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A Mixed Methods Study: Visualizing Identity and Lived Experience in Patient Engagement

Haley Wymbs
University of South Carolina School of Medicine Greenville
Jeffrey Woodward
University of South Carolina School of Medicine Greenville
Amy Neira
University of South Carolina Patient Engagement Studio
Maushmi Patel
University of South Carolina Patient Engagement Studio
Jaime Fivecoat
University of South Carolina Patient Engagement Studio
Katie Parris
University of South Carolina Patient Engagement Studio
Sebrena Brink
University of South Carolina Patient Engagement Studio
Nabil Natafgi
University of South Carolina Patient Engagement Studio
Ginny Cartee
University of South Carolina Patient Engagement Studio
Kenneth Baxter
University of South Carolina Patient Engagement Studio
Ann Blair Kennedy
KENNEDA5@greenvillemed.sc.edu

University of South Carolina School of Medicine Greenville

Research Article

Keywords: patient engagement, patient involvement, word portrait, word cloud, medical research, reflexive, reflexivity, survey, thematic analysis, patient and public involvement (PPI)

Posted Date: February 27th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-8757740/v1

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Additional Declarations: No competing interests reported.

Abstract

Background

Evidence demonstrated that lived experiences and personal identities shape patient contributions when engaging in medical research as a patient partner. However, tools to understand these factors are lacking. This project explores word portraits as a participatory method to capture layered identities and lived experiences of patients, researchers, and collaborators in the University of South Carolina (USC) Patient Engagement Studio (PES).

Methods

An exploratory mixed-methods approach was employed to co-develop and pilot word portraits as a tool for visualizing the layered lived experiences of Patient Experts and other PES stakeholders. Respondents opted in by completing a researcher-developed survey where they identified self-descriptive words and assigned importance weights to demographic categories. These responses were used to generate individualized and group-level word portraits, with reflexivity practiced throughout the process. Thematic analysis was performed.

Results

Of the individual word portraits, 45 were generated, 10 requested revisions, 5 were revised over Zoom, and 5 were revised through email. Several participants sought clarification on the context and application of the individual portraits. Several participants noted their portrait would likely change depending on their role, subject matter, stage of research process, or additional change in context. Importance weights assigned to demographic descriptors were commonly, though not always, reflective of minority status. The health conditions, disabilities, or chronic conditions most impacting respondents or someone they care for, as determined by average importance weight, were long COVID (95), deconditioning (80.0), and neurodevelopmental disorder (72.7). The group favored the group word portrait that preserved the exact phrases provided by the participants and represented category frequency by word size.

Conclusions

Importance weights are a viable means for generating an individual word portrait, while word size representative of category frequency worked best for the group word portrait. It was determined by both the research team and the participants that layered lived experience word portraits are a viable means for engagement in participatory research. By promoting identity-centered reflection and representation, the word portrait method advances the science and practice of inclusive, reflexive patient engagement by recognizing intersectional contexts, diverse identities, and lived experiences from an individual as well as a group perspective.

Trial registration

not applicable

PLAIN ENGLISH SUMMARY

This project explored a new way to help people share the parts of their identity and life experiences that shape how they show up when engaging with research teams. Traditional demographic forms often reduce people to checkboxes, which can overlook the complexity of their lived experiences. To address this, the University of South Carolina (USC) Patient Engagement Studio (PES) worked with patient partners to create “Layered Lived Experience” (LLE) word portraits, which are visual displays of self-chosen identity terms rated by importance.

Participants completed a survey where they assigned importance weights to roles, identities, health conditions, and experiences that influence how they engage in research. These responses were used to generate individual and group word portraits. Participants then reviewed and refined their portraits, both individually and as a group, to ensure they accurately reflected how they see themselves. After reviewing two versions of the group word portrait, participants preferred the version that preserved full phrases and most accurately represented diversity of experience.

Participants reported that creating and discussing word portraits helped them self-reflect and better understand one another. The portraits revealed meaningful differences in life experiences regardless of demographic similarity, demonstrating that intersectionality matters in engagement work. The study concluded that LLE word portraits are a feasible, meaningful tool for participatory research that helps to humanize patient partners, encourage reflexivity, and provide researchers with a richer understanding of who is contributing to their work. Future efforts may expand the tool and explore its impact on research engagement and retention.

BACKGROUND

The role of Intersectionality and Layered Lived Experiences in Engagement Science

Researchers who seek the services of the University of South Carolina (USC) Patient Engagement Studio (PES) [RRID: SCR_026046] may focus more so on the identifying characteristic or experience of their study without considering the complexity of these individuals and their experiences.(1) While demographics such as race, gender, education level health conditions, and past or present socioeconomic status (SES) may be important aspects of identity for research participants, research teams generally do not gather demographic data on their own team. Understanding that personal demographics can impact a patient partner’s point of view, the intersectionality and layers of these data, including past experiences, are equally impactful in determining the point of view of Patient Experts.

Intersectionality provides a lens for understanding how multiple social identities (such as race, sex, gender, socioeconomic status, etc.) overlap to shape an individual’s lived experience.(2,3) Scholars argue that an intersectional approach can illuminate heterogeneity within broad categories (for example, recognizing that “women” or “patients” are not monolithic groups) and link individual experiences with broader social determinants.(3) A person’s experience influenced by these identities may be thought of as a layered experience that ultimately produces a unique set of health

challenges and needs. For example, a patient with low socioeconomic status utilizing housing in an environmentally unjust area where there is high pollution burden implies one set of healthcare challenges or needs. Another layer to this lived experience may be that the patient is a parent, pregnant, or disabled, further complicating this picture. It is important to note that this intersectional experience is greater than the sum of its parts, meaning that analyses ignoring these overlapping influences will miss how people are uniquely marginalized.(4) Without a framework that acknowledges such intersectional experiences, important aspects of patients' lives remain invisible and their origins misunderstood.(3) Embracing intersectionality is therefore critical in health research to fully grasp the complexity of health inequities and lived experiences.(5,6) By acknowledging and valuing these layered identities, efforts engaging patients in medical research become more inclusive, and the resulting research can better address subgroup-specific needs and disparities.(3,5,7) Ultimately, intersectionality in engagement science helps move beyond one-size-fits-all approaches, encouraging tailored strategies that empower diverse patient partners and improve the relevance of research outcomes for different communities.(3)

