

Context, Prioritization, and Unexpectedness: Factors Influencing User Attitudes About Infographic and Comic Consent

Xengie Doan
xengie.doan@uni.lu
SnT, Université du Luxembourg
Esch-sur-Alzette, Luxembourg

Annika Selzer
annika.selzer@sit.fraunhofer.de
Fraunhofer Institute for Secure
Information Technology
Darmstadt, Germany

Arianna Rossi
arianna.rossi@uni.lu
SnT, Université du Luxembourg
Esch-sur-Alzette, Luxembourg

Wilhelmina Maria Botes
maria.botes@uni.lu
SnT, Université du Luxembourg
Esch-sur-Alzette, Luxembourg

Gabriele Lenzini
gabriele.lenzini@uni.lu
SnT, Université du Luxembourg
Esch-sur-Alzette, Luxembourg

ABSTRACT

Being asked to agree to data disclosure is a ubiquitous experience in digital services - yet it is rare to encounter a well-designed consent experience. Considering the momentum for a European data space where personal information easily flows across organizations, sectors, and nations, solving the thorny issue of "how to get consent right" cannot be postponed any further. In this paper, we describe the first findings from a study based on 24 semi-structured interviews investigating participants' expectations and opinions toward a consent form redesigned as a comic and an infographic in a data-sharing scenario. We found that time, information prioritization, tone, and audience fit are crucial when individuals are invited to disclose their information and the infographic is a better fit in biomedical scenarios.

CCS CONCEPTS

• **Security and privacy** → **Social aspects of security and privacy**; **Usability in security and privacy**; • **Human-centered computing** → *Empirical studies in visualization*.

KEYWORDS

consent UX, health data sharing, data governance, comics, transparency, visualizations

ACM Reference Format:

Xengie Doan, Annika Selzer, Arianna Rossi, Wilhelmina Maria Botes, and Gabriele Lenzini. 2022. Context, Prioritization, and Unexpectedness: Factors Influencing User Attitudes About Infographic and Comic Consent. In *Companion Proceedings of the Web Conference 2022 (WWW '22 Companion)*, April 25–29, 2022, Virtual Event, Lyon, France. ACM, New York, NY, USA, 12 pages. <https://doi.org/10.1145/3487553.3524632>

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WWW '22 Companion, April 25–29, 2022, Virtual Event, Lyon, France

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ACM ISBN 978-1-4503-9130-6/22/04.

<https://doi.org/10.1145/3487553.3524632>

1 INTRODUCTION

The European Union has a vision for the future: the European Strategy for Data [8], aiming to advance innovation and develop new digital solutions by enabling data to flow across organizations, sectors, and Member States. It also envisions the creation of a common European Health Data Space where a solid infrastructure will enable the secure sharing and access of health data by multiple parties to support healthcare delivery, informing health policies, and enabling health research [9]. Among other uses, health data can point to suitable candidates for clinical trials and contribute to scientific advancements, bringing benefits to public health (e.g., identifying hot spots of disease outbreaks to implement counter-measures) and to individuals (e.g., taking control of disease management and symptoms). However, health data is a special category of personal data that is protected by strict data processing rules, because information about an individual's health status and symptoms may be misused, resulting in discrimination and other harms.

The free flow of high-quality data is but one element of the European single market that can only be realized by establishing formal mechanisms of trustworthy data governance, today proposed in the Data Governance Act proposal [7]. In this respect, data trustee models have increasingly been discussed, designed, or implemented [6, 17, 20, 35, 36] to act as an independent party between those who provide data and those who process that data. Data trustees offer independent data stewardship and are subject to the legal responsibility of guaranteeing that data sharing and use occur to the benefit of a specific group of people and organizations [17], as opposed to companies that unilaterally control the use and disclosure of people's personal information for their own exclusive benefit.

In a health research scenario, data trustees can assist in finding suitable participants for clinical trials in a privacy-friendly manner: individuals can transfer their data to a data trustee in exchange for various benefits (e.g., financial compensation, services), that passes them on to organizations that intend to carry out clinical trials (hereinafter "service providers"). In this and other cases, engaging individuals in a user-friendly consent experience is fundamental to enable them to meaningfully and freely signify their agreement or disagreement with a sense of satisfaction [12]. Readability and comprehensibility of consent notice are necessary but insufficient measures to determine whether consent is asked in a transparent manner that complies with legal obligations and ethical safeguards.

Considering that the everyday Europeans' experience with consenting is the web cookie consent, often accused of being opaque and manipulative [2, 14, 18, 21–23, 33, 40], it becomes clear how consenting to data sharing, especially when it comes to sensitive data, must be designed in a different manner to enable a trustworthy data-informed economy.

In this study, we created different visualizations of an informed consent form, i.e., a comic and an infographic. We examined how various document design elements, such as graphical elements and the writer-reader relationship, affected the study participants' engagement and experience. The results hint at how critical it is for people to skim through the consent notice to quickly grasp the main points, although time spent on reading appears to depend on context (e.g., type of data collected, entity collecting the data), and shed light which information design elements may attribute to this goal. The information should be relevant for the user, concise and direct, and the text supported by graphical elements. The findings also show that individuals have formed expectations about how consent should look like and that the consent medium and its tone of voice should fit the target audience and the context, thus comics should be used cautiously. Infographics seem to be a better fit for biomedical contexts and it additionally allows strategic reading and enables understanding. Both mediums raise interest and attention due to their unconventionality, with a possible influence on user engagement. Considering all these elements may contribute to extending the conceptualization of user-centered transparency beyond text readability, graphical aids, and UI elements. These insights can inform the design of consent requests to adequately engage different user groups in thoughtful decision-making.

2 RESEARCH SCENARIO

2.1 Use Case: Consent to Data Transfer

A clinical trial usually has very specific requirements for its participants, e.g., age, disease type, etc. Therefore, finding suitable candidates can be difficult and usually includes processing great quantities of possible participants' personal data before finding the few that meet the criteria. A data trustee can minimize the amount of personal data service providers can see, with a service provider applying to get only the personal data of individuals that fit the criteria of a proposed clinical trial. The data trustee contacts the relevant individuals, explains the reason, and asks them if they consent to transfer their information to the service provider.¹ Our use case focuses on the consent asked of individuals to transfer their personal data to a specific service provider. The consent a service provider would need from individuals to allow their participation in a clinical trial is not part of our use case.

