

# Developing Infographics to Facilitate HIV-Related Patient–Provider Communication in a Limited-Resource Setting

Samantha Stonbraker<sup>1,2</sup> Mina Halpern<sup>2</sup> Suzanne Bakken<sup>1,3</sup> Rebecca Schnall<sup>1</sup>

<sup>1</sup> Columbia University School of Nursing, New York, New York, United States

<sup>2</sup> Clínica de Familia La Romana, La Romana, Dominican Republic

<sup>3</sup> Department of Biomedical Informatics, Columbia University, New York, New York, United States

**Address for correspondence** Samantha Stonbraker, PhD, MPH, RN, Columbia University School of Nursing, 530 West 168th Street, Mail Code 6, New York, NY 10032, United States (e-mail: Slb2201@Cumc.Columbia.Edu).

Appl Clin Inform 2019;10:597–609.

## Abstract

**Background** Productive patient–provider communication is a recognized component of high-quality health care that leads to better health outcomes. Well-designed infographics can facilitate effective communication, especially when culture, language, or literacy differences are present.

**Objectives** This study aimed to rigorously develop infographics to improve human immunodeficiency virus (HIV)-related patient–provider communication in a limited-resource setting. A secondary purpose was to establish through participant feedback that infographics convey intended meaning in this clinical and cultural context.

**Methods** We adapted a participatory design methodology, developed in a high-resource setting, for use in the Dominican Republic. Initially, content to include was established using a data-triangulation method. Then, infographics were iteratively generated and refined during five phases of design sessions with three stakeholder groups: (1) 25 persons living with HIV, (2) 8 health care providers, and (3) 5 domain experts. Suggestions for improvement were incorporated between design sessions and questions to confirm interpretability of infographics were included at the end of each session.

**Results** Each participant group focused on different aspects of infographic designs. Providers drew on past experiences with patients and offered clinically and contextually relevant recommendations of symbols and images to include. Domain experts focused on technical design considerations and interpretations of infographics. While it was difficult for patient participants to provide concrete suggestions, they provided feedback on the meaning of infographics and responded clearly to direct questions regarding possible changes. Fifteen final infographics were developed and all participant groups qualitatively confirmed that they displayed the intended content in a culturally appropriate and clinically meaningful way.

**Conclusion** Incorporating perspectives from various stakeholders led to the evolution of designs over time and generated design recommendations that will be useful to others creating infographics for use in similar populations. Next steps are to assess the feasibility of using infographics to improve clinical communication and patient outcomes.

## Keywords

- ▶ patient–provider communication
- ▶ participatory design
- ▶ patient education
- ▶ health literacy
- ▶ infographics
- ▶ nursing informatics

received  
April 11, 2019  
accepted after revision  
June 20, 2019

© 2019 Georg Thieme Verlag KG  
Stuttgart · New York

DOI <https://doi.org/10.1055/s-0039-1694001>.  
ISSN 1869-0327.

## Background and Significance

Effective communication is a central component of high-quality health care<sup>1</sup> that leads to better patient outcomes when successfully completed.<sup>2-4</sup> Unfortunately, productive health communication presents many challenges for health care providers and patients and can contribute to health inequity.<sup>5,6</sup> For instance, providers must acquire, synthesize, and present massive amounts of complex information to patients<sup>7</sup>; and patients must receive, process, and use that information, which, despite best intentions, is frequently presented in a complicated format or riddled with advanced medical terminology.<sup>8,9</sup> In limited-resource settings, patients' educational attainment, language discrepancies, and cultural perspectives on health further complicate clinical communication.<sup>10,11</sup>

This acquisition and digestion of health information is essential for persons living with chronic conditions such as human immunodeficiency virus (HIV); yet, these individuals are less likely to understand health information as they are disproportionately more likely to have limited health literacy (LHL).<sup>12,13</sup> Health literacy is defined as "the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions."<sup>14</sup> Those with LHL are less able to use health care services and experience worse health outcomes, which further contributes to health disparities.<sup>10,11,15,16</sup>

In the Dominican Republic (DR), an estimated 37% of people finish the equivalent of high school, and literacy is estimated between 94 and 99%,<sup>17</sup> though in an international comparison of academic achievement, adolescents in the DR ranked among the lowest in the world.<sup>18</sup> The prevalence of HIV in the DR is 0.9% among the general population,<sup>19</sup> and ranges to as high as 11% among high-risk populations such as transgender women.<sup>20,21</sup> Limited educational attainment, rural residence, stigma, and high levels of poverty, among other social determinants of health, contribute to Dominican's risk for acquiring HIV infection and their ability to effectively manage it.<sup>22,23</sup> For instance,<sup>17,18</sup> persons living with HIV (PLWH) with LHL in the DR demonstrate difficulties in understanding health information, despite being connected to health care services and receiving health education.<sup>23,24</sup>

Clínica de Familia La Romana (CFLR) is a Dominican nongovernmental organization licensed by the Ministry of Health to provide outpatient care that specializes in the prevention, diagnosis, and treatment of sexually transmitted infections, including HIV. In December 2017, there were 1,944 adults enrolled in their nationally recognized HIV service program, making it the third largest HIV treatment center in the country. CFLR provides HIV-related information to patients in many types of clinic visits (doctor, nurse, psychologist), through educational talks in waiting rooms, during home visits, and includes appointments with an adherence counselor as part of normal care. The predominant language spoken by both patients and staff is Spanish. An estimated 8% of the patient population speak only Haitian Creole, for whom interpreters are available. Despite these numerous opportunities to acquire health information, in a

sample of 107 PLWH who had been attending CFLR for an average of 6.3 years, 80% inaccurately identified a high viral load as desirable.<sup>24</sup> This indicates that even when linked to high-quality care, patients are not receiving health information in a way that they can understand. Thus, exploration of more effective ways to share information with patients is warranted.

One method to improve clinical communication is to use infographics to support patient education.<sup>25-27</sup> "Infographic" is an abbreviation of the phrase, information graphic, and can be defined as a "visual representation of information, data, or knowledge intended to clarify and integrate difficult information quickly and clearly."<sup>28-30</sup> Infographics enhance communication because people are more engaged with content when it is processed both auditorily and visually.<sup>31-33</sup> By carefully selecting content and rigorously designing infographics, they can portray a wealth of meaningful information in a culturally appropriate and visually appealing way.<sup>31-35</sup> When used to support health education, infographics can improve risk communication, increase information recall, and augment attention span.<sup>36,37</sup>

Researchers and clinicians have developed many visual aids of varying types over the past 20 years using numerous development and evaluation methods.<sup>38-42</sup> Many of these have focused on communicating risk and on sharing information about medications.<sup>36,38,43-46</sup> Particularly relevant to those living with HIV in limited-resource settings, Dowse et al developed an information leaflet including pictograms for use among PLWH with LHL in South Africa<sup>47</sup> and found it improved HIV-related knowledge and self-efficacy.<sup>48</sup> Because infographics have been developed across conditions, in various formats, for a variety of audiences, and their evaluation has been inconsistent, there are not established "best practices" for their development nor their evaluation. As a result, systematic methods to generate and evaluate infographics, and other visualizations, are being developed,<sup>42,49-52</sup> but evidence on if, and how, these processes can be used in limited-resource settings is lacking.

## Objectives

The primary purpose of this study was to use an iterative participatory design process to rigorously develop a set of infographics meant to improve HIV-related patient-provider communication in a limited-resource setting. A secondary purpose was to establish, through qualitative participant feedback, that the infographics convey intended meaning in this clinical and cultural context.

## Methods

### Study Setting

Design sessions with patients and health care providers took place in a private meeting room at CFLR in the DR (see Introduction). The design session with experts took place in a private conference room at Columbia University School of Nursing.

