CASE REPORT
Volume 4 (2023), No. 1, pp. 1 – 10
DOI: 10.15367/ch.v4i1.542

The "Our Words Matter" Campaign to Reduce Stigma and Bias in Clinical Communication: A Case Report

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Language choice in clinical communication has become increasingly important and timely given that patients now have access to their full medical record, as required by the 21st Century Cures Act. Students and faculty within Temple University Health System (TUHS) identified stigmatizing language as a significant issue impacting patient care. This case report describes the process of assembling a multidisciplinary team to create an educational campaign with the goal of reducing stigma and bias in the medical record. The campaign team leveraged a grassroots approach, a network of champions, iterative materials development and community engagement to design and implement this initiative within a complex academic health system. Changing language alone will not address all the disparities experienced by marginalized patients and communities but provides an important initial step for clinicians. Campaigns like this one can serve as models for medical and public health professionals who seek to advance health equity.

Keywords: *open notes, stigma, medical training, bias*

Background

With adoption of final rules from the 21st Century Cures Act in April 2021,[1] patients gained access to their full medical record, including notes written by their health care team. This change prompted discussion about language use within Temple University Health System (TUHS) and inspired the creation of the Our Words Matter (OWM) campaign, an educational initiative to decrease stigma and bias in clinical communication. Stigma is the social process of labeling, stereotyping, and rejecting human difference as a form of social control.[2] Language is one way that stigma is operationalized on the individual, interpersonal and structural level.[3] The developers of the OWM campaign recognize that stigmatizing language is often unintentional and can reflect implicit biases that are reinforced in medical practice and education. Language that reflects provider attitudes is common. For example, in a qualitative study of physician documentation, Park et al.[4] described several themes of both negative and positive language found in outpatient clinic notes that reflected clinician attitudes toward patients. The categories of negative language identified in the 600 notes were: questioning patient credibility, disapproval, racial or class stereotyping, references to the difficult patient and unilateral decision making.[4] The language providers use may also impact patient care. Pejorative terms can deter patients from accessing medical treatment,[5] and influence provider judgements. In a 2019 survey study, more than a third of people who use drugs reported that they chose not to seek medical care because of fear of mistreatment due to stigma around drug use.[6] Adverse health outcomes attributable to stigma for other groups, such as gender minorities, have been well documented in prior literature.[3] In a 2010 study,[7] use of the term "substance abuser" in a patient vignette was more likely to be associated with the belief that the patient was personally culpable for their problem. A 2018 vignette study of medical students and residents demonstrated that exposure to stigmatizing language was associated with choosing less aggressive management of the patient's pain in the case of sickle cell disease.[8] Two additional studies demonstrate that patients from historically marginalized groups are more likely to have stigmatizing language in their medical records.[9,10] The first cross-sectional study identified stigmatizing language in 2.5% of all admission notes, with a greater frequency in the notes of non-Hispanic Black patients, those with diabetes, substance use disorder and chronic pain.[9] The second identified negative patient descriptors using machine learning, and showed that Black patients had 2.54 times the odds of having a negative patient descriptor in their notes.[10]

A Grassroots Campaign

The OWM campaign was a grassroots effort originally spurred by student advocacy. In the summer of 2020, medical students at the Lewis Katz School of Medicine reported a disconnect between the language they were taught to use in the classroom and the written and spoken language they observed on clinical rotations in the Temple University Health System (TUHS). TUHS is an urban, academic medical center which serves a structurally vulnerable community in the neighborhoods collectively known as North Philadelphia. Philadelphia has no public hospital system. Temple cares for a population that is almost 70% Black or Latinx, with a 50% Medicaid and 30% Medicare payer mix, and at least 25% of patients are below the federal poverty line.[11] In the clinical skills didactic curriculum, students are taught to use person first language. The goal of person-first language is to humanize the medical record by placing the person before the disease. Instead of referring to a patient as a "diabetic," someone using person-first language would say "a patient with diabetes." However, students on clinical rotations reported this did not consistently happen in clinical practice. Students in the medical school's Addiction Medicine Interest Group (AMIG) were particularly concerned about the language used to describe patients who use drugs, people with whom greater stigma is targeted across medicine and society. When persons who use substances are referred to as addicts or substance abusers, they are more likely to be considered as having a moral failing by the public[12] and the medical field[7] and are less likely to be included in treatment decisions or to be prescribed medications for substance use disorder e.g., buprenorphine.[13] When medical records or experimental vignettes use the phrase 'person with a substance use disorder' or 'person who uses drugs,' the public and clinicians are more likely to treat the condition as a chronic illness for which medication management is accepted[7,12]. The students were unsure how to best advocate for patients in real time, especially considering the hierarchical nature of medicine. Students and faculty together began brainstorming a potential educational campaign to improve the language used in clinical communication at TUHS. While the project initially focused on language about patients who use drugs, it was broadened to address stigmatizing language used to describe other marginalized populations and disease conditions where stigma is prevalent (e.g., obesity, diabetes, mental illness).[14,15,16]