2.2 Informed consent and transparency requirements under the GDPR

The GDPR defines consent as any freely given, specific, informed, and unambiguous indication of the individual's wishes by which they signify agreement to the processing of their personal data (Art. 4(11)). Consent to the processing of sensitive information such as

health data needs to also be explicit (Art. 9). Children, under certain circumstances², are allowed to give consent starting from the age of 16 years.

Consent must also be intelligible for the average person (i.e., free from jargon and concise), expressed in clear and plain language (i.e., straightforward and concrete statements), and accessible (Art. 4(11) and 7(2)) [33]. Audience fit figures among the user-centered requirements for consent to be informed: the logic of what information should be presented and how must derive from the identification of the audience needs (e.g., minors vs adults), also based on empirical studies [3]. Organizations have latitude as to how to present information to consenters in the form of "written or oral statements, or audio or video messages", which can also be layered to respect the two-fold obligation of being concise and complete at once [3]. The organizations that are responsible for GDPR compliance shall also make the withdrawal of consent as easy as its provision (Art. 7(3)), otherwise, consent may be considered invalid [3].

Informed consent requirements overlap with the user-centric transparency requirements set forth in Art. 12, which encompass the "quality, accessibility and comprehensibility of the information" [24] illustrating the data processing practices and the individual's rights. One of the novelties introduced by the GDPR is the obligation for privacy and consent notices to be purposely *designed* as effective informative tools [31] for the intended audience. The regulation explicitly mentions icons to provide "in an easily visible, intelligible and clearly legible manner a meaningful overview of the intended processing" (Art. 12(7)) (whose concrete implementation and effectiveness in achieving such goals is currently subject to an intense debate, though [30, 32]). It also refers to other visual design means, such as "cartoons, infographics, flowcharts" to enhance the comprehensibility of information, and specifically to "comics/cartoons, pictograms, animations" [24].

3 RELATED WORK

Implementations of the consent requirements described above vary greatly. The case of cookie consent is well known: numerous studies have demonstrated that cookie banner UIs are often designed to extort users' agreement in a manipulative manner, thereby circumventing the tenets of the law described earlier [2, 14, 18, 21–23, 33, 40]. Whether informing online users or patients, it is difficult and time-consuming to establish an adequate level of being informed with respect to informed consent obligations. In clinical trials settings, a systematic review of 30 studies about informed consent found that when participants were informed about the clinical trial aims, risks, benefits, and more, only about half the content was understood [11].

Legal communication increasingly deviates from conventional lengthy, off-putting walls of legalese and makes use of information design elements [25] meant to enhance the readability, comprehensibility, navigability, and memorability of information [28], based on the different needs and abilities of the intended audiences [27]. The affordances offered by a document go beyond mere plain language criteria to embrace a whole set of best practices against which

¹For further details on the data trustee model we based our interviews on, please refer to [36].

²The age mentioned in Art. 8 refers to a child's consent in relation to information society services and can be reduced to no younger than 13 years by national law.

Language	How easy it is for people to understand the words	Design	The visual impact of the document and the way its design influences usability
Directness	Using direct language to make clear who's doing what.	Legibility	Use of legible fonts and text layout.
Plain words	Extent to which the vocabulary is easily understood.	Graphic el.	Use of tables, bullet lists, graphs, charts, diagrams, etc.
Grammar	Conformity with the practice of good standard English.	Structure	Quality of the document's organization in relation to its function.
Readability	Ease with which the reader can follow the argument of the text.	Impression	Attractiveness and approachability of the document's overall appearance.
Relationship	How far the document establishes a relationship with its users.	Content	How the content and the way it is organised deliver the document's purpose.
Who from	Is it clear who is communicating?	Relevance	How relevant the content is to the recipient.
Contact	Whether there are clear contact points and means of contact.	Subject	Whether it is clear what the communication is about.
Audience fit	Appropriateness to the knowledge and skills of the users.	Action	Clarity about what action is required of the user.
Tone	Matching the style and language to the context.	Alignment	Compliance with the organization's intended aims and values.

Table 1: Document quality criteria elaborated by R. Waller [41]

documents' benchmarking can be carried out [41] concerning language, writer-reader relationship, information design, and content (Table 1). When it comes to sensitive data sharing, the statutory requirement of transparency about data processing practices similarly applies to the information notices and consent requests that describe and ask user permission about such practices ("transparency by design") [29]. Asynchronous communication, in addition, entails risks of misunderstandings, as a professional is not present to clarify doubts, and risks of mindless consenting to data sharing which has been shown in other digital consent experiences (e.g., cookies)[19]. However, digital communication also offers new opportunities, i.e., experimenting with various media (i.e., e-mail, messages, webpages, videos, chatbots, etc.), interaction modes, scalability, [39] and timing [29].

To communicate information more effectively than traditional plain text documents, innovative media are increasingly being explored. The use of comics, for example, seems promising as it combines textual and graphical means, uses a conversational style, and develops a narrative in a specific context allowing readers to identify with the depicted characters. Comics can also attract and retain attention by fighting notice fatigue [29], i.e. the habituation and alienation derived by the longstanding habit of experiencing inscrutable prose, and they have been used in contracts [16] and privacy policies [28]. To successfully bridge language barriers between scientists and indigenous populations in South Africa, in our previous work we created, tested, and refined a comic to ask consent for participation in a genomic research project [4, 37]. The study revealed that the population had specific expectations on how they wanted to be depicted in the comic to counter the exclusion and discrimination that happened in the past. The comic also increased general understanding of the research process and strengthened the ability to make fully informed consent decisions.

Other mediums to enhance consent engagement have also been studied in different contexts. Wang et al. [42] conducted a study comparing the use of infographics, comics, and illustrated text to communicate data-heavy information, such as graphics about renewable energy in Europe, finding that young academic students from different countries (aged 18-35) preferred comics, with the greatest understanding, engagement, and enjoyment of all mediums, while infographics performed best in aesthetics and exploration and were second to comics in the other dimensions.