### Participatory Design Methodology

We made numerous adaptations to a participatory design methodology, developed and operationalized at Columbia University,<sup>35</sup> to generate infographics in the limited-resource setting of our study site. First, we added health care providers directly involved in patient care as design session participants. Second, patients and providers were recruited from the target clinic rather than from current or past research participants. Third, as the purpose of the infographics in this study is to support HIV-related communication with all PLWH who attend CFLR, the infographics we designed were static rather than tailored with individual data. Fourth, final infographics were paper-, rather than computer-, based, as this would be the format available for use at CFLR. Consistent with other participatory design methodologies,<sup>35,53–55</sup> the resulting method, described in the “Development of Infographics through Iterative Participatory Design Sessions” section, enabled us to codesign infographics alongside three key stakeholder groups: (1) health care providers who offer HIV-related services at CFLR, (2) experts in informatics, visualization design, and participatory design, and (3) PLWH who receive services at CFLR.

### Design Session Participants

#### Providers

Previous visualization work indicates final designs are more clinically meaningful when health care providers are involved in the design process.<sup>35,56</sup> Moreover, our infographics were intended for use by providers during patients' clinic visits, thus health care providers were included as study participants. All health care professionals who provide services to adult PLWH at CFLR were eligible. Participants were purposefully selected to ensure interdisciplinary representation in design sessions, with an overrepresentation of physicians, who would eventually use the infographics during clinic visits.

#### Experts

Informatics-based approaches to system design consistently include domain experts to identify design flaws,<sup>57–59</sup> as expert review is considered a cost effective and rigorous way to identify critical design flaws in visualization.<sup>51,57</sup> As five experts are recommended to identify flaws,<sup>51,60</sup> five doctorally prepared nurses with expertise in informatics, visualization, and participatory design from the visualization design studio of a funded center of excellence and informatics department at Columbia University were invited to participate. Each has extensive experience working with participants in community-based settings as researchers and nurses as well as numerous publications detailing this work.

#### Patients

Including patients in design processes can aid in the comprehension, cultural acceptability, and eventual uptake of final products (in this case, infographics).<sup>46,55,61</sup> During recruitment, any adult PLWH who presented to CFLR on days when design sessions were held was eligible. CFLR staff

identified potential participants, confidentially confirmed their HIV status, and provided preliminary study information to participants. Interested participants were referred to speak with a study team member who provided a detailed explanation of the study's purpose, design session procedures, and obtained verbal informed consent. Patient participants received lunch during sessions.

### Selection of Content to Include in Infographics

The content to include in infographics was determined by using a data sources triangulation method to establish the priority topics that PLWH need to receive as part of patient education in this clinical context.<sup>62</sup> Complete results of this analysis are reported elsewhere,<sup>62</sup> but the five priority health education topics to address with HIV-related infographics were: information about medication (antiretroviral therapy or ART) and adherence, HIV transmission (including risks and prevention), mental health management, general knowledge of HIV, and results of laboratory analyses.

### Development of Infographics through Iterative Participatory Design Sessions

Participatory design sessions took place between November 2017 and June 2018 in five phases (–Table 1). Iterative design through these numerous phases with our three participant groups enabled a fully collaborative design process that allowed participants to work alongside the design team to make critical design decisions. To ensure all participant feedback was truly incorporated, all design sessions were audio recorded and transcripts were carefully reviewed to verify comments were incorporated into designs.

#### Phase I—Providers

Initially, we conducted three design sessions in Spanish with health care providers (6–8 per session) to establish infographic prototypes. A member of the research team, a note taker, and a graphic designer were present at each session to enable collaboration with participants on the creation of infographic designs. During the first session, we introduced the purpose of the study and discussed how infographics might be used in a clinical setting, reviewed relevant design principles,<sup>35,63</sup> and presented a selection of infographics on nonrelated topics to provide examples of what final designs might look like without guiding participants' design choices. We then went through each of the five priority education topics to be included and asked providers to suggest symbols/images and designs they wanted to incorporate. Participants were each provided a large white paper and a set of markers if they wanted to sketch preliminary ideas. Following the initial session, the graphic designer created initial infographic prototypes in Adobe Illustrator. In the second and third sessions, providers reviewed prototypes and made suggestions for refinement.

#### Phase II—Experts

One design session with five experts was conducted in English between the second and third provider sessions.

**Table 1** Phases of participatory design methodology

Phase I: Generate prototype infographics with providers ( <i>N</i> = 8)	
Session 1	<ul style="list-style-type: none"> <li>• Review purpose of study and explore ways to clinically use infographics</li> <li>• Review relevant design principles</li> <li>• Provide an overview of content to include in infographics</li> <li>• Show examples of infographics designed for similar, but not directly related, topics</li> <li>• Brainstorm ideas for potential infographics</li> </ul>
Session 2	<ul style="list-style-type: none"> <li>• Review prototype infographics generated from previous session</li> <li>• Solicit feedback and recommendations for future iterations</li> </ul>
Session 3	<ul style="list-style-type: none"> <li>• Review prototype infographics generated from previous session</li> <li>• Solicit feedback and recommendations for future iterations</li> </ul>
Phase II: Review of prototype infographics with experts ( <i>n</i> = 5)	
Session 1	<ul style="list-style-type: none"> <li>• Review prototype infographics generated in provider sessions with an emphasis on relevant design principles</li> <li>• Solicit feedback regarding effective display of included content</li> </ul>
Phase III: Iterative refinement of infographics with PLWH ( <i>n</i> = 25, 3–5 unique PLWH in each session)	
Sessions 1–6	<ul style="list-style-type: none"> <li>• Review designs generated in provider and expert design sessions</li> <li>• Solicit PLWH feedback regarding interpretability of designs and recommendations for refinements</li> <li>• Qualitatively assess perceived comprehension, meaningfulness, and usefulness of designs</li> </ul>
Phase IV: Review of semifinal infographics with experts ( <i>n</i> = 5)	
Individual review	<ul style="list-style-type: none"> <li>• Review designs to qualitatively assess that each is interpretable and has the potential to improve patient-provider communication</li> <li>• Request final feedback and/or recommendations</li> <li>• Confirm the acceptability and aesthetic of each infographic</li> </ul>
Phase V: Review of semifinal infographics with providers ( <i>n</i> = 6)	
Individual review	<ul style="list-style-type: none"> <li>• Review designs to qualitatively assess each is interpretable and has the potential to improve patient-provider communication</li> <li>• Request final feedback and/or recommendations</li> <li>• Confirm the acceptability and aesthetic of each infographic</li> </ul>

Abbreviation: PLWH, persons living with human immunodeficiency virus.

Note: The graphic designer incorporated suggested revisions in infographics between each design session.

With experts, each prototype infographic was reviewed and feedback on the overall layout, content, and interpretability of each was requested. Experts were also asked to verify relevant design principles<sup>35,63</sup> were adhered to.

#### Phase III—Persons Living with HIV

After incorporating modifications from provider and expert sessions, we conducted six iterative design sessions in Spanish with PLWH (3–6 unique participants per session). In each session, participants were involved in design choices by providing feedback on infographic prototypes and the meaning of the symbols/icons within each. Open-ended questions such as “what does this symbol mean to you?” or, “what are we trying to say with this infographic?” were asked. Participants were also asked how to improve designs to enhance comprehension for all patients at CFLR. In instances when PLWH were unable to, or did not, provide recommendations to ameliorate confusion they experienced when looking at an infographic, we discussed potential sources of confusion and their respective modifications. At the conclusion of each session, we asked patients if designs were meaningful and if they thought they would be useful.

#### Phase IV—Experts

Experts independently reviewed semifinal infographics to provide final design suggestions, confirm interpretability, potential to improve patient-provider communication, and readiness for feasibility testing.