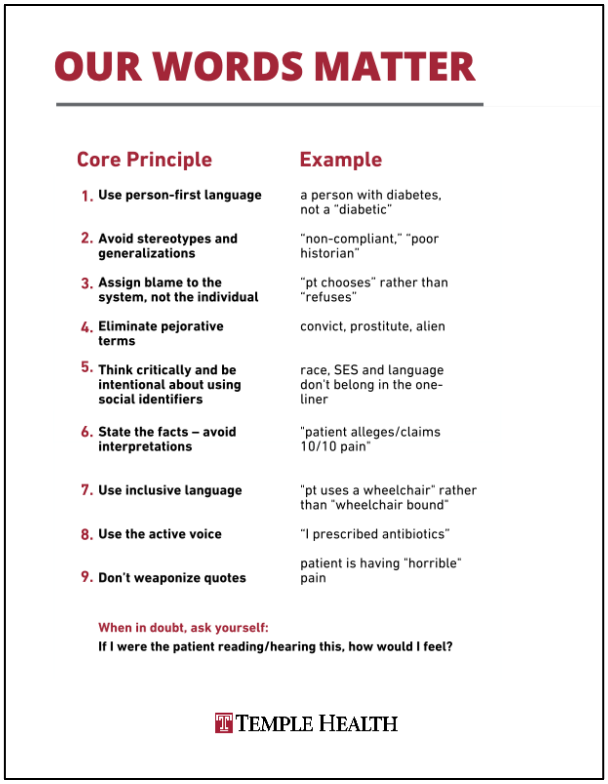
Stakeholder Identification

Changing the patterns of clinical communication in a large academic health system requires input from a broad coalition of both clinical and non-clinical personnel. The initial campaign team, which convened in the summer of 2020, consisted of medical students and physician faculty across multiple specialties. Non-clinical faculty from the school's Center for Urban Bioethics were brought into the project over the next few months due to their previous success with a similar project centered on improving the experience for LGBTQ+ patients in the health system. The initial stakeholder group also included a representative from marketing who was interested in incorporating best practices for patient-centered language in advertising and communication. Representatives from nursing were also included, as well as content experts with addiction medicine and public health experience. Members of the Patient Experience Office, who interface regularly with patients and families, were consulted throughout the development of the initiative. Ultimately, a core group of three students, three physicians, one nurse, two non-clinical faculty and one hospital administrator were identified. A flat leadership structure was employed. One physician organized the meetings, but the agenda and decision making were driven by group consensus. The group met biweekly and completed a needs assessment, by requesting ad hoc qualitative feedback and taking detailed notes over a series of four virtual meetings about the patterns of perceived stigmatizing language across a diverse array of healthcare settings, including medical and surgical, inpatient and outpatient, written and spoken language. The group categorized the feedback into broader themes, such as pejorative terms and patient labeling, to organize the input. The group also sought community member input during live presentations multiple times during the year and a half long planning effort.

Strategy for Institutional Culture Change

The core campaign team had several initial meetings to explore the most effective strategy for creating institutional culture change. Given the multidisciplinary approach, the project did not fall under the supervision of one office or committee within the health system or medical school. Executive champions advised that the campaign team should first compile sample educational materials and bring those to hospital leadership for approval.