Enjoyment and emotions are an integral part of human-computer interactions [5] and can offer rich insights in conjunction with usability studies [1]. In addition, other fields such as marketing also incorporate emotions to influence users [10][38]. Concerning consent, a study used emotions derived from Plutchik's emotion wheel

[26] and reported that over 50% of users felt annoyed and indifferent from cookie consents [15], which may influence individual attitudes about consent in general. Another study investigated the influence of emotions on information processing and decision making in a clinical trial informed consent and found that fear significantly increases the average time spent reading the procedures and the benefits of participation [13]. Thus emotions seem to impact engagement with consent processes and should be investigated.

4 METHOD

This study sought to answer the following research questions:

- (1) What are participants' general experiences with informed consent processes?
- (2) Considering specific document quality criteria concerning language, design, content, and relationship with the reader:
 - (a) What are participants' expectations prior to exposure to different consent mediums?
 - (b) What are their preferences after exposure to consent in the infographic and comic mediums and why?
 - (c) What elements reportedly influence their engagement with the infographic and comic mediums?
- (3) What kind of emotions do the infographic and comic mediums trigger?

To answer these questions, in the autumn of 2021 Author 2 carried out 24 semi-structured interviews. To answer each research question, we created an interview guideline (Appendix A) validated prior to the interviews with three potential participants (recruited by word-of-mouth) to ensure that all questions were understood as intended.

4.1 Participants

We used word-of-mouth to find the participants in Germany, who were all German native speakers (as the interviewer's mother tongue is German). The 24 participants included 8 participants from each age range: 18-30, 31-55, and 56-90, with 4 men and 4 women in each age group. Within those groups, there was an even split into 2 interviewees whose highest degree is a school-leaving certificate or a finished apprenticeship and 2 interviewees whose highest degree is from a college or university. The sample was meant to gain a broad perspective of a cross-section of the German adult population across age, sex, and education level. The interviews took 60-75 minutes on average and the interviewees were offered to be compensated with 30 Euros for their time.

4.2 Study material

We created an exemplary plain text form that asked consent for the transfer of personal data from a data trustee to a service provider (see Sec. 2.1 and Appendix A.2), which included short sections on "Who are we?", "Which of your data do we process and where did we get it from?", "What happens if you agree?", "What exactly do we ask consent for today?", a section to accept or reject by signature, and a section about withdrawal of data. Author 1 designed 4 additional variations in different mediums: newsletter, infographic, comic, and video including only the subsection "What happens if you agree?" of the consent form (see Appendix C.1). All consent forms differed in design, but the core consent text was the same across all mediums. Following best practices for information transparency (see Sec. 3), all versions of the aforementioned subsection were designed with the aim of enabling participants to better engage with the material.



Figure 1: A section of the infographic study material

English translation: *What happens if I agree? If you allow the trustee to share your contact with the hospital, the following will happen: 1. Contact; The hospital will contact you.*

In this paper, we only discuss the infographic and comic, the most and least preferred mediums respectively. The infographic (Figure 1, Appendix Figure 5) was designed to have a mixture of text and graphics with structured sections and a step-by-step flow, i.e., short summary sentences under a numbered header with relevant icons. The comic (Figure 2, Appendix Figure 6) was designed to have a mixture of text and graphics with a narrative element that also had a step-by-step flow, i.e., using stick figure people to illustrate the consent process and outcomes as a story.

4.3 Study design

The interviews took place in German via an online video conference system and were documented by a summary transcription written right after each question and finalized right after each interview.

4.3.1 Use Case for Interviews. The participants were verbally presented with the fictional use case explained in Sec. 2.1 and were invited to imagine that they were a person who is contacted by a data trustee to obtain consent for the transfer of their data to a



Was passiert, wenn ich zustimme?

Figure 2: A section of the comic study material

English translation: *the trustee is asking for consent...if you allow the trustee to share your contact...What happens if I agree? ...the hospital will contact you. – (hello?) –*

service provider who wants to carry out a clinical trial. We stressed that the data trustee only asks consent for the data transfer itself, not for participation in the clinical trial. The participants were also asked to read through the full, plain text version of the consent form we created and were invited to clarify any doubt with the researcher. We did so to ensure full understanding of the use case and to provide an example of a consent form that would be expected when giving consent within the use case, as we later on only presented the interviewees with a subsection of the consent form in different mediums since reading through all of the text multiple times would have taken too long.

4.3.2 Previous experiences and personal expectations about consent. We then asked participants about their previous experience with consent forms, then we showed them Plutchik's emotion wheel (Appendix Fig. 4) to choose one or more emotions at their leisure to describe how they felt during their past consent experiences (Q3, Q4) [26]. We then enquired about their expectations in regard to a consent form that would encourage them to engage with it (Q5, Q6-Q10).

4.3.3 Rankings of various consent forms, emotions, and meeting of expectations. After that, we showed them the subsection "What happens if I agree?" in different mediums (i.e., comic, infographic, plain text, newsletter, and video) in a random order. We asked them to rank the different forms according to their preference and clarify why, and whether they met their expectations (Q12). We stressed that we showed only a subsection of a complete consent form. We used Plutchik's emotion wheel (Appendix Fig. 4) to explore the interviewees' emotion(s) when shown the various designs. Furthermore, we asked if their expectations about consent engagement were met by the various consent forms (Q13-16).

4.4 Data Analysis

As the interviews were documented in German, to collaboratively analyze them with the non-German authors, anonymized answers

were translated into English via DeepL <https://www.deepl.com/> translator and proof-read by Author 2 to ensure the translations' adherence to the original meaning. Such verification continued throughout the qualitative coding process in various sessions in November–December 2021 with the multidisciplinary team with Authors 1, 2, 3, and 4 (with expertise spanning data protection law, usable privacy, bioethics, bioinformatics, legal design), using the software MAXQDA <https://www.maxqda.com/>. We inductively and iteratively established a codebook over three 2-hour sessions of data labeling. The codebook combines a top-down approach with categories derived from the design, language, content, and relationship criteria for good documents [41] (see Table 1) and the Plutchik's emotions along with codes created from a bottom-up approach through analysis of the data (e.g., the concept of trust) (Appendix D). To address the fact that we translated German interviews into English, we ensured that during the coding of the interviews both an English native speaker (Author 1) and a German native speaker (Author 2) were present. Furthermore, we made sure to look at both the English and the German version of the emotion wheel while coding the emotions and discussed any uncertainty.