Patients as Partners, Not Data Points

Contemporary health research philosophy emphasizes that patients should be treated as partners in the research process rather than as passive subjects or data points.(8–10) Patient engagement is defined as the meaningful, active involvement of people with lived experience (patients, caregivers, families, community members) in all stages of research, from governance and planning to conduct and knowledge translation.(9–13) This collaborative approach recognizes patients as experts in their own experiences, valuing experiential knowledge on par with scientific knowledge.(5,9,10,14) Treating patients as partners has been shown to improve the quality, relevance, and acceptability of research.(8,15–17) Studies report that involving patient partners leads to more patient-centered research questions, improved study design, higher enrollment and retention, and outcomes that better reflect patient priorities.(5,18–20) Equally important, genuine partnership fulfills an ethical imperative: patients have a fundamental right to be involved in research that affects their health and lives.(5,21–23) In such models, patients often serve as advisors or even co-investigators on projects, helping ensure studies address real-world needs and respecting patients as equal stakeholders.(13,22–25) By viewing patients as partners instead of data points, research becomes a joint endeavor; enriching the study with diverse insights and increasing the likelihood that results will be applicable and beneficial to the communities intended.(5,20,21)

Word Portraits as a Creative Tool for Expressing Layered Lived Experiences

Innovative, visual methods are increasingly used in qualitative and participatory health research to help patients articulate their experiences and to enrich data beyond traditional interviews or surveys.(26–29) Photovoice, for example, is a well-established participatory methodology that uses photography and narrative to prioritize the lived experiences and perspectives of patients or community members.(25,30–34) Techniques such as this one have many benefits, namely improving the research team's ability to explore delicate health topics, empowering Patient Experts to share their story as they see fit, integrating reflexivity, encouraging open dialogue, and reflecting community interests and needs in medical research.(25,30,32,35)

Similarly, word clouds are a participatory methodology that has recently gained traction as a creative, patient-centered tool in health research. A word cloud is a visual depiction of text data where word size reflects frequency or emphasis, allowing key themes to stand out at a glance. While simpler than photovoice, word clouds can effectively summarize and communicate what matters most to participants. For instance, a 2023 study demonstrated the use of *"lived experience-centered"* word cloud "portraits" to amplify patient voices in setting research priorities.(36) The inclusion of these personalized word clouds enabled underrepresented stakeholder perspectives to be heard earlier in the process than typical, directly influencing which research questions were deemed important.(36) Visual tools like this serve as powerful equalizers—they communicate patients' experiences in an accessible format and can prompt immediate empathy and insight among research team members. Moreover, creating a word cloud "portrait" can be an affirming experience for patient partners, as it tangibly reflects the lived experiences they have contributed to the project.(36,37) Existing approaches typically center on summarizing topic-specific input or research priorities. There remains an opportunity to explore visual tools that represent the broader constellation of identities, roles, and lived experiences participants contribute to engagement work, not just their views on a particular topic, and to understand such tools may support reflection, relationship building, and context-setting within research partnerships.

The objective of this study was to determine whether or not the process of generating word portraits representative of Patient Experts' layered lived experiences may serve as a process by which to gather, capture, analyze, and display the intersectionality of experiences at the PES to then report to researchers. Ultimately, the goal is to find a way to show these layered lived experiences to show each individuals' complexity when engaging in medical research.

METHODS

Ethics and Oversight

This study was conducted with approval from the University of South Carolina Institutional Review Board (Approval #Pro00145867). All participants provided informed consent electronically before beginning the survey. Participation was voluntary and uncompensated. The project's patient-led, co-creative nature was overseen by the PES leadership to ensure adherence to ethical standards for engagement.

Study Design, Population, and Setting

This descriptive, exploratory mixed-methods study uses participatory approaches to co-develop and pilot a novel tool for visualizing the layered lived experiences of patient partners. The design integrates both quantitative and qualitative data collection, with an emphasis on reflexivity and co-creation throughout. Data collection took place over a one-month period (June 25 to July 28, 2025). For clarity, in this manuscript involvement refers to Patient Experts serving as research partners (co-developers and co-authors), while participation refers to individuals who opted into the pilot survey and/or feedback meetings. Because the PES mailing list includes Patient Experts and non-patient collaborators, researchers, and clinicians, study participants included people in multiple roles. Furthermore, given the importance and impact of patient-centered and inclusive engagement

research, Patient Experts were involved as research partners throughout the life of the project, and three Patient Experts are included as authors on this manuscript (JF, GC, and KB).

Patient and Public Collaboration

The development of this project reflects a multi-year, patient-driven effort to better represent the lived experiences of members of the PES. Patient partners initially collaborated on an earlier survey that relied on preset demographic categories and extensive checkbox lists of health conditions. Although useful for some purposes, that approach was burdensome and did not allow individuals to describe themselves in their own words. Through ongoing conversations, PES members emphasized the need for a more flexible, meaningful, participant-defined way to communicate who they are to the researchers they advise.