To begin this process, the medical students and faculty on the campaign team completed a review of the academic literature regarding stigmatizing language. The team also searched the gray literature using conventional internet search engines to identify recommendations across diverse sources, including other institutional campaigns, patient advocacy resources and public health agencies. For example, Boston Medical Center created a pledge campaign to improve language used in clinical communication.[17] Michigan's state health department enacted a campaign called "End the Stigma."[18] Many of the recommendations came from addiction-related sources, but other disease and population specific guides were also identified (e.g., obesity, diabetes, cancer).[19, 20, 21] The team also compiled language recommendations specific to historically marginalized groups, such as LGBTQ+ patients and patients with disabilities. Common themes were extracted, and guidance was distilled into core principles for clinical care at TUHS based upon group consensus over a series of six meetings. This literature search led to an initial draft of Core Principles (see Figure 1).



OUR WORDS MATTER

Core Principle	Example
1. Use person-first language	a person with diabetes, not a "diabetic"
2. Avoid stereotypes and generalizations	"non-compliant," "poor historian"
3. Assign blame to the system, not the individual	"pt chooses" rather than "refuses"
4. Eliminate pejorative terms	convict, prostitute, alien
5. Think critically and be intentional about using social identifiers	race, SES and language don't belong in the one-liner
6. State the facts – avoid interpretations	"patient alleges/claims 10/10 pain"
7. Use inclusive language	"pt uses a wheelchair" rather than "wheelchair bound"
8. Use the active voice	"I prescribed antibiotics"
9. Don't weaponize quotes	patient is having "horrible" pain

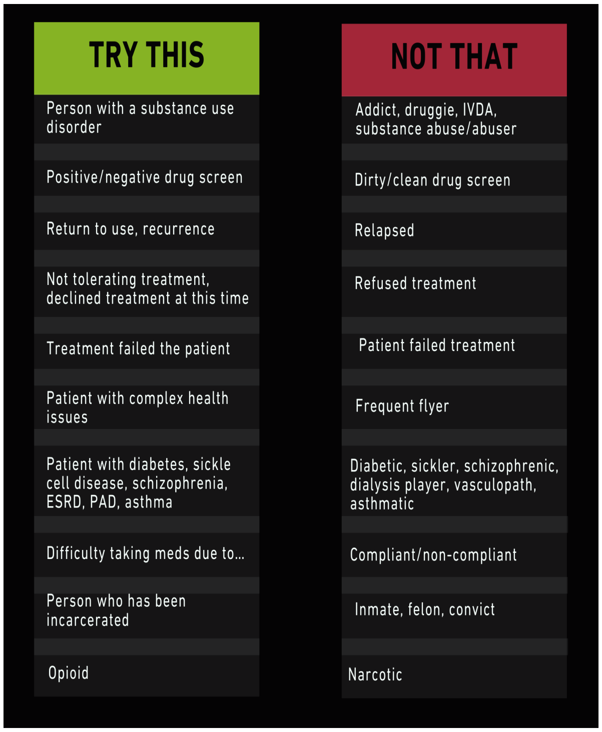
When in doubt, ask yourself:
If I were the patient reading/hearing this, how would I feel?