4.5 Ethical and Legal Considerations

The study design was authorized by the Research Ethics Committee at the University of Luxembourg (No. ERP 21-038 LeADS). We chose a summary transcription over a word-by-word-protocol to enable an easier anonymization of the interview documentation later on. Once manually anonymized, the transcripts were securely shared with the authors from the other organization.

5 RESULTS

5.1 Prior Experiences with Consent

Regarding RQ 1, we found that all participants had previous experience with consent before the study, with the majority citing consent in the context of healthcare and/or cookie banners (Q3-4). When asked how long they would engage with consent, 20 participants reported time estimates: more than half the participants (n=11) claimed they spent 1-5 minutes, two spent 30 seconds to one minute, five from 0 to 30 seconds, and two did not spend any time before consenting or rejecting (Q5). However, the time spent on consent also depends on contextual elements. For example, Participant 19 (P19) said, *"With cookies, I immediately refuse as much as possible. At the doctor's office, for example, I would read through a consent form twice [...] 5 minutes,"* while Participant 9 (P9) said, *"[I]t depends on who asks it, accordingly I read more attentively or not. If it is something more important e.g. about my finances I read with more attention."* Most participants indicated they would spend "as much time as necessary to understand" (n=10), followed by "as little as possible to sign" (n=8), dependent on perceived trust (n=6) with Participant 16 (P16) saying, *"At the doctor's office, I take little time because I have a lot of trust there. I skim over these consents briefly, taking maybe 30 seconds. On the Internet, I usually take a closer look,"* "as much time needed just to skim" (n=5), and four based on other reasoning.

5.2 Expectations for Consent

Concerning RQ 2a about users' expectations of the consent process, results yielded 148 segments coded according to the document criteria shown in Table 1 (Q6-Q10). Coded segments refer to the extracts of interview text where codes were applied, including overlaps in the text referring to multiple unique and relevant codes.

5.2.1 Design criteria. In terms of design criteria (n=36), graphic elements like bullet points, highlighting, and headings were most cited (n=19) as with, *"I would say that words or passages in bold type stick in my memory, so I would find it desirable, especially with long texts, [...] so that the most important information could be filtered out directly at a glance"* (P1). They were followed by structural elements like sections and organization (n=9), and impression (n=7).

5.2.2 Language criteria. Regarding language criteria (n=35), interviewees most valued textual directness and conciseness (n=21), for example, P10 said, *"When consent forms are particularly long and complicated, I feel like I'm being misled. In the example scenario, I find consent easy to understand. If I am to give consent in a stress-free way, I expect clear and pictorial language that clarifies what actually happens to the data"*. Following that category was plain language (n=8), readability (n=5), and grammar (n=1), although interestingly two participants specifically expected technical terms, such as *"[...] The advantage of a few technical terms is that everything is easier to understand. At the same time, it takes longer to describe these terms in simple language. And that would take too long to read"* (P5).

5.2.3 Relationship criteria. As for the relationship criteria (n=18), or how the document establishes a relationship with the reader, the most cited one was audience fit (n=12), which refers to the appropriateness to the knowledge and skills of the users, such as *"From consents I expect that an average citizen can understand them"* (P17). Another relevant category was tone (n=5), which concerns how style and language match the context.

5.2.4 Content criteria. Regarding the expectations about the content of the consent form (n=12), participants predominantly mentioned how it is relevant to them (relevance, n=10), for example: *"[A]s an affected person, I would like to see a few examples to get a better understanding of what may be done with my data"* (P1), and what actions they can take e.g., withdrawal (n=2).

5.3 Preferences for the infographic and comic

This section reports the results about participants' preferences based on their self-reported experience with the mediums (Q12-Q16). To address RQ 2b, participants were asked i) to rank the mediums, ii) whether they met their expectations, iii) provide explanations for their answers. Participant explanations were coded into subcategories termed "reasoning" if it was general, such as *"What I like about the infographic is that I have everything at a glance"* (P13) or "personal preference" if they explicitly mentioned their own preferences, such as *"To my taste, the graphics are a bit too colorful, but that would be complaining on a high level"* (P23).

5.3.1 Rank and expectations. We only include the results of the most highly ranked medium, the infographic (11 ranked first), and the lowest-ranked one, the comic (10 ranked fifth) out of five mediums. What stands out from the results is that half the participants

(n=12) stated that the infographic met their expectations in terms of consent and none mentioned that it did not. For the comic the opposite is true, i.e., 11 participants stated that it did *not* meet their expectations, with only 3 affirming that it did.

5.3.2 Personal preference. Participants also referred to their own experiences to motivate why one form was preferred, concerning the comic (n=10): "I like the comic best simply because I like reading comics" (P2) as opposed to "The comic does not appeal to me already from the form. I'm not a comic reader and wasn't as a child." (P3). Six participants disliked comics personally, while one liked comics and three had other personal preferences. However, for the infographic (n=11) the personal preferences were less instantly dismissive and centered largely on the design elements (n=7). The other personal preferences for the infographic centered around the unconventional format (n=4), one saying, "The display itself looks to me like something I would hang up somewhere, like an advertisement." (P9).

5.3.3 Reasoning. Participant reasoning yielded 48 coded segments for the infographic and 24 for the comic. Subcategories of reasoning may denote positive and/or negative impacts, for example helping or hindering comprehension, or both within the same medium in different parts. Looking at rank by the participant and the reasoning (Figure 3), we inferred that the infographic (n=48) ranked first due to enabling understanding, impacting time mostly positively, raising interest and attention, and allowing prioritization of information and skimming. The infographic were a clear winner in ranking and in the number of coded segments explaining their reasoning. This contrasts the results for the comic (n=24), which were scattered across ranks and reasoning with no clear pattern, and ranked last.

