject: Johns Hopkins IUT Animation Survey

Hello,

Would you like to help improve patient education material about intrauterine transfusion (IUT) procedures for the Johns Hopkins Center for Fetal Therapy? You would take **15 minutes** to review an educational video and answer questions about it in an online survey. All data will be collected anonymously.

If you are interested in participating, please click the link below to complete the survey:

[Link to Survey]

If you choose to participate, please access the survey by **Friday, March 7th**.

Completion of this survey will serve as your consent to be in this research study. Participation is voluntary, and your decision whether or not to participate in this research will not affect treatment, employment, education, or training at Johns Hopkins. Your responses will be confidential and not linked to your personal identity.

If you have any questions, please contact the principal investigator, **Dr. Jena Miller (jmill260@jhmi.edu)**. This study has been approved by the Johns Hopkins University IRB #00470589.

Appendix D: Qualtrics Survey

Introduction.

Intrauterine Transfusion (IUT) Animation Survey

Thank you for participating in this study to help create better patient education materials for intrauterine transfusion (IUT) procedures. This survey has 3 sections and will take approximately **15 minutes** to complete.

Participation & Consent

Completion of this survey will serve as your consent to be in this research study. Participation is voluntary, and you may stop at any time. Your responses to this survey will not be linked to your personal information and will not be shared with anyone other than the co-investigators of study. The next arrow will take you to the next section.

For any questions or concerns regarding the study, please contact the principal investigator, **Dr. Jena Miller (jmill260@jhmi.edu)**.

→

1. Have you been pregnant before?

Yes

No

Prefer not to say

2. Have you received an intrauterine transfusion (IUT) before?

- Yes
- No
- Prefer not to say

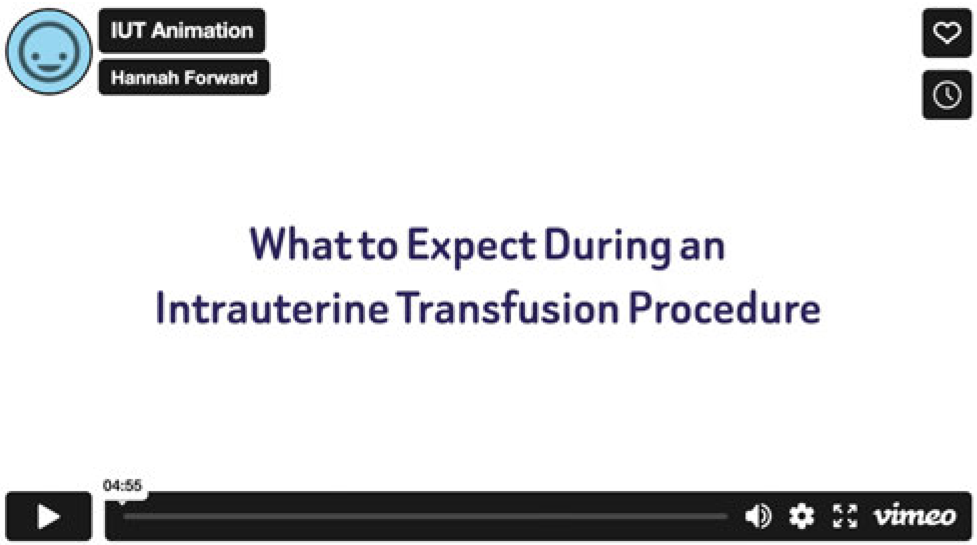
3. How familiar are you with intrauterine transfusion procedures?

- 1 - Not at all familiar
- 2 - Slightly familiar
- 3 - Moderately familiar
- 4 - Very familiar
- 5 - Extremely familiar

→

Animation.

Please watch the video below and then read the following instructions. You are welcome to return to the video at any point in this section.



Section A.

Agree/Disagree Questions

Guidance for rating the material:

- Rate an item "Agree" when a characteristic occurs throughout a material, that is, nearly all of the time (80% to 100%). Your guiding principle is that if there are obvious examples or times when a characteristic could have been met or could have been better met, then the item should be rated "Disagree."
- Do not use any knowledge you have about the subject before you read or view the patient education material. Base your ratings ONLY on what is in the material that you are rating.
- Do not let your rating of one item influence your rating of other items. Be careful to rate each item separately and distinctly from how you rated other items.

Q1. Content: The material makes its purpose completely evident.