TEMPLE HEALTH

Figure 1: Core Principles of Our Words Matter Campaign

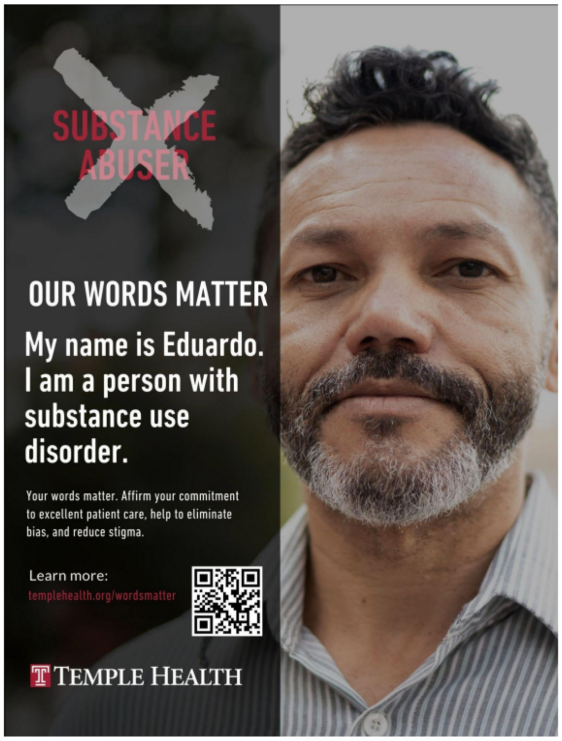
Iterative Materials Development

Next, under guidance of a team member with marketing expertise, sample educational materials were created including the Core Principles document, a Try This/Not That suggested language document (Figure 2), and sample posters to hang in clinical areas (Figure 3). Team members were especially mindful that the posters would be viewed by staff and the public and both perspectives were considered in the materials development phase. It was important for the team to bring sample campaign materials to community members for input early. Temple Physicians, Inc., the main hospital's Patient and Family Advisory Council (PFAC), and members of the North Philadelphia Collective, a grassroots group of community leaders, were consulted early and the materials were updated as a result. For example, community representatives gave feedback on the poster headings, leading to the creation of the campaign title "Our Words Matter," meant to be inclusive of and directed toward both hospital staff and the public.



TRY THIS	NOT THAT
Person with a substance use disorder	Addict, druggie, IVDA, substance abuse/abuser
Positive/negative drug screen	Dirty/clean drug screen
Return to use, recurrence	Relapsed
Not tolerating treatment, declined treatment at this time	Refused treatment
Treatment failed the patient	Patient failed treatment
Patient with complex health issues	Frequent flyer
Patient with diabetes, sickle cell disease, schizophrenia, ESRD, PAD, asthma	Diabetic, sickler, schizophrenic, dialysis player, vasculopath, asthmatic
Difficulty taking meds due to…	Compliant/non-compliant
Person who has been incarcerated	Inmate, felon, convict
Opioid	Narcotic

Figure 2: Suggested Language Document: Try This/Not That



Your words matter. Affirm your commitment to excellent patient care, help to eliminate bias, and reduce stigma.

Figure 2: Sample Poster for Clinical Areas

A summary presentation of the recommendations was created and presented to the following groups over several months from summer 2021 through the winter of 2022: a large meeting of potential physician champions across specialties, faculty members, residents, medical students, and Patient Experience representatives. This occurred over a series of eight different presentations by core team members to more than 100 different staff members of all roles. Presenting the materials to multiple audiences allowed the team to adapt the mode of delivery, tone, and spokesperson to suit the group and venue. The presentations were structured with dedicated time for feedback and discussion. Open-ended written feedback was incorporated in an iterative process to improve the presentations for clarity and consistency. Peer-to-peer educational sessions were most well received, based on ad-hoc feedback. Final versions of both short (15 minute) and longer form (50 minute) presentations were completed by the early spring of 2022. Some sessions were presented in-person, and some were virtual sessions. From June 2021 to July 2022, the team surveyed 113 audience members after educational sessions, of which 75% identified as residents, 16% as faculty and 9% as medical students or other roles. Most participants agreed or strongly agreed that they felt confident in their ability to identify (94%) stigmatizing language and use non-stigmatizing alternatives (92%) after the session. 96% saw value in using non-stigmatizing language. The majority reported being likely to suggest non-stigmatizing alternatives to peers (78%) and superiors (59%) upon hearing the use of stigmatizing language. For example, clearer examples were added to the Core Principles document and wording was simplified. An additional element of the strategy included coordinating with the medical school's diversity and inclusion office and aligning the campaign with a push for inclusive teaching and curricular review. This allowed stakeholders from a broader swath of the organization to be included in early training, and to act as champions for the work, and ensured synergy between faculty members' dual roles as clinicians and educators.

Navigating Pushback

Pushback to the campaign came in three varieties. First, some individuals wanted more evidence that language directly impacts patient outcomes. There is limited literature tying language to clinical outcomes. However, we assert that language reflects our stereotypes and by improving language choice we can challenge our own biases, encourage more compassionate care, improve the patient experience and, ideally, the utilization of healthcare services. The team stressed the inherent value of neutral, respectful, patient centered language, especially given patient access to medical records. This pushback created an important opportunity to educate providers about the importance of the patient experience and patient satisfaction, important standalone goals. Second, some individuals expressed initial resistance to changing their familiar language patterns. The team found that the best way to navigate this concern was by discussing the dynamic nature of many aspects of medical practice that require continuing education, research, and quality improvement. It proved helpful to cite specific examples of language that is no longer used because it reflects a dated and inaccurate understanding of disease, such as "gay related immune deficiency (GRID)," a term used commonly during the initial emergence of the HIV/AIDS epidemic in the US. Finally, some providers expressed frustration with the number and evolving nature of recommendations. This feedback led to the creation of a guiding rule: "If I were a patient reading/hearing this, how would I feel?" The team also stressed that individual providers should use their best judgment and engage in ongoing dialogue with their patients about language choices, when possible. The team also normalized the experience of making errors with language and the value of providing real time feedback to help one another.