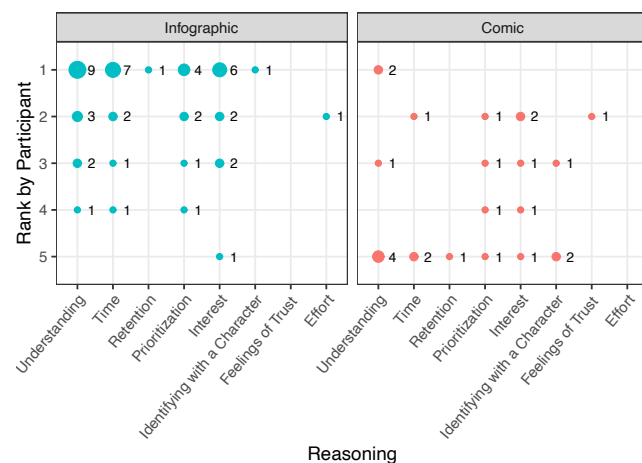


Figure 3: Ranking Reasoning by Rank and Medium
Infographic (coded segments=48) and Comic (coded segments=24)

Looking more closely at whether the reasoning indicated positive or negative outcomes, we compared and contrasted the top three most cited reasoning categories from both the infographic and comic. First, the Understanding category for the infographic was the most cited reasoning (n=15), exclusively in a positive way, "With the bullets, you know right away what each is about in the text written underneath. In general, this is easy to grasp [...]" (P3) contrasting

with the comic, which had 7 coded segments for Understanding, but only 4 in a positive context, saying "[...] I know what the next steps are when I read through it" (P11) versus "The comic totally confuses me. I basically try to read everything diagonally first and that's not possible here" (P15). Interest was the second most cited category in the infographic (n=11) and comic (n=5). For the infographic, 10 out of 12 gave positive reasoning segments, saying "The layout catches my attention and I am glad because it is made easy for me to look at it and read it carefully" (P13). The comic had 4 out of 5 positive reasoning segments, P7 said, "Out of pure interest, and because it looks quite nice, I would spend more time with it." Last, Time was the third most common reasoning given. In the infographic (n=11), 9 out of 11 coded segments were positive, such as "[...] I feel like the most important things were conveyed to me in a concise manner" (P11). However, in the comic (n=3), 2 out of 3 coded segments were negative, with P7 saying, "[T]his type of presentation drags out the reading process. You have to spend a lot more time with it because you can't grasp the information by just skimming over it....]"

5.4 Positive and negative elements in the infographic

If we analyze the reasons why the infographic was preferred to answer RQ 2c, out of a total of 60 coded segments, a great majority concerns design criteria (n=51); in particular step-by-step elements, icons, bold headings, bullet points, and color (Q13-Q16). There were only a few mentions to the overall impression (n=6), such as "I found the overall structuring particularly pleasing and that you can immediately see that you have little to read" (P18), and tone (n=3), the interplay of text and graphics (n=3) and readability (n=2) from the relationship criteria, content criteria, and language criteria respectively.

The motivations to dislike the infographic (n=25) mentioned the design criteria in the majority as well (n=15). They mainly mentioned the graphic elements (n=9), in particular, the over-use of color and icons and how large the infographic was. Impression (n=5) was also mentioned, for example, "But at first glance, you don't expect it to be a privacy statement. It looks more like a flyer where something is advertised or promoted." (P6). Tone (n=4) and audience fit (n=3) were disliked in the relationship criteria, and in content criteria, the subject (n=2) and interplay of text and graphics (n=1) were negatively received.

5.5 Positive and negative elements in the comic

To understand RQ 2c for the comic, we found that the comic had 23 positive coded segments, mostly in design criteria (n=10), in particular graphic elements (n=7) with mention of the support of text by graphics, narrative elements, and illustrations (Q13-Q15). There were only a few mentions to the tone and audience fit in relationship criteria (n=8), P10 saying, "The comic is easier to process and is more appealing or casual in comparison to a normal text. It doesn't feel like an interrogation," then interplay of text and graphics and story element in content criteria (n=5).

The number of coded segments of negative elements for the comic (n=45) was almost double than that of positive elements. More than half of total dislikes were part of the relationship criteria (n=24), in particular the audience fit (n=10) and tone (n=8), with

participants saying, *"I'm out of the age where I still like comics. [...] I don't feel like I'm being taken seriously as a customer with a consent form like this"* (P16). The design criteria had 16 negative elements, mainly in impression (n=9), with participants reacting very strongly and saying, *"If I had this in my hands, I wouldn't even read it, I'd put it down right away"* (P4), with graphic elements (n=5) concerning the execution of illustrations, legibility (n=1), and structure (n=1) also present. There were also negative elements in language criteria (n=4) and content criteria (n=1).

5.6 Emotions triggered by infographic and comic

To address RQ 3, we compared the number of coded segments from overlapping emotions from comic (n=64) and infographic (n=52) that participants indicated on the emotion wheel (Appendix Figure 4, Q13-Q16). Anticipation, interest, acceptance, and surprise are the top 4 emotions present in the infographic, while in the comic the top 3 emotions are surprise, disapproval, interest, and distraction. For example, P8's emotions around the infographic: *"It is unusual, yet I like it because it is creative and surprising. When reading the infographic, I feel the emotions are attentive and trusting"* while P11 said, *"I feel surprised, confused, and dismissive because it would seem unserious to me."* Anticipation and acceptance in the infographic (n=7) denote positive emotions and disapproval and distraction in the comic (n=9 and n=8 respectively) denote negative emotions. In fact, interest and distraction are opposites on the emotion wheel. Not all emotions were stark contrasts though, as the overlap in surprise for infographic (n=6) and comic (n=10) mainly concern the unconventional medium of consent, such as, *"My emotions are accepting, attentive, but also surprised because it is a new way of processing,"* (P15) about the infographic and, *"Looking at the comic I feel surprised and amazed in a positive sense"* (P18). Only 3 out of 10 participants meant surprise in a negative sense for the comic and 1 out of 6 for the infographic. Interest also denoted curiosity in our codebook, and this word was most often mentioned in this category in both the infographic and comic.