#### Phase V—Providers

Health care providers individually reviewed final infographics with a study team member to provide any last recommendations as well as to confirm clinical utility, interpretability of infographics, and readiness for planned feasibility testing.

## Results

### Participant demographics

#### Providers

Eight health care providers (5 physicians, 1 nurse/community outreach worker, 1 counselor, and 1 psychologist) participated in design sessions. All were female and the mean age was 33 years (standard deviation [SD] = 7.63). They had a mean of 9.8 years working in health care (SD = 5.73), and a mean of 3.2 years working at CFLR (SD = 3.64).

## Experts

The five experts were all female nurses with a PhD (2 nursing, 2 nursing informatics, and 1 public health informatics). All held professorial titles and had an average of 18.8 years of informatics, visualization design, and/or participatory research experience (SD = 12.56).

## Patients

Patient participants included 25 PLWH. The average age was 42.2 years (SD = 13.62) and about half (52%) were female; 17 had some, or all, of a primary (elementary or middle) school education (68%), 7 had some or all of a secondary (high) school education (28%), and 1 participant had completed some university (4%). The average time participants had been living with HIV was 9.24 years (SD = 5.61) and participants had been attending CFLR for an average of 8.07 years (SD = 5.60).

## Evolution of Infographics

Several infographic designs for each of the five priority education topics (the “Selection of Content to Include in Infographics” section) were generated during initial sessions. These designs then progressed over the 7-month study period as feedback from iterative design sessions was incorporated. **→Fig. 1** shows how a selection of these images, from each of the five priority education topics, evolved. Generally, initial design sessions brainstormed large ideas which led to preliminary infographics that lacked organization, included extra symbols/icons, and were confusing to many participants. In midpoint sessions, participants provided design suggestions that clarified images, especially the inclusion of labels, which led to more precision. Conversations during final design sessions focused on refining details and overall style and confirming meaning. Thus, as **→Fig. 1** shows, initial designs are lacking details and labels, include extra icons/symbols, and are more difficult to decipher, whereas the final designs are well organized, clearly labeled, and lend themselves to meaningful interpretation.

## Observations from Each Design Session Phase

### Phase I—Providers

The first design session focused on large ideas of how to represent the five priority health education topics. For example, what is the best way to show CD4 cells defending the body against a virus? Ideas ranged from a battle scene in which CD4 cells were defending the “patria” or homeland (representing the body) against HIV viral “invaders,” to brainstorming less war-like representations, such as using boxing gloves (**→Fig. 2A1–A3**). Additional considerations were how to show bodily functions such as dizziness or diarrhea or what symbols/images would clearly show the reciprocal relationship between CD4 and viral load, among many others. In the second and third sessions, providers asked questions about items in the prototype infographics they found confusing, identified missing elements, and discussed the best representation of key concepts such as if the passage of time is linear or circular (**→Fig. 1D–F**). Generally, providers drew from their clinical experience and interac-

tions with patients to guide recommendations for refinements. As one provider stated, “I think it is good to put the medication bottles [as opposed to pills to represent medications], because they [patients] recognize their medications more by the container than by the pills themselves.”

### Phase II—Experts

Experts drew on their clinical experiences as nurses, knowledge and experience with effective visualization design, and experiences with previous research participants to provide concrete design suggestions and clarify imagery to enhance intended meaning. For example, it was recommended to keep the sun and moon in the infographic to represent medication timing, but to present them outside the clock to make them an “aura” rather than a watch design (**→Fig. 1B** and **C**). An additional comment on that infographic was to make the clock digital, so the time could simply be filled in (**→Fig. 1C**). One thought a dizzy person might be interpreted as an angel with a halo (**→Fig. 2B**) and recommended refining that icon. It was also suggested the cap of the medication bottle, “looked like a worm or a barcode” (**→Fig. 2C**). Other comments were to “take out numbers if there is not an order, because numbers imply a process,” or regarding the visual complexity of images, “there is too much going on, you cannot decode it” and recommended simplifying infographics with better use of white space.

### Phase III—Patients

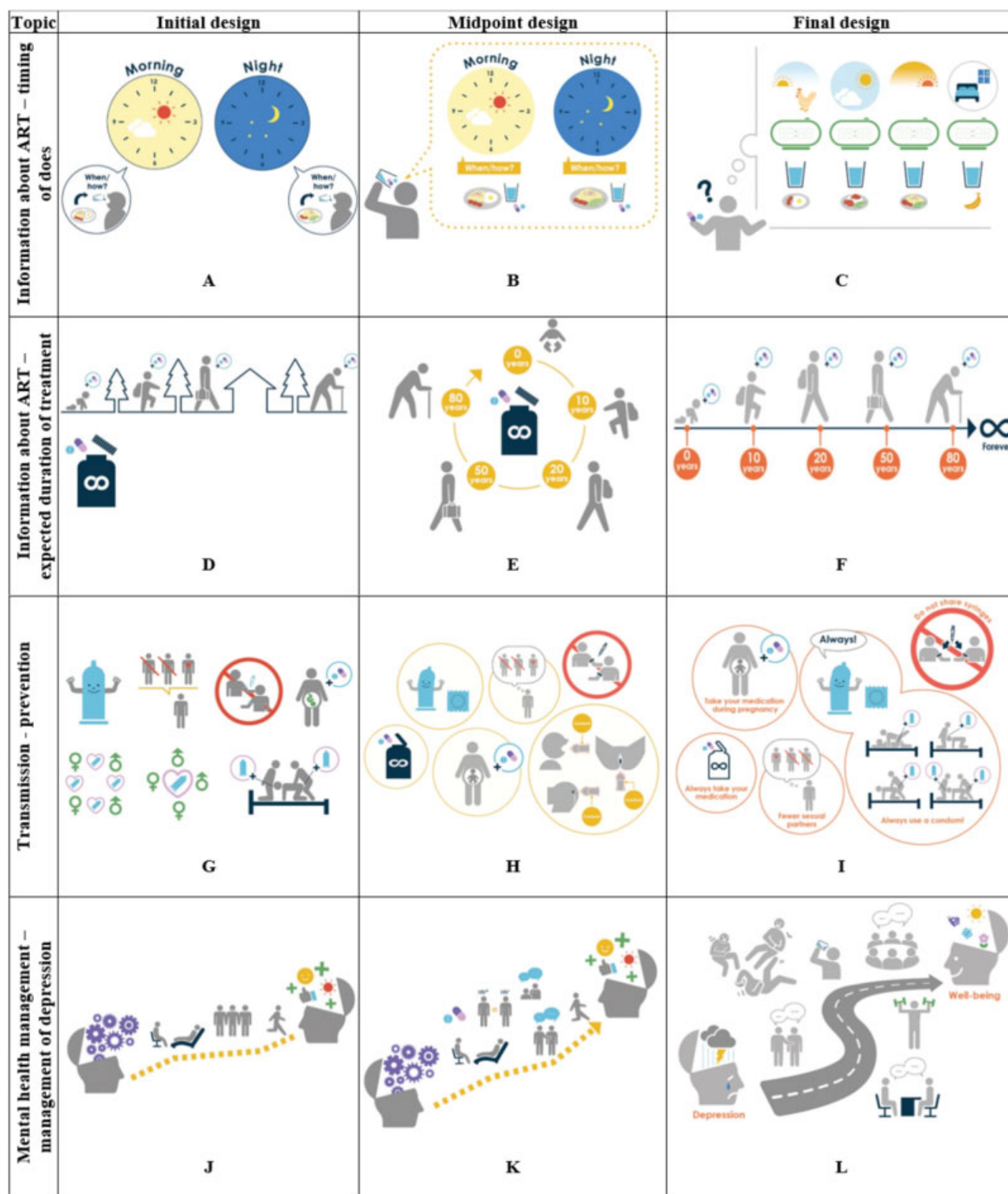
Initially, a lack of understanding of infographics, simply described with comments such as, “I am not sure what that means,” was demonstrated. However, despite obvious confusion, it was difficult for many patients to provide concrete design suggestions to improve clarity. Patients only provided comments/suggestions that were more meaningful than, “I like it” or “I don’t like it” when specific questions were asked. For instance, “do you prefer methods to prevent transmission to be shown as **→Fig 1H** or **I?**” or “what does this symbol [the road in **→Fig 1L**] mean to you?” or “what are the colors in **→Fig 1R**, saying about CD4 count?” A few designs did immediately “work” for participants and required little revision; for example, one participant easily interpreted **→Fig. 3** as “these [the two sides representing life with, and without, HIV] are equal, it is a normal life.” Patients responded the most positively to images that were straightforward and contained less information from which they had to extrapolate meaning.