The material's title makes it clear what the material is about, or at the beginning of the material the narrator or the displayed text makes it clear what the material is about.

Agree

Disagree

Q2. Word Choice & Style: The material uses common, everyday language.

The material uses common, everyday language that would be easy to understand for most consumers or patients nearly all of the time. Abbreviations or acronyms are spelled out or defined the first time they are used.

Agree

Disagree

Q3. Word Choice & Style: Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.

The material does not use medical terms except to educate the audience about the medical terms. When medical terms are used they are explained. The explanation of a medical term is easy to understand.

Agree

Disagree

Q4. Word Choice & Style: The material uses the active voice.

The material almost always uses the active voice. If the material uses the passive voice in a single instance, but overall uses active voice you should agree with this item. The active voice is when the subject performs the action it expresses (e.g., the nurse will give you the medication). The passive voice is when the subject is acted upon by the verb (e.g., you will be given the medication by the nurse).

Agree

Disagree

Q5. Organization: The material breaks or "chunks" information into short sections.

The material is broken into "chunks," which can be accomplished with the narrator introducing a new section (e.g., now we're going to talk about X), or text or a screenshot to break up the information presented.

Agree

Disagree

Q6. Organization: The material's sections have informative headers.

Headings are specific and let the user know what to expect in that section.

Agree

Disagree

Q7. Organization: The material presents information in a logical sequence.

The information in the material is presented in an order that makes sense to the user. The information builds in a natural way. Main messages or most important ideas are at the beginning of sections.

Agree

Disagree

Q8. Organization: The material provides a summary.

The material has a summary of the key points or reviews the key points at the end of the material, either in writing or orally.

Agree

Disagree

Q9. Layout & Design: The material uses visual cues to draw attention to key points.

Visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) help draw the user's attention to key points in the material. Visual cues are only used for key points. If the material overuses visual cues (i.e., uses them indiscriminately), choose "Disagree."

Agree

Disagree

Q10. Layout & Design: The material allows the user to hear the words clearly (e.g., not too fast, not garbled).

The material allows the viewer to hear the words clearly. The narrator or voiceover is not speaking too fast nor is it garbled or hard to understand in any other way.

Agree

Disagree

Q11. Use of Visual Aids: The material uses illustrations that are clear and uncluttered.

If the material is not both clear and uncluttered, choose "Disagree."

Agree

Disagree

→

Section B.

Please answer the following questions about the animation.

QA. What is your overall star rating of the animation, with five stars being the best rating?

Star rating: ☆☆☆☆☆

QB. How likely would you be to recommend this video to someone about to undergo an IUT procedure?

1 - Very unlikely

2 - Unlikely

3 - Neutral

4 - Likely

5 - Very likely

QC. What was most helpful or educational about the video?

QD. What emotion(s) do you associate with the video?

QE. Do you have any suggestions for how to improve this video? (Optional)

QF. Do you have any additional feedback or comments? (Optional)

Appendix E: PEMAT-A/V

Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V)

How To Use the PEMAT To Assess a Material

There are seven steps to using the PEMAT to assess a patient education material. The instructions below assume that you will score the PEMAT using paper and pen. If you use the **PEMAT Auto-Scoring Form**, a form that will automatically calculate PEMAT scores once you enter your ratings, you can skip Step 5. The form is available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html.

Step 1: **Read through the PEMAT and User's Guide.** Before using the PEMAT, read through the entire User's Guide and instrument to familiarize yourself with all the items. In the User's Guide a (P) and (A/V) are listed after an item to indicate whether it is relevant for print and audiovisual materials, respectively.

Step 2: Read or view patient education material. Read through or view the patient education material that you are rating in its entirety.

Step 3: Decide which PEMAT to use. Choose the PEMAT-P for printable materials or the PEMAT-A/V for audiovisual materials.

Step 4: Go through each PEMAT item one by one. All items will have the answer options "Disagree" or "Agree." Some—but not all—items will also have a "Not Applicable" answer option. Go one by one through each of the items, 24 for printable materials and 17 for audiovisual materials, and indicate if you agree or disagree that the material is meeting a specific criterion. Or, when appropriate, select the "Not Applicable" option.

You may refer to the material at any time while you complete the form. You don't have to rely on your memory. Consider each item from a patient perspective. For example, for "Item 1: The material makes its purpose completely evident," ask yourself, "If I were a patient unfamiliar with the subject, would I readily know what the purpose of the material was?"