6 DISCUSSION

Concerning RQ 1 about consent experiences, an element that emerged from the results is the importance of time: the majority of the participants clearly indicated that they spent only as long as necessary to understand, however almost half of them also mentioned that it should not take longer than one minute. That said, time spent on consent seems to be contextual and depends on the type of data and the entity asking to share such data. It emerged that individuals are aware that they do not engage in attentive, word-by-word reading of consent forms, as they also expect consent (RQ 2) to be short, concise, direct, and with elements that allow the visual prioritization of some information over others. Rather they engage in strategic reading [41] depending on their objective: as readers need to find "surface-level cues" to skim effectively, the consent document should include headings, bullet points, and highlights to help people navigate it efficiently and quickly grasp which information is more important than other. Our results confirm the findings of Schriver [34] that an informative document should enhance skimming and provide information in a time and context

relevant to the needs and preferences of the reader. Moreover, as individuals read through the documents quickly, the information should be concise and essential, otherwise, the working memory becomes easily overloaded. Conciseness, though, is in contrast to the copious information that is required by transparency requirements. The relevance of content to the reader seems also crucial, as opposed to the provision of abstract and general information.

Comparing the infographic and comic, the infographic was ranked first due to enabling understanding, impacting time positively, and allowing prioritization of information and skimming. The answers concerning RQ 2 and 3 clearly show specific expectations about consent forms, though they did not necessarily need to resemble a conventional plain text document and it may be dependent on personal preferences. Both mediums raised participants' interest and attention, which could be reflected in user engagement. Comics were considered appropriate by some, but mostly inappropriate (e.g., *childish, unserious*) due to the seriousness of the medical settings and mostly sparked negative emotions like distraction and disapproval. Again, context is key. Contrary to our findings, Wer-muth [43] found that comics proved useful in a medical setting with medical experts and patients (both adults and children). However, Wer-muth paid attention to maintaining appropriate intent, style, tone, and emotional salience. Our prior work on consent to genomic research [4, 37] how comics can be deemed appropriate by certain communities and enhance their involvement in the process. Thus ensuring the correct depiction of the audience's culture, style and tone are critical aspects for the acceptance and success of comics as a consent communication medium. In contrast, the infographic was more well-received with positive emotions like anticipation, interest, and acceptance. The implications of emotions must not be ignored: positive first impressions may enhance attention and interest towards the consent form and increase engagement, while negative ones may alienate potential readers right after their first impression and even before they engage with consent.

Hence, tone of voice and audience fit are important aspects that are rarely considered in the transparency of privacy information, whereas plain language accompanied by graphical elements and illustrations to support understanding and information navigation are nowadays recommended as best practices and their appreciation is reflected in our results [24, 28]. Privacy communication, as well as legal communication more in general, has traditionally ignored the audience it intends to reach, by flattening the style to a communication made "by lawyers for lawyers" and that focuses on the precision of the rules, rather than on the possibility of the intended audience to grasp their meaning and act upon such rules [25]. But as a user-centered design approach enters the realm of law, legal communication increasingly becomes permeable to considerations about the audience fit, see e.g., the importance of tone of voice and the use of comics in contracts [16]. Comics or other mediums may still be unacceptable for some, however, layered approaches that present the information in complementary multimedia are increasingly being experimented with and could be meaningful to better tune legal-technical communication to different needs and preferences.

Trust has also been mentioned to explain certain reasoning, although it was not a specific focus of the study. For example, P19 said that they have different behaviors for cookies compared to

doctor's office, or P9 said they evaluate the person asking, or P16 distrusted the internet more than the doctor's office. The approach to consent may be influenced by the (perceived) trustworthiness of the institution asking it (e.g., doctors). A few participants also stressed that consent should not contain any misleading statement or any deceptive information. This reference to potential manipulation of one's own choices is also reflected in the ongoing lively discussion about digital consent, recalled in Sec. 3. Further research may elucidate what consent elements may increase trust in data disclosure.

From these observations, consent is a complex process that does not happen at a single point in time when the form is presented to individuals. Rather, it carries expectations derived by previous experiences and can trigger a whole set of emotions. Finding the right medium for certain audiences is not trivial, opening the question of whether standardization of consent is really possible.

7 LIMITATIONS AND FUTURE WORK

The interviewees were a small number of German residents, thus the study has limited generalizability, like many other qualitative analyses, and should be repeated with other user groups. However, we successfully obtained balanced age, education, and sex representation. Although coding was performed on English translations of German, their correctness was continuously evaluated by the German native speaker and the English native speaker authors, before and during the coding sessions, also with the help of the official translation of the emotion wheel and language resources. Additionally, the research scenario with a data trustee has a simpler consent process compared to informed consent in clinical trials, which generally has greater ethical-legal safeguards. The results should thus not be generalized to all contexts of consent.

Since the study materials were all created by Author 1 with only internal consultation, the design and text choices could have influenced participant attitudes more than the medium (e.g., professional comics may elicit different responses) and to suit each medium the base consent text had minor edits or added text (i.e., headers, ellipses). Consistent text and design in consultation with professionals should be considered. Another limitation that future work will seek to address is that interviews can only reveal opinions explicitly self-reported (e.g., stated preferences) but cannot reveal anything about actual user behavior.

The results raise interesting questions about the impact that user expectations deriving from prior experiences with consent and from personal and cultural experiences with different mediums have on the engagement with unconventional consent documents. Another facet to study is how trust influences user expectations and behavior. We are also finalizing the results from all five mediums of consent presented to participants (i.e., plain text, newsletter, infographic, comic, and video) to address unanswered questions about participant attitudes towards engagement, transparency, and consent management. It could also be interesting to investigate emotions in terms of their intensity as other emotion wheels such as the Geneva emotion wheel³ allow for.

³<https://www.unige.ch/cisa/gew>

8 CONCLUSIONS

This interview study about informed consent to personal data processing analyzed the expectations of 24 individuals and how various document design elements reportedly affected their engagement and their overall experience with the comic and infographic. Among the alternatives we presented for the use case of a data trustee asking consent to share personal data with a service provider who wants to carry out a clinical trial, the infographic appears to be the most promising medium in a biomedical context as it enables understanding, allows prioritization when reading and raises interest and attention. The comic though, despite the praise of the support of text with graphics and narrative elements, should be employed with caution as the audience fit and tone may be experienced as inappropriate, at least for the context of medical consent. Beyond this scenario, many others exist: the sharing, reuse, and analysis of data trustee can encourage the use of data across *smart city actors* to improve e.g. the health of smart cities citizens during a pandemic or to improve the educational system – in short: to make a smart city even more liveable [36] and [35]. In such cases, the complexity of personal data processing and disclosure, and the consent process accordingly, can increase dramatically in comparison to the use case presented in these pages. The initial findings reported here should encourage more research into the understanding of how to engage individuals into the data economy composed of increasingly complex data-informed services.