In middle design sessions, despite having not previously seen infographics, participants demonstrated more comfort with designs and provided useful comments. For example, some participants identified elements that were missing from designs. One patient said the time they take their medication (after dinner before bed), which was not an option on the infographic being discussed (**→Fig. 1B**). Patient participants consistently demonstrated very literal interpretations of images; for example, on an infographic to show ideas to promote adherence, one said, “the purse does not work, because, for example, I use a backpack to go to work.” Another participant cautioned against too many details

because with “too many details, you can lose meaning.” It was also recommended to add words and/or descriptions to infographics. As one participant commented, “it would be good to clarify with words,” and another, “label the top of the image, ‘If you want to be healthy, act like this. And, if you want to be unhealthy, act like this.’” Another participant contributed that labels should be large, “you read [labels] in

big letters and if someone can’t read, they can look at the pictures.”

In final sessions, participants predominantly confirmed interpretations of infographics rather than suggesting refinements. For example, one participant interpreted a revised figure of a very ill person as, “this person is very sick because they have a lot of spots on their body”



**Fig. 1** Evolution of a selection of infographic designs from each of the priority health education topics over the course of the participatory design sessions.

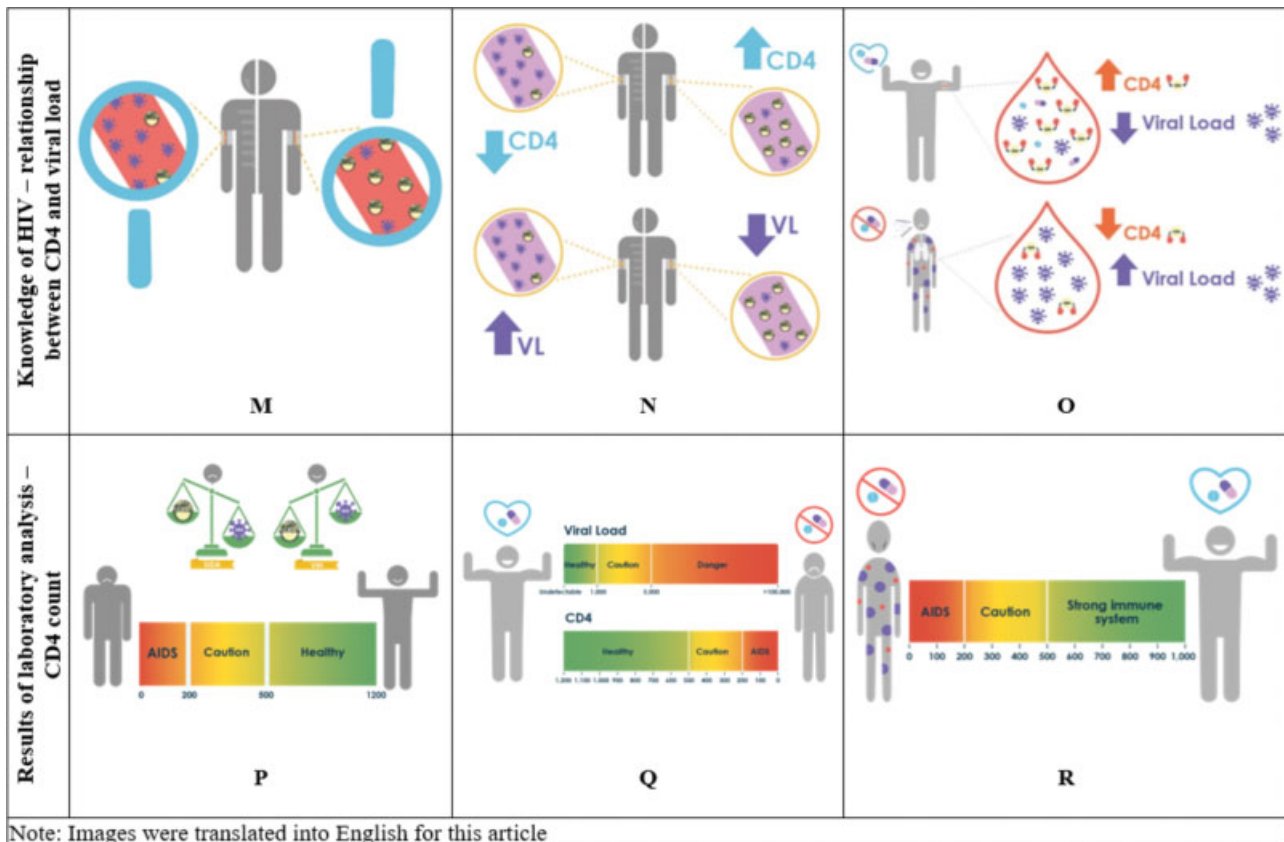


Fig. 1 (Continued)

(→ Fig. 2D). Or another commented on the infographic for the expected duration of treatment, “really, I understand the idea that this [ART] is forever” (→ Fig. 1F).

Throughout sessions, patients confirmed this project is useful to enhance learning. As one participant said, “yes [infographics will be useful], because there are some people who are a little complicated, you have to explain to them, explain to them, explain to them, explain to them. With an image, it makes learning easier and makes it easier for the patient.” Another participant stated, “It [this project] has a beautiful message, it will make the people who have HIV and AIDS understand. It should come out in the newspaper.”

#### Phase IV—Additional Feedback from Experts

Experts independently confirmed designs were interpretable, actionable, and ready for feasibility testing. Final recommendations included simplifying one infographic for clarity and checking the grammar in image labels.

#### Phase V—Additional Feedback from Providers

Six providers (two left CFLR before the study ended) confirmed interpretability of designs and showed interest in using them during clinic visits. Final recommendations included tweaking details such as adding a small pill bottle, changing colors, or the wording of labels.