Building on this feedback, patient partners co-developed the current LLE approach, including the shift to open-ended self-descriptors, the use of importance-rating sliders, and the workflow for revising individual word portraits. The study also incorporated two patient meetings in which the portraits were presented to participants, including Patient Experts involved as research partners, for feedback. In the first session, participants reviewed their individual portraits and collectively examined the draft group word portrait, providing detailed feedback on clarity, weighting, color use, repetition, and the interpretability of overlapping categories. Their recommendations led to revisions in how the group portrait was constructed and displayed. A second session was held to present the updated version, confirm that changes reflected their input, and refine the approach for future use. Throughout this process, patient partners served as co-developers—shaping study materials, testing procedures, informing revisions, and guiding the evolution of the LLE method.

Data Collection and Survey Instruments

Eligible participants were adults on the PES mailing list who had previously partnered with the Studio. An informational email was sent in advance of the study, followed by a survey invitation sent to all 287 individuals on the list including Patient Experts/partners, and other PES collaborators (e.g. researchers, staff, and clinicians). The email contained a written explanation of the study, a video explaining the study, and the word portrait-generating survey (Supplement 1). Recipients were informed that this study was to be entirely voluntary and uncompensated, and that the survey is able to be completed on a mobile device or a computer. Participants were informed, “This is more than a demographic exercise—this project reflects the PES belief that our community is made up of *people*, not data points. Your voice matters, and we hope you’ll take a few minutes to share your story.”

Willing participants completed this survey using the Qualtrics platform. In this survey (Supplement 2), participants identified identity terms (e.g., roles, communities, personal experiences) and assigned importance weights to better quantify their layered lived experience. Higher values represented a greater weight of importance, and lower values represented a lesser weight of importance (0-100 on a sliding scale). Responses were used to generate individualized and group-level word portraits using WordArt.com’s system. Respondents were also asked to identify two to three colors they would like incorporated into their individual word portrait. The frequency and size of the words utilized in the word portrait were made to be reflective of the respondent-assigned

importance weights. After initial creation, the individual word portraits were emailed back to the respective participants for member-checking and refinement. Participants were invited to review their portrait and provide feedback or request alterations if the visualization did not adequately represent their intended identity profile. The team offered to make revisions either asynchronously (via email feedback) or in real-time through a virtual meeting. This collaborative refinement process ensured that each individual's word portrait authentically reflected their layered lived experiences in their own eyes.

A group word portrait was created to visualize the collective identities, roles, and lived experiences of the PES community. At the end of the survey, participants identified their top three most meaningful descriptors to include in the group portrait. These responses were cleaned and processed; all multi-word phrases were preserved as single units. The first group word portrait was generated using WordArt.com based solely on raw term counts after the text-cleaning process. Frequency of the term in the dataset was used to determine the maximum size of the term represented in the portrait as well as how often the term appeared in decreasing size throughout the portrait. Although technically accurate, participants reported that this frequency-driven display did not feel like an authentic representation of "who we are." They noted that repeated terms became disproportionately large, while important but less commonly used descriptors were minimized. They also shared that the overall visualization flattened the richness of the group's layered experiences. This feedback prompted a reconsideration of the analytic and visualization strategy.

In response to participant feedback, the research team re-analyzed the data using R and introduced a classification system to organize descriptors into six thematic categories reflecting domains of lived experience. These responses were categorized into one of six categories and color-coded as such: (1) Identity & Demographics, (2) Patient Health/Family & Caregiving, (3) Professional Roles, (4) Advocacy & Community, (5) Lived Experience & Life Context, (6) Values & Traits. Using this refined analytic structure, two new group portraits were created in R: 1) Term-frequency weighted version where word size reflected the cleaned frequency of each descriptor, but terms were now placed into categories and color-coded accordingly; 2) Category-weighted version where word size reflected the total number of descriptors within each category rather than the frequency of individual terms, producing a more balanced visualization of the group's collective experiences.

At the conclusion of the word portrait refinement process, respondents were invited to a final group meeting to collectively view and discuss the group word portrait, as well as to share their individual word portraits as a means of reflexivity and as a tool for personal and professional storytelling as it pertains to their layered lived experience. With participant consent, the session was audio-recorded to capture insights related to the visualizations and how participants perceive their identities in relation to research engagement. After the individual portraits were shared, both R-generated group word portraits were presented during a meeting. Participants compared the two versions, discussed clarity and resonance, and evaluated how well each captured the community's layered lived experiences. This group activity was designed to promote reflexivity, deepen mutual understanding among participants, and highlight the richness of layered lived experiences within the PES community. In addition to improving representation, we intentionally used the portrait review and group discussion as a relationship- and capacity-building activity for teams doing

engaged research together, supporting shared language, trust, and role clarity across patient partners and other collaborators.

Data Analysis

This study utilized a mixed-methods analysis approach that combines basic descriptive statistics with qualitative thematic analysis to explore participants' layered lived experiences as represented in individual and group word portraits. Quantitative analysis included using descriptive statistics to summarize frequency and diversity of identity terms, distribution of importance weights assigned to each term, and the number and type of terms selected across different domains (e.g., health conditions, community roles, social identities). This data was visualized in both individual and group word portraits.

Qualitative analysis included thematic analysis of participant feedback collected via open-ended survey responses, feedback sessions, and the final group storytelling session. Themes were identified regarding participants' identity, reflexivity, engagement, and perceptions of the tool's relevance, accuracy, and emotional impact. An iterative and refinable codebook was subsequently developed with input by all members of the research team, including the patient partners. Quantitative and qualitative findings were integrated during the interpretation phase to assess how the word portrait represents the complexity of participants' lived experiences and to evaluate their usefulness as a patient engagement tool. Participant reflections were used to contextualize and validate the quantitative data.