ACKNOWLEDGMENTS

This project has received funding from the European Union's Horizon 2020 Innovative Training Networks Grant Agreement ID:956562 "Legality Attentive Data Scientists" and is partially supported by the Luxembourg National Research Fund (FNR) Grant Agreement IS/14717072 "Deceptive Patterns Online (Decepticon)". Authors 2's contribution has been partially funded by the German Federal Ministry of Education and Research and the Hessen State Ministry for Higher Education, Research and the Arts within their joint support of the National Research Center for Applied Cybersecurity ATHENE. The research has partially been conducted during Authors 2's research visit to the University of Luxembourg in 2021. The authors thank Giusi Abagnale and Ines Geissler for their assistance in the interview documentation.

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A EXTRACT OF INTERVIEW GUIDELINE

In this section of the appendix we show the extract of the interview guideline we used for the interviews that is relevant to the paper (some questions asked for participant attitudes towards consent management and withdrawal and were not part of the scope of this paper) we address in this contribution, here translated from German into English:

Question 3

What do you know about consent to the processing of your personal data in general?

Question 4

What are your experiences with (a) a website or (b) a hospital requesting your consent? Which emotions did you have while engaging with the consent (showing the emotion wheel for guidance)

Question 5

How long do you usually take time to engage with a consent form before you give or refuse your consent it?

Question 6

What would be your expectations or preferences of consent in the context of the data processing context presented?

Question 7 (if not already answered under 6)

What would be your expectations of consent in relation to the text?

Question 8 (if not already answered under 6)

What would be your expectations of consent in terms of form (e.g. paper-based, digital text, audio file)?

- Digital vs. physical
- Audio vs. written vs. video

Question 9 (if not already answered under 6)

What would be your expectations of consent in terms of engaging while receiving information?

Question 10 (if not already answered under 6)

What would be your expectations of consent in terms of being given relevant information transparently and giving consent?

(there is a presentation of the consent text again (1) as text form formatted as a newsletter as well as (2) as an infographic (3) in form of a comic and (4) in form of a video.

Question 12

Please rank the four different ways of consent form information in the order you prefer, from most favorite to least favorite.

Question 13-16 (for each of the consent forms separately asked, in the order of best to least favorite)

What do you like about the consent form and why? To what extent does it meet the expectations you have for consent in terms of text and form? How did you experience the consent – which emotions did you have while experiencing the consent (showing the emotion wheel in a powerpoint slide for guidance), which elements were particularly enjoyable, which elements helped you actively engage with the consent? Are there elements of the consent form that you don't like and why?

B EMOTION WHEEL

During the interviews, participants were shown the German version of the emotion wheel⁴, and the English version is shown in Figure 4. Participants were asked to describe their emotional response to the mediums shown.

C STUDY MATERIAL

C.1 Full Consent Text (English)

Who are we? We are Company XYZ, Test-Street 5, 12345 Test-City (Test-Country). We are a trustee, an independent organization that collects and shares data with trusted partners that carry out clinical trials in a lawful way. We get contacted by hospitals that want to carry out clinical trials to cure certain diseases and that search for participants with specific diseases and symptoms. Once we get contacted by a hospital, we contact everyone in our database that fits the criteria of the specific disease and symptoms and ask them for consent to share their data with the hospital that wants to carry out the clinical trial.

What data do we process and where did we get it from?

We process the following of your data which we got from hospital ABC: Your name and email address, your diagnosis and symptoms.

What happens after I agree? The hospital will contact you. As a rule, the hospital will ask you to bring all your medical records. Then you will be examined. After the examination, you will participate in an educational discussion about the clinical trial. You can

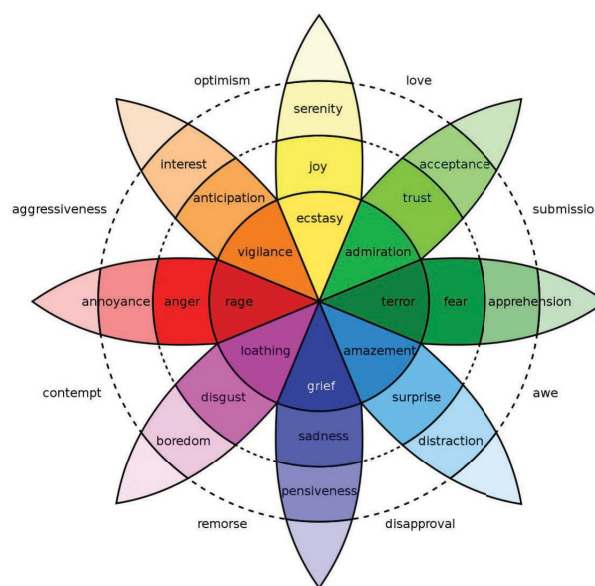


Figure 4: Plutchik's emotion wheel

Image sourced from Wikipedia, at https://en.wikipedia.org/wiki/Robert_Plutchik#/media/File:Plutchik-wheel.svg.

then decide whether you want to participate in the clinical trial. If you choose to participate in the clinical trial, you must consent to the processing of your personal data. Your personal data will be processed, among other things, in order to be able to monitor your health during the clinical study.

What exactly do we want consent for today? The hospital of Darmstadt would like to be able to contact you to invite you to participate in a clinical trial that is carried out to cure allergies against lactose. Do you consent that we, the company XYZ as a trustee, hand out your name, email address, diagnosis, and allergy-related symptoms to the hospital of Darmstadt so that they can contact you to invite you to the clinical trial?

Yes, (please sign if you consent).

No.

You can withdraw your consent at any time by sending an email to withdrawal@xyz.test. Please note that the withdrawal develops effectiveness starting from the time of withdrawal. Therefore, if we already sent your data to the hospital of Darmstadt by the time you withdraw your consent, you will need to send a request for data erasure to the hospital of Darmstadt in order for them to no longer process your data.