#### Differences in Patient, Provider, and Expert Responses

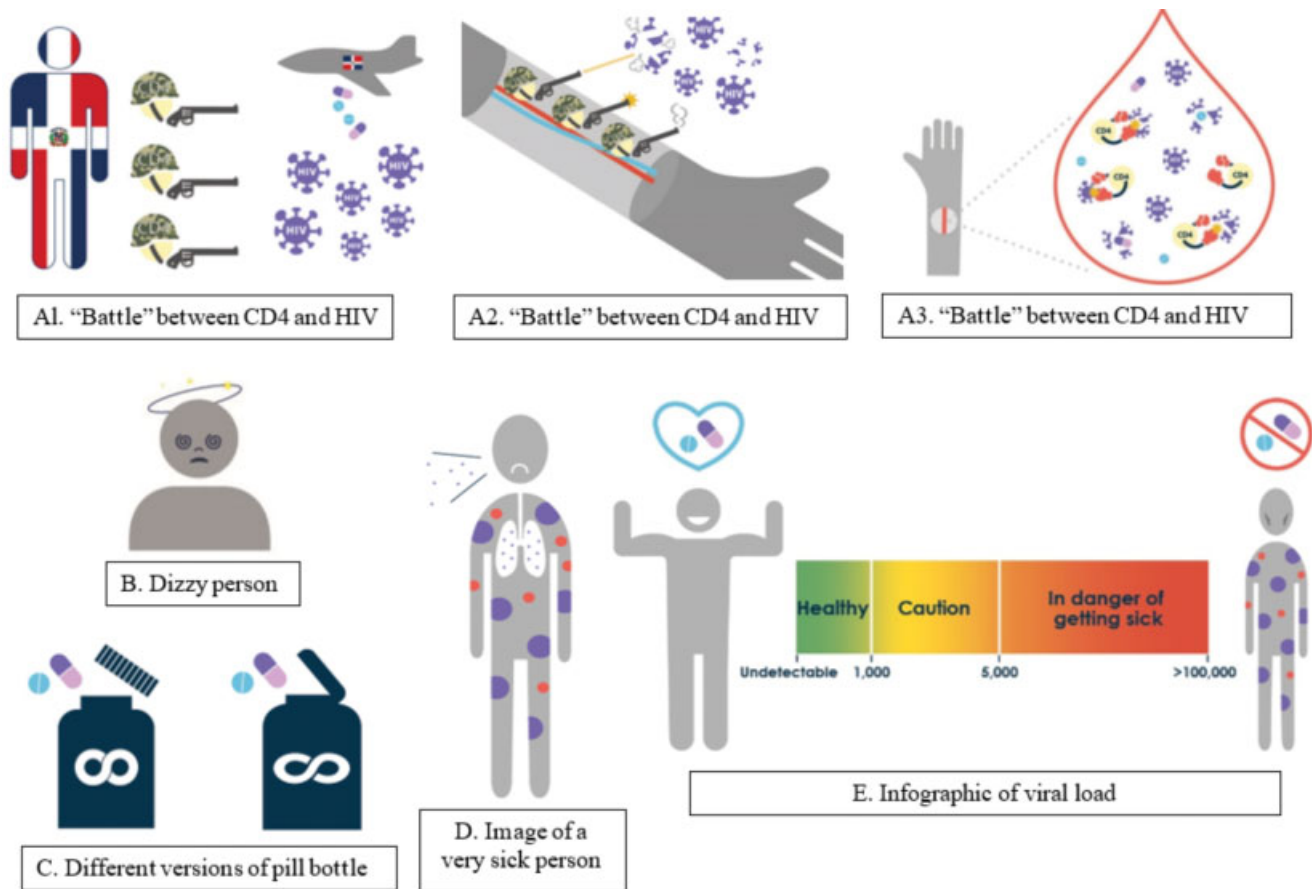
In general, patient participants had a difficult time providing concrete design suggestions. Across sessions, patients consis-

tently indicated what they really want to see in infographics is what precisely they need to do to maintain health and not transmit the virus to others. Providers were much more apt to make suggestions to generate, and refine, infographics. Their comments consistently reflected the analogies and ideas they had frequently shared with patients during clinic visits. Experts were more practiced at the exercise of providing recommendations to improve infographics, especially regarding image interpretation and technical details.

Over the course of the study, there were discrepancies in recommendations received from each participant group. For example, patients and providers preferred brighter colors and images containing more activity than experts. Additionally, the level of detail participants were comfortable with in regard to the presentation of sexual acts varied. One expert indicated participants in a previous study had not shied away from graphic images (→ Fig. 1H), whereas both providers and patients preferred more conservative depictions of condom use (→ Fig. 1I).

#### Use of Color

Color was discussed throughout design phases by all participants. As one expert said, “the color is the most important thing...what is clueing me in is the color in the icons.” Providers and experts agreed that the figures used throughout infographics to represent people should not fall in the range of natural skin tones to ensure designs were as neutral and all-inclusive as possible. There was agreement across all participant groups on the stoplight color analogy where



**Fig. 2** Selection of infographic components modified during design session.

green represented a healthy CD4 count or viral load, yellow represented cautionary levels, and red indicated a dangerous CD4 count or viral load (→ Fig. 2E).

### Final Designs

Fifteen infographics were established, with between two and four for each of the priority information topics. Final print-outs of infographics are printed in color and laminated so health care providers can use erasable markers to clarify meaning during use.

### Discussion

We sought to develop contextually relevant infographics to improve HIV-related patient-provider communication in a limited-resource setting using an adapted participatory design methodology. Collaborating with patients, providers, and experts in design sessions enabled us to combine a unique set of viewpoints to generate comprehensive infographics. The combination of varying opinions did, however, provided a distinct set of challenges. Providers and experts were able to discuss different shapes, forms, and representations of ideas during sessions but it was difficult for patients to do the same. This could be because of a lack of experience completing similar tasks, uncertainty regarding the potential appearance or clinical use of infographics, or because limited education can lead to difficulty thinking

abstractly.<sup>64</sup> Another practical concern of having numerous participant types was making design choices when there were conflicting suggestions. In these instances, priority was given to patient's feedback, as they are the ones who must eventually understand and use the information presented. Therefore, if in the final design sessions (after the patient sessions were completed) an expert or provider suggested a refinement that contradicted a previously indicated patient preference, we simply did not make that change. Similarly, if there were discrepancies between providers' and experts' suggestions, we deferred to the providers' preferences, as they are the experts in their clinical context and are the ones who will need to effectively use infographics as clinical tools.

Feedback received during design sessions can provide valuable guidance to clinicians, researchers, and other professionals designing infographics for similar populations or in comparable settings. First, similar to others developing visual aids or other patient-facing materials through iterative design with multiple stakeholders,<sup>35,52</sup> we found the inclusion of numerous stakeholders to be critical to generate images, despite the challenges this presented. Where our patient participants were unable to provide enough concrete details to generate images, they were able to communicate the parts of infographics that were meaningful to them. From there, providers and experts were able to blend previous experience with patient feedback to inform what all participant groups deemed usable infographics.