RESULTS

Demographics and Assigned Weight

Survey respondents included Patient Experts and non-patient collaborators, reflecting the composition of the PES mailing list. A total of 45 individuals completed the survey out of the 287 who received the invitation, resulting in a 15.7% response rate. The most common identities and experiences among respondents were Patient Expert (48.6%), woman or female (71.4%), utilization of she/her/hers pronouns (73.7%), straight or heterosexual (81.8%), Generation X or Millennial Generation (61.4%), White, Caucasian, or European (65.9%), denominational and non-denominational Christian (50.0%), variation of left regarding political affiliation (77.1%), married or partnered (70.7%), parent (92.6%), employed (66.7%), middle income during childhood (64.9%) and as a teen (71.4%), and low or middle income as an adult (67.6%). The identities and experiences most shaping the respondents' perspectives in collaboration with the PES, as determined by average importance weight, were PES role, adult SES, gender, and parental status. These results may be found in Table 1.

Highest level of education, insurance status, and government assistance proved to be particularly difficult to quantify due to the free-response nature of the questions and the high degree of variability in specificity of response. Majority of participants said that they have always been insured. Among those who assigned an importance weight to their insurance status, the average weight was 53.4. A few participants explained that they had lapses in coverage in the past, or that they are insured or better insured now with Medicare. Government assistance was one of the

layered lived experiences least responded to, receiving only 19 responses. Most responses detailed what form of government assistance they received, including “VA disability,” “tuition support,” “SSDI,” “Obamacare,” “FEMA,” and “SNAP.” Among those who assigned an importance weight to their government assistance, the average weight was 34.4.

Layered Lived Experiences Free Response

Participants were offered an opportunity to list any health conditions, disabilities, or chronic conditions that impact them or someone they care for. Terms offered by the participants included, but were not limited to, “obesity,” “hypothyroidism,” “substance use disorder,” “chronic kidney disease,” “chronic pain,” “hypertension,” “dementia,” “Long COVID,” and “diabetes.” After collapsing terms, 25 categories were identified. Categories with the greatest frequencies were mental illness (13), dementia or neurocognitive impairment (9), obesity or overweight (7), and other (7). The health conditions, disabilities, or chronic conditions most impacting respondents or someone they care for, as determined by average importance weight, were long COVID (95), deconditioning (80.0), and neurodevelopmental disorder (72.7). These results may be found in Table 2.

Participants were also offered an opportunity to list any additional terms, identities, or experiences that they feel will shape how they approach their collaborations with the PES. Terms offered by the participants were highly variable and included, but were not limited to, “engineer,” “teacher,” “eldest daughter,” “immigrant,” “first-generation college student,” “advocate,” “survivor of ACEs,” and “caregiver.”

Word Portraits

Of the 45 individual word portraits that were generated, ten participants requested revisions: five were revised over Zoom, and five were revised via email. Several participants sought clarification on the context and application of the individual portraits in order to better understand how to revise their word portrait. From this, a common theme was noted that individual word portraits would likely change depending on the role of the individual, subject matter, stage of research process, or additional change in context. Examples of individual portraits from both PES staff members and Patient Experts can be found in Figure 1.

Five participants attended the final group meeting. Each participant shared their own individual word portrait, and discussion followed. The participants noted during this discussion that, even among colleagues who have been involved in the PES and have known each other for a while, they learned things they did not previously know about each other. Examples included background and upbringing, tendency towards introversion vs extroversion, and importance of the selected lived experiences. Participants also noted similarities and trends among individual word portraits, with one of the participants stating, “We’re different, but we’re all alike.”

Once the individual word portraits had been shared and discussed, the group was presented with the two versions of the group word portrait. Both versions can be found in Figure 2, where Version 1 is labeled 2a, and Version 2 is labeled 2b. Both versions of the example project were also provided at this time, and these can be found in Figure 3, where Version 1 is labeled 3a, and Version 2 is

labeled 3b. The group unanimously preferred Version 2, where the exact phrases provided by the participants were preserved and word size was representative of category frequency. This was based on general appearance, preservation of the original phrases provided by the participants, better opportunity to appreciate the diversity of category and lived experience, and accurate representation of the whole group.

In revisiting Version 1 during the meeting, participants clarified that their concerns were not about individual weighting but about how a simple frequency count distorted the group's identity. They emphasized that Version 1 made certain terms appear visually dominant only because multiple people used the same wording, not because those experiences were more central to the group. For example, the phrase "Black woman" appeared large in Version 1 because several participants used this exact phrase, whereas equally meaningful identities contributed by only one person appeared small or were visually overshadowed. Participants noted that this approach minimized important but less frequently shared experiences and failed to reflect the layered nature of the group.

Participants also stressed the importance of preserving whole phrases rather than splitting or substituting them. One member explained that "Black woman" cannot be separated into "Black" and "woman" without losing essential meaning, while another highlighted that labels like "educator" flattened distinct experiences (e.g., a retired schoolteacher versus a higher-education expert).

By contrast, Version 2 (category-weighted) allowed unique descriptors to remain visible while still conveying the prominence of shared experience domains. Participants felt this approach avoided misrepresenting the group by preventing frequently repeated phrases from overshadowing the full range of identities present. The disaster survivorship example reinforced this point: in the Version 1 frequency display, phrases like "retired schoolteacher" became as visually prominent as "disaster survivor" solely because of repetition, whereas Version 2 provided a more balanced and accurate representation of contributors' lived experience.

When asked to share any additional feedback pertaining to the project, the participants noted that they may have answered differently had they received more information about the goal of the project and the generation of the image from their responses. They also noted that they may have answered differently had it been more heavily emphasized that identity weight and perceived importance should be assigned in relationship to the project at hand, not necessarily with regards to what is most important to them in general.