Step 5: Rate the material on each item as you go. After you determine the rating you would give the material on a specific item, enter the number (or N/A) that corresponds with your answer in the "Rating" column of the PEMAT. Do not score an item as "Not Applicable" unless there is a "Not Applicable" option. Score the material on each item as follows:

If Disagree	Enter 0
If Agree	Enter 1
If Not Applicable	Enter NA

Suggested Citation:

Shoemaker SJ, Wolf MS, Brach C. Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V). (Prepared by Abt Associates, under Contract No. HHSA290200900012I, TO 4). Rockville, MD: Agency for Healthcare Research and Quality; October 2013. AHRQ Publication No. 14-0002-EF.

Fig. 39: PEMAT-A/V page 1

Additional Guidance for Rating the Material on Each Item (Step 5):

- Rate an item "Agree" when a characteristic occurs throughout a material, that is, nearly all of the time (80% to 100%). Your guiding principle is that if there are obvious examples or times when a characteristic could have been met or could have been better met, then the item should be rated "Disagree." The User's Guide provides additional guidance for rating each item.
- Do not skip any items. If there is no "Not Applicable" option, you must score the item 0 (Disagree) or 1 (Agree).
- Do not use any knowledge you have about the subject before you read or view the patient education material. Base your ratings ONLY on what is in the material that you are rating.
- Do not let your rating of one item influence your rating of other items. Be careful to rate each item separately and distinctly from how you rated other items.
- If you are rating more than one material, focus only on the material that you are reviewing and do not try to compare it to the previous material that you looked at.

Step 6: Calculate the material's scores. The PEMAT provides two scores for each material—one for understandability and a separate score for actionability. Make sure you have rated the material on every item, including indicating which items are Not Applicable (N/A). Except for Not Applicable (N/A) items, you will have given each item either 1 point (Agree), or 0 points (Disagree). To score the material, do the following:

- ***Sum the total points*** for the material on the understandability items only.
- ***Divide the sum by the total possible points***, that is, the number of items on which the material was rated, excluding the items that were scored Not Applicable (N/A).
- ***Multiply the result by 100*** and you will get a percentage (%). This percentage score is the understandability score on the PEMAT.

    - **Example:** If a print material was rated Agree (1 point) on 12 understandability items, Disagree (0 points) on 3 understandability items, and N/A on one understandability item (N/A), the sum would be 12 points out of 15 total possible points (12 + 3, excluding the N/A item). The PEMAT understandability score is 0.8 (12 divided by 15) multiplied by 100 = 80%.

To score the material on actionability, repeat Step 6 for the actionability items.

Step 7: Interpret the PEMAT scores. The higher the score, the more understandable or actionable the material. For example, a material that receives an understandability score of 90% is more understandable than a material that receives an understandability score of 60%, and the same goes for actionability. If you use the PEMAT to rate the understandability and actionability of many materials, you may get a sense of what score indicates exceptionally good or exceptionally poor materials.

2 Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-AV)

Fig. 40: PEMAT-A/V page 2

Title of Material:

Name of Reviewer: Review Date:

Read the PEMAT User's Guide (available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/) before rating materials.

UNDERSTANDABILITY

Item #	Item	Response Options	Rating
Topic: **Content**			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
Topic: **Word Choice & Style**			
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
Topic: **Organization**			
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material[1]=N/A	
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material[*]=N/A	
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	
11	The material provides a summary.	Disagree=0, Agree=1, Very short material[*]=N/A	
Topic: **Layout & Design**			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	
13	Text on the screen is easy to read.	Disagree=0, Agree=1, No text or all text is narrated=N/A	
14	The material allows the user to hear the words clearly (e.g., not too fast, not garbled).	Disagree=0, Agree=1, No narration=N/A	

[1] A very short audiovisual material is defined as a video or multimedia presentation that is under 1 minute, or a multimedia material that has 6 or fewer slides or screenshots.

Fig. 41: PEMAT-A/V page 3

Item #	Item	Response Options	Rating
Topic: **Use of Visual Aids**			
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	

***Total Points*: ____________**

***Total Possible Points*: ____________**

Understandability Score (%): ____________
(*Total Points* / *Total Possible Points* × 100)

ACTIONABILITY

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, diagrams=N/A	

***Total Points*: ____________**

***Total Possible Points*: ____________**

Actionability Score (%): ____________
(*Total Points* / *Total Possible Points*

Fig. 42: PEMAT-A/V page 4

Appendix F: Open Response Comments

QC: What was most helpful or educational about the video?