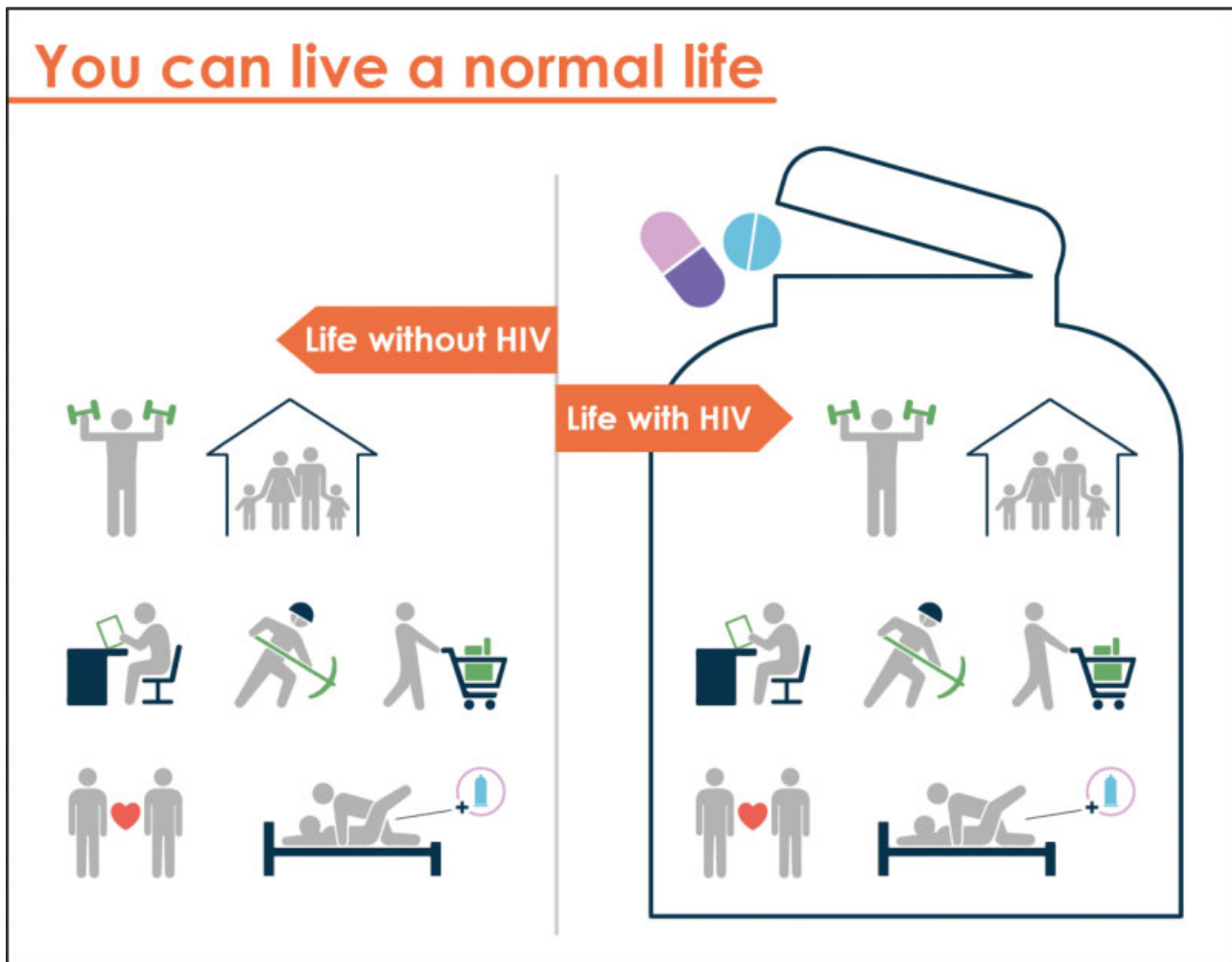


Fig. 3 Example infographic translated from Spanish to English.

This work adds to the literature by providing many specific design recommendations. First, combining large, easily legible, and straightforward text with imagery is a preferred method for presenting information. This is consistent with other studies that indicate combining words with images improves comprehension<sup>47,56,65</sup> and is important to note, as those working to design infographics for those with LHL tend to limit, or eliminate, text from designs. Our participants also preferred bright colors and clearly recognizable symbols. This may vary depending on the cultural group of target end users and again emphasizes the importance of participatory design with intended participants. Then, similar to studies conducted by Arcia et al and Medhi et al, we found patient participants demonstrated literal interpretations of images.<sup>35,66</sup> This indicates that it is crucial to consider all possible interpretations of images during the design process. Additionally, Arcia et al concluded if there is not enough information in infographics to provide context and facilitate comprehension, even if designs are literacy appropriate, images will not be useful to intended participants.<sup>35</sup> We agree that sufficient content must be included for infographics to be effective, but similar to another study with participants with LHL,<sup>67</sup> our participants cautioned against too much detail; thus, balancing between providing

sufficient information to enable comprehension, but not so much as to overwhelm users, will be an ongoing design challenge.

This work further adds to the literature by presenting a participatory design methodology that can be used to develop infographics in limited-resource settings. An additional contribution is that our infographics focus on improving clinical communication, and therefore are designed for two simultaneous end users (patients and providers), whereas other visualization work tends to focus on one end user to improve their risk comprehension,<sup>37,43,68,69</sup> comprehension of other topics,<sup>47,70</sup> readability of patient materials,<sup>65,71</sup> design of interactive materials or interfaces,<sup>66</sup> patient education materials such as brochures or leaflets,<sup>47,72</sup> or to provide information tailored to individual patients.<sup>73</sup> Establishing methods to develop infographics and other tools to enhance patient education that can be used in various settings globally, with multiple end users, can help health care providers and organizations overcome the challenges they face in providing relevant information to patients.

Because the infographics in this study are meant to facilitate communication, distinct design and evaluation challenges emerged. For instance, it was difficult to determine content

and designs relevant to both parties in a clinical dyad (patient and provider) with little common ground. We overcame this challenge by asking providers to establish preliminary content and then having patients further refine it. Other methods to incorporate varying opinions merit further exploration. Regarding the evaluation of these infographics, their purpose was to improve patient-provider communication, not to improve comprehension as an isolated construct. Additionally, their effectiveness depends on how they are presented to patients. Thus, we did not quantitatively assess patients' comprehension of presented ideas. However, a formal evaluation is still necessary, as preferred images may not enhance understanding.<sup>35,63</sup> The next step in this research is to determine the best way to use infographics during clinic visits and establish if their use can improve communication, patient comprehension, and, subsequently, patient outcomes.

This study had numerous limitations. To mitigate the effects of potential social desirability bias,<sup>74,75</sup> we attempted to create a comfortable and private setting,<sup>74</sup> ensured confidentiality,<sup>75,76</sup> and used indirect questioning techniques.<sup>77</sup> Regardless, participants may have overstated agreement with interpretability and actionability of designs.<sup>74-77</sup> The group setting may also have led to social bias where those who consider themselves of a lower status may defer to an outspoken thought leader.<sup>35,78</sup> Or, in this case, participants who may not have been able to read could have gathered answers and explanations from those reading titles and labels aloud. To minimize the effect of this bias in each design session, opinions were solicited from each participant and all participants were asked to articulate reasoning for their comments. Additionally, because of the gender composition of professions where both the experts and providers were recruited, these two groups lacked gender diversity. Future work in this area would benefit from a more diverse participant sample.

## Conclusion

Using a participatory design methodology, we generated a set of infographics confirmed by patients, health care providers, and domain experts to represent previously established priority health education topics in a limited-resource clinical setting. Varied perspectives from participant groups facilitated the evolution of designs over time, which led to increased interpretability, as confirmed by participants. Regardless of patients' affinity for designs, these infographics are meant to facilitate patient-provider communication, so how they are presented in a clinical setting will play a large role in their clinical utility.

## Clinical Relevance Statement

Clinicians and other professionals working to create infographics in limited-resource settings can use this methodology to generate designs that are culturally relevant and clinically meaningful to target end users. Additionally, our participants' feedback and resulting design recommendations can be used to further inform the creation of meaningful, patient-facing materials.

## Multiple Choice Questions

1. What are the potential benefits of using well-designed infographics during patient education? (Select all that apply)
  - a. Present information in a culturally appropriate way.
  - b. Provide meaningful clinical results.
  - c. Minimize comprehension differences between those with high and low health literacy.
  - d. Improve patient-provider communication.

**Correct Answer:** The correct options are a, c, and d. Well-designed infographics contain a breadth and depth of information presented in simple, visually appealing formats. Previous studies show infographics can improve health communication and improve patient-provider engagement. Additionally, having visual aids can augment health education when culture or language differences are present by presenting familiar images that are meaningful to patients. This can improve understanding among diverse end users, which can minimize comprehension differences between those with high and limited health literacy (see the "Background and Significance" section).

2. When designing infographics for end users with low health literacy, adhering to which of the following suggestions will improve acceptability of final designs? (Select all that apply)
  - a. Minimize the use of text.
  - b. Select large, bold fonts.
  - c. Use a monochromatic color scheme.
  - d. Include multiple end users in design process.