DISCUSSION

This project demonstrates how LLE word portraits can help patient partners, caregivers, members of the research team, and other collaborators express the parts of their identity that shape how they show up in research. It was determined by both the research team and the participants of the study that layered lived experience word portraits are a viable means for engagement in participatory research. Participants described this activity as affirming and sometimes eye-opening, especially when they saw their words displayed together with others. The process supported deeper conversations about identity and lived experience that do not typically happen in research meetings. This aligns with work in patient engagement showing that people participate more fully

when they feel seen as whole individuals rather than reduced to a single role or diagnosis.(38–40) By inviting participants to choose their own words, the method also reflects principles of intersectionality, which emphasize that identities are layered and interconnected rather than isolated into neat categories.(41–43) The methodology that worked for the individual word portraits did not work for the group word portrait, requiring innovative strategy to ensure the word portrait was reflective of the group as a whole.

Given that the prompts asked about layered lived experiences respondents bring when engaging with the PES, it was unsurprising that respondents more heavily weighted their PES role. The prominence of this role is consistent with the literature describing how people in research partnerships, including patient partners and other collaborators, often situate their research role as a part of a broader lived experience rather than as a purely functional identity.(39, 44–48) It was speculated by the research team that those with identities most heavily and historically marginalized in society would assign greater importance weights to these identities. This was true for those who used less conventional pronouns, those who identified as lesbian, gay, or bisexual, older respondents, and Black respondents. However, there were three exceptions that did not follow this pattern. With regards to gender, those identifying as men or males had a slightly higher average importance weight. With regards to religious affiliation, denominational and non-denominational Christian had the highest average importance weight by a significant margin. Lastly, with regards, to SES, those with higher SES throughout childhood, teenage years, and adulthood had the highest average importance weight. It is important to consider, as was aforementioned, that these experiences are layered, and that some identities or experiences may buffer others and mitigate some of the impact. Likewise, some identities in combination may have a greater weight than they would in isolation. This reflects the fundamental concept of intersectionality, where identities are not experienced independently but in relation to each other, producing effects that cannot be captured by single categories alone.(4, 42)

While those who participated in this activity were predominantly composed of White, cisgender, heterosexual women, the word portraits were all very unique, reflecting a variety of layered lived experiences regardless of homogenous demographics. This finding supports calls in patient engagement research to look beyond surface-level demographics and attend instead to the complexity of lived experience, which often contains more diversity than demographic labels alone suggest.(5, 38, 49) This further emphasizes the importance of gaining broader understanding of these participants in medical research and highlights the utility of the word portrait.

This study has several limitations. As an exploratory, descriptive project grounded in participant self-definition, the LLE portraits reflect what individuals chose to share and how they chose to describe themselves. Open-ended responses naturally vary in depth, vocabulary, and level of detail; while this variability can complicate researcher-led categorization, it is central to the purpose of the method and reflects the autonomy of participants' self-presentation. Because identities are dynamic and context dependent, some experiences may not have been disclosed or may not have felt salient to participants in this setting.(50, 51) This aligns with qualitative and participatory approaches in which participants, not researchers, determine what is most important to represent.(52) Additionally, the categorization of terms for the group portrait required researcher interpretation, and different analytic decisions may have generated alternative visual representations. The survey

design allowed participants to skip questions, and the reasons for nonresponse are unknown; however, optionality is an important ethical consideration when inviting people to describe aspects of their identity. Nonresponse in such contexts may reflect comfort level or personal boundaries, both of which are important to respect in identity-centered work. Finally, findings represent a single patient engagement community and may not generalize to other groups without further testing and refinement.

Ultimately, the PES has begun to include group word portraits in research review session reports given the positive impact and feasibility of this project. This practice encourages the adoption of Patient Experts as true collaborators in the research process rather than as demographic data points. This project specifically contributes to a broader shift in research culture by exemplifying how creative methods foster inclusivity.(5) This is consistent with engagement frameworks emphasizing that meaningful involvement depends on recognizing patients as whole individuals whose perspectives are shaped by lived experience, not just their clinical backgrounds.(5, 18, 53, 54) Future inquiry should examine how completion of this activity affects the involvement/retention of participants within the PES and patient-center research. Next steps may also include refining the group word portrait generation process as well as creation of a computer/mobile application for generating word portraits. This aligns with recent calls to integrate engagement tools into routine research workflows, making activities like reflexivity, identity mapping, and relationship building more assessable and scalable.(7, 37, 39, 55) This would allow a greater number of individuals to engage in the reflexive practice of making their own word portrait.

CONCLUSIONS

In summary, the LLE word portrait technique enriches the discussion section of participatory research by providing a concrete example of how intersectional, patient-centered engagement can be achieved in practice. It not only produces insightful visual data, but also actively contributes to building equitable partnerships through the process of its creation. By grounding our discussion in established literature – from intersectionality theory and inclusive engagement frameworks to recent innovations in patient-experience visualization – we have situated LLE word portraits within the evolving landscape of health research engagement.(7, 37, 39) We have also reframed the method’s limitations as reflections of human complexity, arguing that these are in fact integral to its strength as a qualitative tool. Looking ahead, continued refinement, technological enhancement, and application of LLE word portraits in various settings can further demonstrate their utility. As a participatory engagement and team-building tool, LLE word portraits help bridge the gap between diverse lived experiences and the research enterprise, ensuring that all voices are seen, heard, and valued in the journey towards better health outcomes.

Abbreviations

LLE = Layered Lived Experience

PES = Patient Engagement Studio

SES = socioeconomic status

USC = University of South Carolina

Declarations

ETHICAL APPROVAL AND CONSET TO PARTICIPATE

This study is IRB was approved by the University of South Carolina Institutional Review Board (Approval #Pro00145867). Clinical trial number: not applicable.

CONSENT FOR PUBLICATION

Consent for publication of the individual word portraits included in this manuscript was obtained, and the appropriate consent forms were obtained prior to submission.

AVAILABILITY OF DATA AND MATERIALS

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

COMPETING INTERESTS

The authors declare that they have no competing interests.

FUNDING

The authors have no funding to report.