C.2 Various Consent Mediums

During our study we presented five different consent mediums to the interviewees: plain text, newsletter, infographic, comic, and video covering the section, "What happens after I agree?" from the full consent text. In this appendix, we show the full infographic (Figure 5) and comic (Figure 6) used during the interviews, as we

⁴https://de.wikipedia.org/wiki/Robert_Plutchik#/media/Datei:Plutchik-wheel_de.svg



Figure 5: Infographic

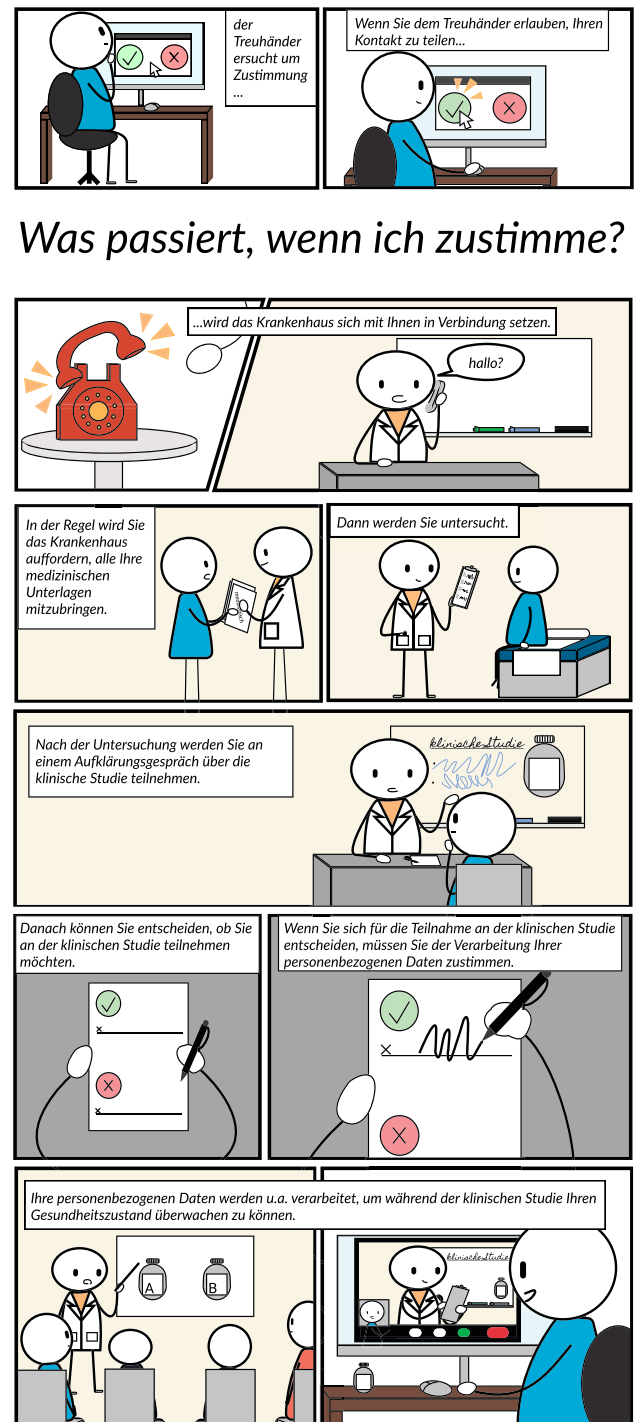


Figure 6: Comic

compare these two within this contribution. The other consent mediums are available here: <https://dropit.uni.lu/invitations?share=81187cb4f41181692809>.

English translation of the infographic: *What happens after I agree?* If you allow the data trustee to share your contact data with the hospital, the following will happen: 1. *Contact* The hospital will contact you. 2. *Medical record* As a rule, the hospital will ask you to bring all your medical records. 3. *Medical examination* Then you will be examined. 4. *Educational discussion* After the examination you will participate in an educational discussion about the clinical trial. 5. *Decision* You can then decide whether you want to participate in the clinical trial. 6. *Consent* If you choose to participate in the clinical trial, you must consent to the processing of your personal data. Your personal data will be processed, among other things, in order to be able to monitor your health during the clinical study.

English translation of the comic: *What happens after I agree?* The data trustee requests consent... – If you allow the data trustee to share your contact... – ...The hospital will contact you. – (hello?) – As a rule, the hospital will ask you to bring all your medical records. – Then you will be examined. – After the examination, you will participate in an educational discussion about the clinical trial. – Afterwards, you can then decide whether you want to participate in the clinical trial. – If you choose to participate in the clinical trial, you must consent to the processing of your personal data. – Your personal data will be processed, among other things, in order to be able to monitor your health during the clinical study.

D CODEBOOK

The full codebook may be downloaded at this link: <https://tinyurl.com/bdha99mu>.

Presented here are first and second-level codes. When referenced in the text, longer codes such as Interest/Attention were shortened to only Interest.

- (1) **Prior Knowledge of Data Processing:** *no Knowledge, some Knowledge, lots of Knowledge.*
- (2) **Prior Experience with Consent:** *Recruiting, Financial Consent, Healthcare Consent, Cookie Banners, General Experience.*
- (3) **Time Spent On Consent:** *Context, Reasoning, 0sec, 0-30sec, 30sec-1min, 1+min.*
- (4) **Expectations for Consent:** *Content Criteria, Relationship Criteria, Design Criteria, Language Criteria, Other.*
- (5) **Enables:** *Identifying with a Character, Effort, Interest/Attention, Prioritization/Skimming, Retention/Memory, Feelings of Trust, Consent Management, Interactivity, Time, Understanding/Clarity.*
- (6) **Infographic Experience:** *Personal Preference/Experience, Meets Expectations, Likes, Dislikes.*
- (7) **Comic Experience:** *Personal Preference/Experience, Meets Expectations, Does Not Meet Expectations, Likes, Dislikes.*
- (8) **Emotions:** *Other, Disgust, Boredom, Contempt/Rejection, Annoyance, Vigilance/Alertness/Clear, Anticipation/Attention, Interest, Optimism, Joy, Serenity/Calmness, Admiration, Apprehension/Anxiety, Amazement, Surprise, Distraction/Confusion, Disapproval.*