Context and Limitations

There are many useful lessons from this campaign for those who want to affect culture change in medicine, however it is also important to consider the context and limitations of our setting. It is especially important to consider the impact of stigma and bias in language for communities that have been historically marginalized, given the recent studies demonstrating the higher likelihood of this language being found in the medical record of patients who are Black, patients with diabetes, and patients with a history of substance use disorder and chronic pain.[9] Bias in clinical communication may be especially important to consider in settings where marginalized patients are less represented, as the impact of language may be compounded. There may also be issues of importance to other marginalized groups that were not adequately captured in our literature search, though we did make efforts to mitigate this by identifying the resources from the gray literature. Ultimately, we believe that the principles of this campaign are applicable across a diverse array of practice settings and benefit all patients.

Language interventions cannot be implemented alone. Structural forces drive health disparities for marginalized patients. However, it is important to account for the lived experience of stigma and bias, and individual/interpersonal interventions like this one can be one piece of a larger strategy to address healthcare inequities. For instance, stigmatizing language is in many ways embedded in our technology. ICD-10 codes include medical terminology such as "substance abuse," despite expert recommendation to use neutral alternatives. Federal governmental agencies that oversee substance use programming have called for an end to this terminology.[22]

Strengths

Temple University has several strengths that were leveraged in the creation of this campaign. The Lewis Katz School of Medicine has a Center for Urban Bioethics (CUB), whose faculty teach and research health equity and social determinants of health. CUB faculty have worked closely with clinical faculty on other initiatives related to community engagement, medical education, and anti-racism. Experts from the Patient Experience Office and College of Public Health were readily accessible given the structure of a university-based health system and were integral to the design and implementation of the campaign. Feedback from community members was another key component of campaign development, which was facilitated through the PFAC and the strong relationship between CUB and community partners, via the North Philadelphia Collective. A multidisciplinary approach and incorporation of iterative feedback were key to the success of the initiative.

Lessons Learned

The timing of the campaign coincided with new legislation requiring patient access to their medical records and helped build momentum and drive buy-in from various stakeholders, including hospital administration. Some helpful lessons could be drawn from studies of healthcare workers who had piloted open notes before the law took effect in the spring of 2021.[23]

Multidisciplinary input was essential to our success. For instance, the title of a campaign focused on language was an important consideration. The decision was the result of feedback from patients and community members, who identified that improving the language of the public was essential and that campaign materials in the clinical areas should be community-facing as well.

Primary concerns of many of the healthcare providers we spoke to were maintaining efficiency in charting and preserving information sharing. As a result, the campaign team focused on creating both overarching principles, as well as practical examples. Creating clear example language decreased perceived burdensomeness of the initiative. The team also sought to stimulate conversation amongst clinicians about best practices in clinical communication, and examples provided a helpful jumping off point for discussion in the education sessions.

A network of early adopters who acted as champions within their own spheres of influence was particularly helpful in spreading the message of the campaign and achieving later buy-in from hospital and medical school leadership. In early presentations to small groups of trainees, the team was able to incorporate iterative feedback, build allyship and create awareness of the campaign. This led to invitations at larger venues, including departmental grand rounds, interdisciplinary committees, and ultimately hospital leadership meetings. Champions were then encouraged by hospital leaders to use the materials to initiate their own small group discussions in natural settings, such as didactics, staff meetings and teaching rounds.

Incorporating evidence from the academic and gray literature strengthened the campaign. Fortunately, there have been several recent quantitative and qualitative publications that describe stigmatizing language in the medical record. The team noted the lack of an overarching guideline for language best practices that extend across specialties and medical conditions. Much of the guidance comes from patient advocacy groups. A subgroup of the OWM team simultaneously worked to fill this gap with the creation of a guide to stigmatizing language for generalists that was published earlier this year.[24] Overall, the Temple Health OWM Campaign was unique, as it set out to create a broad and practical guideline that incorporated these various recommendations.