AUTHORS' CONTRIBUTIONS

HW contributed to the analysis and interpretation of data and also drafted and substantially revised the work. JW contributed to the conception and design of the work, the acquisition, analysis, and interpretation of data, and also drafted and substantially revised the work. GC contributed to the design of the work, provided critical insight, and revised the manuscript. JEF and KB contributed to the design of the work and provided critical insight. AN, MP, KP, SB contributed to the design of the work and substantially revised the manuscript. ABK contributed to the conception and design of the work, acquisition and interpretation of data, created the code, and substantially revised the work. All authors have approved the submitted version and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the wonderful and passionate members of the Patient Engagement Studio for their monumental contribution in sharing their stories and layered lived experiences with researchers in order to both improve the quality of the research executed and ensure the results are informed and applicable to/for their shared communities.

AUTHORS' INFORMATION (OPTIONAL)

Not applicable.

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Tables

TABLE 1: Demographics and Associated Importance Weights

Demographic	Average Assigned Weight (n, range)
Main PES Role	**73.6** (37, 3-100)
Patient Expert	83.4 (18, 30-100)
Clinician	57 (5, 3-90)
PES Staff	59.4 (5, 30-95)
Other	71.1 (9, 20-90)
Gender	**64.5** (42, 2-100)
Man or Male	65.4 (11, 20-100)
Woman or Female	64.6 (30, 2-100)
Other	57.5 (2)
Pronouns	**50.6** (38, 1-100)
He/Him/His	57.8 (8, 1-100)
She/Her/Hers	47.6 (28, 2-99)
Other	63.0 (2)
Sexual Orientation	**45.2** (33, 1-100)
Straight or Heterosexual	41.3 (27, 1-100)
Gay, Lesbian, or Bisexual	62.7 (6, 25-100)
Age	**58.2** (44, 13-100)
Silent Generation & Baby Boom Generation (1928-1964, i.e. 61-97 years old)	69.3 (12, 31-93)
Generation X & Millennial Generation (1965-1996, i.e. 29-60 years old)	52.6 (27, 13-100)
Generation Z & “Zillennial” (1997-2012, i.e. 13-28 years old)	62.0 (5, 40-100)
Race and Ethnicity	44.8 (44, 1-100)
White, Caucasian, or European	39.6 (29, 10-80)
Black or African American	61.2 (9, 25-96)
Asian or Asian American	40.7 (3, 11-99)
Other	50.3 (3, 1-100)
Religious Affiliation	**49.3** (42, 10-100)
Denominational and Non-Denominational Christian	64.9 (21, 12-100)
Jewish	29.0 (2)

Spiritual	34.0 (7, 14-75)
Agnostic	52.3 (3, 25-90)
Areligious or Atheist	25.5 (2)
Other & 2+ Religions	29.0 (7, 10-63)
Political Affiliation	**50.8** (35, 0-100)
Variation of Left	57.6 (27, 0-100)
Independent or Center	30.5 (6, 0-70)
Variation of Right, Non-Affiliated, or Other	19 (2)
Marital Status	**43.2** (41, (0-100)
Single	48.4 (8, 7-100)
Married or Partnered	42.8 (29, 0-96)
Divorced	10.0 (2)
Widowed	67.5 (2)
Parental Status	**61.1** (27, 10-94)
Parent	63.9 (25, 10-94)
Non-Parent	26.0 (2)
Employment Status	**57.9** (39, 10-100)
Employed	52.2 (26, 10-100)
Retired	62.6 (7, 10-91)
Unemployed, Student, or Disability	76.8 (6, 50-100)
Childhood SES	**54.5** (37, (2-100)
Low Income	58.1 (11, 2-100)
Middle Income	50.7 (24, 10-100)
High Income	80.0 (2)
Teen SES	**55.8** (35, 2-100)
Low Income	69.5 (6, 2-100)
Middle Income	49.9 (25, 11-99)
High Income	71.8 (4, 50-80)
Adult SES	**63.8** (34, 20-100)
Middle or Low Income	58.1 (23, 20-100)
High Income	75.8 (11, 20-99)

TABLE 2: Health Conditions, Disabilities, or Chronic Conditions and Associated Importance Weight

Category	Average Assigned Weight (n, range)
Arthritis	43.8 (5, 10-80)
Autoimmune condition	61.7 (3, 20-100)
Cardiovascular ailment	66.3 (3, 29-100)
Deconditioning	80.0 (2)
Dementia or neurocognitive impairment	66.4 (9, 20-100)
Dermatologic ailment	50.0 (2)
Diabetes	67.5 (4, 20-100)
Gastroenterological ailment	45.5 (2)
Gynecologic ailment	67.5 (2)
Hearing impairment	55.0 (2)
Hypertension	55.2 (6, 11-100)
Long COVID	95.0 (4, 80-100)
Malignancy	48.8 (6, 20-75)
Mental illness	63.2 (13, 35-100)
Musculoskeletal ailment	59.9 (5, 10-90)
Neurodevelopmental disorder	72.7 (6, 50-100)
Neurologic ailment	24.7 (3, 20-34)
Nonspecific neurologic symptom	65.8 (5, 30-90)
Obesity or overweight	54.6 (7, 31-96)
Other	68.4 (7, 30-100)
Pain as a symptom	70.5 (4, 41-81)
Renal or nephrological ailment	35.0 (3, 10-70)
Respiratory ailment	36.8 (5, 13-71)
Thyroid dysfunction	27.8 (4, 10-60)
Urologic ailment	37.0 (2)