- The explanation of how the blood was administered depending on the position of the baby
- The process in which they iut procedure is performed.
- Seeing the process start to finish is helpful, the visual of the blood going into the umbilical vein is great
- Visuals showing location of needle insertion; distinguishing between fetal blood sampling and IUT
- Basic enough for a first-time IUT
- It's clear as to what can be expected from the IUT procedure.
- The definition and visual representation of fetal anemia, as well as potential locations of transfusion
- Clear explanation as to why this procedure is needed and what occurs during the procedure.
- Info
- It gives the best case scenario in what your care should look like.
- seeing the ways a needle can get new blood into a baby

QD: What emotion(s) do you associate with the video?

- calm - the voice brings a calming tone to it, but I don't particularly like the robotic sound of it, it's just the tone of the voice that makes it sound calming.
- Fear
- Peace/confidence that the people showing me this know exactly what's going on and are prepared and also nervousness that it is a scary procedure to go through
- Security, decisiveness, safety
- Anxious, hopeful
- One could derive additional confidence with their personal experience.
- Neutral. Intense medical procedure the video makes it easy to understand and feels supportive, especially at the end
- Anxiety on the parent's part of trying to help their baby. The video itself seems calm and confident.
- Calm
- It's way over simplified.
- trust & nausea

QE: Do you have any suggestions for how to improve this video? (Optional)

- There was some incorrect information. Most drs don't allow the partner to join them in the OR during an IUT. Guaranteeing someone that their partner can be there can cause distress later on when it doesn't happen.

- Adding additional information in the beginning of video, such as how the doctor determined that baby was anemic. And having a better transition from one subject to the next in certain areas.. Including resources, support groups at the end of the video.
- In my procedures, baby was always paralyzed first, rather than in the middle, I don't know if that was just how my doctor did. I also wonder if it would be helpful to note that it takes a couple hours for the baby to start moving again after the procedure
- Consider explaining that fetal blood sampling is also called cordocentesis or PUBS (even if just written in parenthesis somewhere) because some patients will have heard it or read it this way
- No
- The voice sounds like it was generated by AI or a similar source. It was a bit uncomfortable to listen to it. Utilizing a different voice might be helpful.
- This is minimal but mom and partner (when support person is introduced) look far too happy to be going through this
- If I were the parent I would want to know more about possible complications and what I might expect to happen if those arose.
- Add verbiage to include a more realistic view. Example: it can be difficult to get the needle into the umbilical vain. The doctor may need to try several times to get it right. Etc.

QF: Do you have any additional feedback or comments? (Optional)

- Could be helpful to explain medications given to the mother and/or what the mother will feel
- No
- I recognize and appreciate the use of diversity in all aspects of the video.
- Not everyone gets a support person in the room. I would remove the overall tone of absolutely so people are not disillusioned.

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Vita

Hannah was born in Dallas, Texas, but moved around and spent time in Los Angeles, Denver, and her grandparents' house in British Columbia. Due to a childhood speaking disorder, art was her true first language, and she grew up believing in the power of art to communicate and connect with others. She earned her B.F.A. in Illustration with a concentration in Sequential Art from the Maryland Institute College of Art in 2019.

During her time at MICA, Hannah translated a love of reading comics into writing and illustrating them. In addition to her schoolwork, she enjoyed contributing artwork to charitable art anthologies. After graduation, she made the decision to pivot to medical illustration, returning to school at the University of Colorado Boulder to earn the necessary science credits to apply to a master's program. She soon returned to Baltimore and entered the Medical and Biological Illustration program at Johns Hopkins University School of Medicine, where she went on to earn an Award of Merit at the 2024 Association of Medical Illustrators Student Salon. Her time in the program was supported by the W.B. Saunders, Elinor W. Bodian, and William Didusch Scholarships as well as her Vesalius Trust Research Grant Award and the Joseph M. Dieter, Jr. Scholarship for Creative Design Excellence.

Hannah is expecting her Master of Arts in Medical and Biological Illustration in May of 2025. After, she aims to use her illustrations to connect medical experts with lay audiences and foster communication that promotes accuracy, accessibility, and understanding.