**Correct Answer:** The correct options are b and d. Participants in ours, and other, studies (see the "Discussion" section) preferred images that had enough text to help orient them to images and emphasized that any included text must be in large, legible fonts that are either bold or in bright colors. Our evidence-based design process indicated including multiple stakeholders increased interpretability and acceptability of final designs. This was particularly evident in the responses received from each of our three participant groups during design sessions, as each group focused on different aspects of images and subsequently recommended a wide variety of changes to enhance designs.

### Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects. It was approved by the Institutional Review Board at Columbia University and by "Consejo Nacional de Bioética en Salud" (CONABIOS), the ethical review board in the Dominican Republic. Animal subjects were not included in this project.

### Funding

The first author, S.S., was supported by the National Institute of Nursing Research of the National Institutes of Health under two awards (T32 NR007969 and

K99NR017829). Expert participation in the design process was supported by the Precision in Symptom Self-Management Center at Columbia University (P30NR016587). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

#### Conflict of Interest

None declared.

#### Acknowledgments

We would like to thank Clínica de Familia La Romana for their commitment to this project demonstrated through their willingness to share office spaces, participants' time, and other resources, without which this work would not have been possible. We would also like to thank Fumi Terada, a volunteer of the Japan International Cooperation Agency (JICA) who volunteered countless hours of her time and talent as a graphic designer to develop these infographics.

#### References

- Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med* 2005;61(07):1516–1528
- Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *J Acquir Immune Defic Syndr* 2013;63(03):362–366
- Zolnieriek KB, Dimatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. *Med Care* 2009;47(08):826–834
- Gwam CU, Urquico KB, Etcheson JI, George NE, Higuera Rueda CA, Delanois RE. Use of new interactive patient-provider software improves patient satisfaction and outcomes—a retrospective single-center study. *Arthroplast Today* 2018;5(01):73–77
- Thomas SB, Fine MJ, Ibrahim SA. Health Disparities: The Importance of Culture and Health Communication. Washington, DC: American Public Health Association; 2004
- Thiede M, McIntyre D. Information, communication and equitable access to health care: a conceptual note. *Cad Saude Publica* 2008;24(05):1168–1173
- Parson K, Allen MP, Alvarado-Little W, Rudd R. Health Literacy Insights for Health Crises. 2017. Available at: <https://nam.edu/health-literacy-insights-for-health-crises/>. Accessed November, 2017
- Mackey LM, Doody C, Werner EL, Fullen B. Self-management skills in chronic disease management: what role does health literacy have? *Med Decis Making* 2016;36(06):741–759
- Ancker JS, Send A, Hafeez B, Osorio SN, Abramson E. Health IT usability focus section: adapting EHR-based medication instructions to comply with plain language guidance—a randomized experiment. *Appl Clin Inform* 2017;8(04):1127–1143
- Schiavo R. Health communication in health disparities settings. *J Commun Healthc* 2014;7(02):71–73
- Kreuter MW, McClure SM. The role of culture in health communication. *Annu Rev Public Health* 2004;25:439–455
- Osborn CY, Paasche-Orlow MK, Davis TC, Wolf MS. Health literacy: an overlooked factor in understanding HIV health disparities. *Am J Prev Med* 2007;33(05):374–378
- Lopez-Quintero C, Berry EM, Neumark Y. Limited English proficiency is a barrier to receipt of advice about physical activity and diet among Hispanics with chronic diseases in the United States. *J Am Diet Assoc* 2009;109(10):1769–1774
- Berkman ND, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun* 2010;15(Suppl 2):9–19
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011;155(02):97–107
- Wawrzyniak AJ, Ownby RL, McCoy K, Waldrop-Valverde D. Health literacy: impact on the health of HIV-infected individuals. *Curr HIV/AIDS Rep* 2013;10(04):295–304
- World Bank. Dominican Republic: National Education Profile. 2018. Available at: [https://www.epdc.org/sites/default/files/documents/EPDC\\_NEP\\_2018\\_DominicanRepublic.pdf](https://www.epdc.org/sites/default/files/documents/EPDC_NEP_2018_DominicanRepublic.pdf). Accessed May, 2019
- Programme for International Students Assessment (PISA): Results in Focus. Online: The Organisation for Economic Co-operation and Development (OECD); 2015
- Prevalence of HIV, total (% of population ages 15–49). 2017. Available at: <https://data.worldbank.org/indicator/sh.dyn.aids.zs>. Accessed May, 2019
- Brito MO, Hodge D, Donastorg Y, Khosla S, Lerebours L, Pope Z. Risk behaviours and prevalence of sexually transmitted infections and HIV in a group of Dominican gay men, other men who have sex with men and transgender women. *BMJ Open* 2015;5(04):e007747
- Johnston LG, Vaillant TC, Dolores Y, Vales HM. HIV, hepatitis B/C and syphilis prevalence and risk behaviors among gay, transsexuals and men who have sex with men, Dominican Republic. *Int J STD AIDS* 2013;24(04):313–321
- Budhwani H, Hearld KR, Hasbun J, et al. Transgender female sex workers' HIV knowledge, experienced stigma, and condom use in the Dominican Republic. *PLoS One* 2017;12(11):e0186457
- Castro P, Cameroonortegui F, Nolasco A, et al. Psycho-social and care delivery challenges of HIV/AIDS in the Dominican Republic: impairment of patient outcomes. *J AIDS Clin Res* 2014;5(12):1–6
- Stonbraker S, Smaldone A, Luft H, et al. Associations between health literacy, HIV-related knowledge, and information behavior among persons living with HIV in the Dominican Republic. *Public Health Nurs* 2018;35(03):166–175
- Siricharoen WV. Infographic role in helping communication for promoting health and well-being. Paper presented at: Conference: Proceedings of the Second International Conference on Computer Science, Computer Engineering, and Education Technologies (CSCEET2015). Kuala Lumpur, Malaysia; 2015
- Faisal S, Blandford A, Potts HW. Making sense of personal health information: challenges for information visualization. *Health Informatics J* 2013;19(03):198–217
- Siricharoen WV, Siricharoen N. Infographic utility in accelerating better health communication. *J Mobile Net Applic.* 2018;23(01):57–67
- Scott H, Fawkner S, Oliver C, Murray A. Why healthcare professionals should know a little about infographics. *Br J Sports Med* 2016;50(18):1104–1105
- Krum R. *Cool Infographics: Effective Communication with Data Visualization and Design*. Indianapolis, IN: John Wiley & Sons; 2014
- Siricharoen WV. Infographics: the new communication tools in digital age. Paper presented at: The International Conference on E-Technologies and Business on the Web (EBW2013), Bangkok, Thailand; 2013
- St Amant K. Culture and the contextualization of care: a prototype-based approach to developing health and medical visuals for international audiences. *Commun Design Q Rev* 2015;3(02):38–47
- Kassam R, Vaillancourt LR, Collins JB. Pictographic instructions for medications: do different cultures interpret them accurately? *Int J Pharm Pract* 2004;12(04):199–209
- Bresciani S, Arora P, Kernbach S. Education and Culture Affect Visualization's Effectiveness for Health Communication. Paper presented at: 2018 22nd International Conference Information Visualisation (IV); 2018