Figures

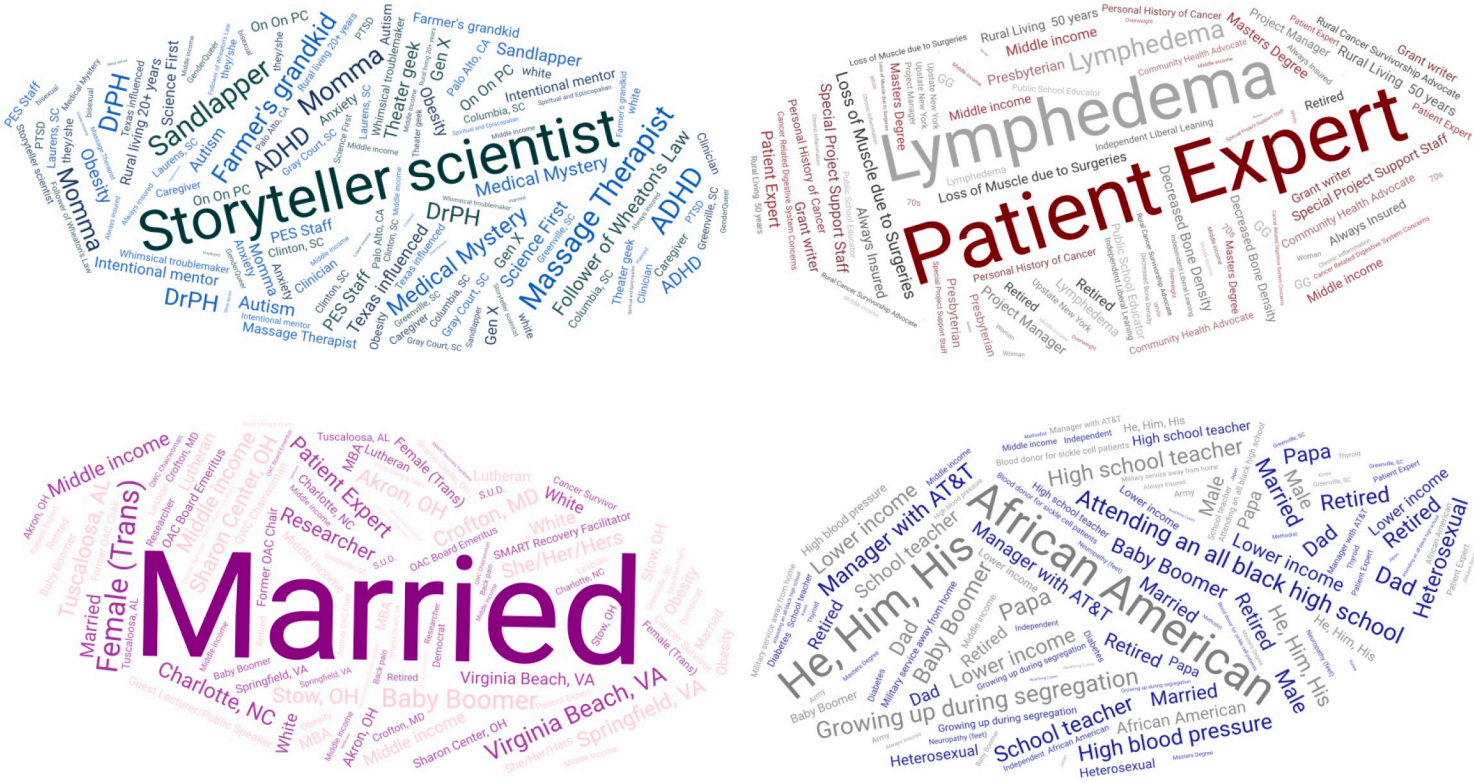


Figure 1

Examples of individual portraits from both PES staff members and Patient Experts.