- 34 Garcia-Retamero R, Dhimi MK. Pictures speak louder than numbers: on communicating medical risks to immigrants with limited non-native language proficiency. *Health Expect* 2011;14 (Suppl 1):46–57
- 35 Arcia A, Suero-Tejeda N, Bales ME, et al. Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *J Am Med Inform Assoc* 2016;23(01):174–183
- 36 Garcia-Retamero R, Okan Y, Cokely ET. Using visual aids to improve communication of risks about health: a review. *ScientificWorldJournal* 2012;2012:562637
- 37 Garcia-Retamero R, Cokely ET. Communicating health risks with visual aids. *Curr Dir Psychol Sci* 2013;22(05):392–399
- 38 Barros IM, Alcântara TS, Mesquita AR, Santos AC, Paixão FP, Lyra DP Jr. The use of pictograms in the health care: a literature review. *Res Social Adm Pharm* 2014;10(05):704–719
- 39 Kripalani S, Robertson R, Love-Ghaffari MH, et al. Development of an illustrated medication schedule as a low-literacy patient education tool. *Patient Educ Couns* 2007;66(03):368–377
- 40 Ghosh K, Crawford BJ, Pruthi S, et al. Frequency format diagram and probability chart for breast cancer risk communication: a prospective, randomized trial. *BMC Womens Health* 2008;8(01):18
- 41 Kasper J, Roemer A, Pöttgen J, et al. A new graphical format to communicate treatment effects to patients—a web-based randomized controlled trial. *Health Expect* 2017;20(04):797–804
- 42 Izard J, Hartzler A, Avery DI, Shih C, Dalkin BL, Gore JL. User-centered design of quality of life reports for clinical care of patients with prostate cancer. *Surgery* 2014;155(05):789–796
- 43 McCaffery KJ, Dixon A, Hayen A, Jansen J, Smith S, Simpson JM. The influence of graphic display format on the interpretations of quantitative risk information among adults with lower education and literacy: a randomized experimental study. *Med Decis Making* 2012;32(04):532–544
- 44 Hawley ST, Zikmund-Fisher B, Ubel P, Jancovic A, Lucas T, Fagerlin A. The impact of the format of graphical presentation on health-related knowledge and treatment choices. *Patient Educ Couns* 2008;73(03):448–455
- 45 Peters E, Hibbard J, Slovic P, Dieckmann N. Numeracy skill and the communication, comprehension, and use of risk-benefit information. *Health Aff (Millwood)* 2007;26(03):741–748
- 46 van Beusekom MM, Kerkhoven AH, Bos MJW, Guchelaar H-J, van den Broek JM. The extent and effects of patient involvement in pictogram design for written drug information: a short systematic review. *Drug Discov Today* 2018;23(06):1312–1318
- 47 Dowse R, Ramela T, Browne SH. An illustrated leaflet containing antiretroviral information targeted for low-literate readers: development and evaluation. *Patient Educ Couns* 2011;85(03):508–515
- 48 Dowse R, Barford K, Browne SH. Simple, illustrated medicines information improves ARV knowledge and patient self-efficacy in limited literacy South African HIV patients. *AIDS Care* 2014;26 (11):1400–1406
- 49 Arcia A, Bales ME, William Brown MC III. Method for the development of data visualizations for community members with varying levels of health literacy. Paper presented at: AMIA Annual Symposium; 2013
- 50 Montagne M. Pharmaceutical pictograms: a model for development and testing for comprehension and utility. *Res Social Adm Pharm* 2013;9(05):609–620
- 51 Forsell C. Evaluation in information visualization: Heuristic evaluation. Paper presented at: 16th International Conference on Information Visualisation (IV); Montpellier, France; 2012
- 52 Peute LW, Knijnenburg SL, Kremer LC, Jaspers MW. A concise and practical framework for the development and usability evaluation of patient information websites. *Appl Clin Inform* 2015;6(02):383–399
- 53 Smith F, Wallengren C, Öhlén J. Participatory design in education materials in a health care context. *Action Res* 2016;15(03): 310–336
- 54 Sanders EB-N. From user-centered to participatory design approaches. In: Frascara J, ed. *Design and the social sciences*. New York, NY: CRC Press; 2003:18–25
- 55 Skeels MM, Pratt W. Participatory design with health consumers. Paper presented at: AMIA Annual Symposium; 2008
- 56 Houts PS, Doak CC, Doak LG, Loscalzo MJ. The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient Educ Couns* 2006;61(02):173–190
- 57 Allen M, Currie LM, Bakken S, Patel VL, Cimino JJ. Heuristic evaluation of paper-based Web pages: a simplified inspection usability methodology. *J Biomed Inform* 2006;39(04):412–423
- 58 Jaspers MW. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. *Int J Med Inform* 2009;78(05):340–353
- 59 Savoy A, Patel H, Flanagan ME, Weiner M, Russ AL. Systematic heuristic evaluation of computerized consultation order templates: clinicians' and human factors engineers' perspectives. *J Med Syst* 2017;41(08):129
- 60 Mack RL, Nielsen J. *Usability Inspection Methods*. New York, NY: Wiley & Sons; 1994
- 61 Hartzler A, Pratt W. Managing the personal side of health: how patient expertise differs from the expertise of clinicians. *J Med Internet Res* 2011;13(03):e62
- 62 Stonbraker S, Richards S, Halpern M, Bakken S, Schnell R. Priority topics for health education to support HIV self-management in limited-resource settings. *J Nurs Scholarsh* 2019;51(02):168–177
- 63 Ancker JS, Senathirajah Y, Kukafka R, Starren JB. Design features of graphs in health risk communication: a systematic review. *J Am Med Inform Assoc* 2006;13(06):608–618
- 64 Medhi I, Menon RS, Cutrell E, Toyama K. Correlation between limited education and transfer of learning. *Inf Technol Int Dev* 2012;8(02):51–65
- 65 Mansoor LE, Dowse R. Effect of pictograms on readability of patient information materials. *Ann Pharmacother* 2003;37 (7-8):1003–1009
- 66 Medhi I, Sagar A, Toyama K. Text-free user interfaces for illiterate and semi-literate users. Paper presented at: 2006 International Conference on Information and Communication Technologies and Development; 2006
- 67 van Beusekom M, Bos M, Wolterbeek R, Guchelaar H-J, van den Broek J. Patients' preferences for visuals: differences in the preferred level of detail, type of background and type of frame of icons depicting organs between literate and low-literate people. *Patient Educ Couns* 2015;98(02):226–233
- 68 Hess R, Visschers VH, Siegrist M. Risk communication with pictographs: the role of numeracy and graph processing. *Judgm Decis Mak* 2011;6(03):263
- 69 Hakone A, Harrison L, Ottley A, et al. PROACT: iterative design of a patient-centered visualization for effective prostate cancer health risk communication. *IEEE Trans Vis Comput Graph* 2017;23(01): 601–610
- 70 Mansukhani SG. The effect of using pictograms on comprehension of medical information—a meta-analysis. *J Pharm Pharm Sci* 2015; 1(01):22–32
- 71 Mackert M, Guadagno M, Lazard A, et al. Improving gestational weight gain and breastfeeding promotion: visual communication to overcome health literacy barriers. *J Commun Healthc* 2016;9 (02):90–97
- 72 Corcoran N, Ahmad F. The readability and suitability of sexual health promotion leaflets. *Patient Educ Couns* 2016;99(02):284–286
- 73 Arcia A, Velez M, Bakken S. Style guide: an interdisciplinary communication tool to support the process of generating tailored infographics from electronic health data using EnTICE3. *EGEMS (Wash DC)* 2015;3(01):1120–1120
- 74 Nederhof A. Methods of coping with social desirability bias: a review. *Eur J Soc Psychol* 1985;15(03):263–280

- 75 Latkin CA, Mai NVT, Ha TV, et al. Social desirability response bias and other factors that may influence self-reports of substance use and HIV risk behaviors: a qualitative study of drug users in Vietnam. *AIDS Educ Prev* 2016;28(05):417–425
- 76 Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. *J Multidiscip Healthc* 2016;9:211–217
- 77 Fisher R. Social desirability bias and the validity of indirect questioning. *J Consum Res* 1993;20(02):303–315
- 78 Davis J, Zaner M, Farnham S, Marcjan C, McCarthy BP. Wireless brainstorming: Overcoming status effects in small group decisions. Paper presented at: 36th Annual Hawaii International Conference on System Sciences; 2003