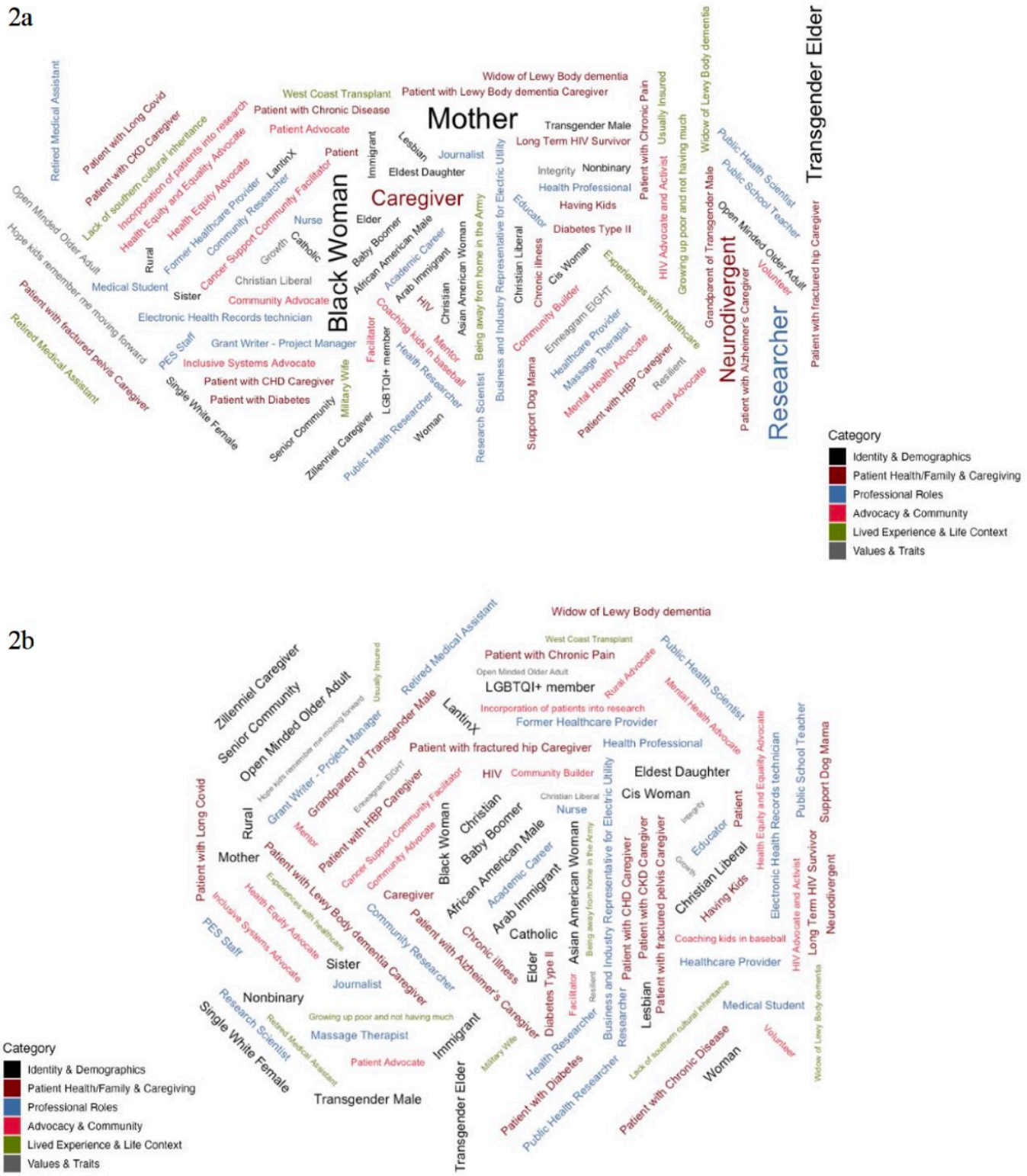


Figure 2

Version 1 (2a), and Version 2 (2b) for the group word portrait.

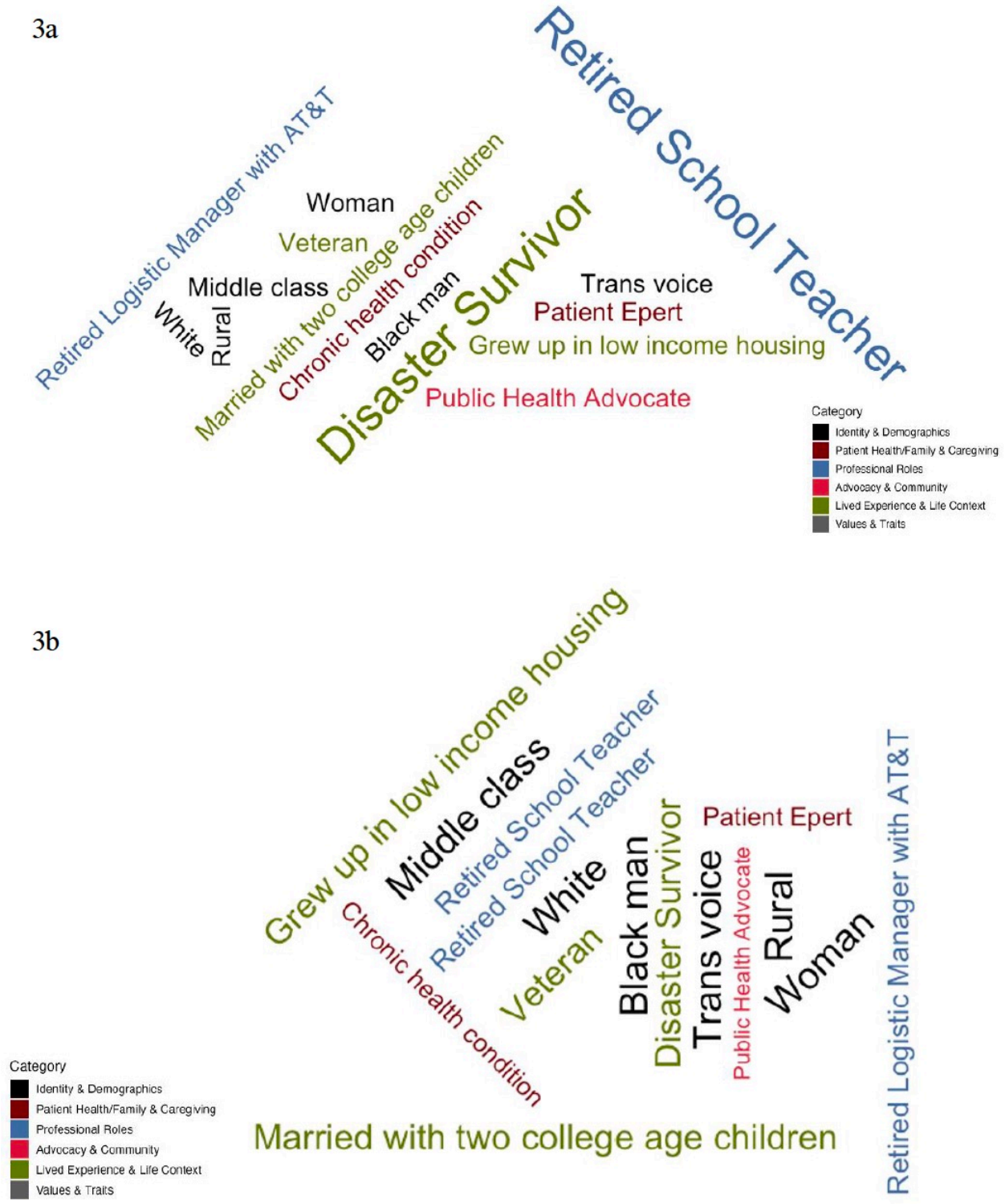


Figure 3

Version 1 (3a), and Version 2 (3b) for the example project group word portrait.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- LLERIE1Supplement.docx
- LLERIE2Supplement.docx