Future Directions

Campaigns like this one that are targeted to improve care at the individual and interpersonal level require ongoing education. We found physicians and physicians-in-training to be most accessible for education and training sessions. Standing series for continuing education provided opportunities for presentations. For instance, we requested training sessions for all incoming residents and fellows for the past two academic years, enabling the training of over 650 trainees at a time each year. Onboarding is a key time to reach new staff with important messages about language choice. Hospital leadership requested the creation of orientation materials for all staff who interface with patients, and that project is currently in process. It is important that employees are consistently trained and that the principles are incorporated into their daily work. For example, the staff who do patient scheduling, those who work in nutrition services and social services, and those who create marketing materials can all benefit from education in best practices for communication that aligns with the health systems mission to serve all patients and provide respectful, quality care. The end goal is for uniform training before team members begin their work at the health system.

The topic of bias in language is dynamic and evolving over time and across contexts. Attention to this important mediator of the relationship between patients and healthcare providers will require both ongoing education and assessment of efficacy. Both quantitative and qualitative research will be essential to describe the potential impact of a campaign like the one described here. By quantifying the use of negative language, such as pejorative terms, we can explore groups who might be at particular risk of this type of bias and determine which interventions are effective in creating behavior change. Some studies have already used natural language processing (NLP) to identify stigmatizing language in the medical record.[6] Similarly, the OWM team has IRB approval to examine the frequency of stigmatizing language use in the electronic health record before and after the educational campaign. Qualitative studies could further explore how this education might impact the beliefs, judgements, and behaviors of various members of the healthcare team. Such work could inform future interventions, such as a program to suggest neutral, patient centered alternatives in real time, using predictive text software.

Conclusion

In this case report, we have outlined how a multidisciplinary team convened to investigate an insidious issue that impacts patient care, compile best practices from the literature, create an educational intervention, and operationalize culture change across a complex institution with many stakeholders. The Our Words Matter campaign used grassroots energy, a flat leadership structure, passionate champions, and community engagement to identify and disseminate best practices to reduce stigma and bias in clinical communication. Advocates across diverse disciplines can leverage these lessons and adapt this model to their own settings to strengthen the relationship between patients and providers and advance health justice.

Conflicts of Interest

We have no conflicts to declare.

Funding Sources

We have no funding source to declare.

References

1. Rodriguez JA, Clark CR, Bates DW. Digital health equity as a necessity in the 21st century cures act era. JAMA. 2020;323(23):2381-2382.
2. Link, Bruce G., and Jo Phelan. “Social Conditions As Fundamental Causes of Disease.” Journal of Health and Social Behavior, 1995, pp. 80–94. JSTOR, https://doi.org/10.2307/2626958. Accessed 12 Aug. 2022.
3. White Hughto JM, Reisner SL, Pachankis JE. Transgender stigma and health: A critical review of stigma determinants, mechanisms, and interventions. Soc Sci Med. 2015 Dec;147:222-31. doi: 10.1016/j.socscimed.2015.11.010. Epub 2015 Nov 11. PMID: 26599625; PMCID: PMC4689648.
4. Park J, Saha S, Chee B, Taylor J, Beach MC. Physician use of stigmatizing language in patient medical records. JAMA Network Open. 2021;4(7):e2117052-e2117052.
5. Barry CL, McGinty EE, Pescosolido BA, Goldman HH. Stigma, Discrimination, Treatment Effectiveness, and Policy: Public Views About Drug Addiction and Mental Illness.
6. Psychiatric Services. 2020/07/13 2014;65(10):1269-1272. doi:10.1176/appi.ps.201400140
7. Meyerson BE, Russell DM, Kichler M, Atkin T, Fox G, Coles HB. I don't even want to go to the doctor when I get sick now: Healthcare experiences and discrimination reported by people

who use drugs, Arizona 2019. Int J Drug Policy. 2021 Jul;93:103112. doi: 10.1016/j.drugpo.2021.103112. Epub 2021 Jan 15. PMID: 33461838.

8. Kelly JF, Westerhoff CM. Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms. International Journal of Drug Policy. 2010;21(3):202-207.
9. P Goddu A, O'Conor KJ, Lanzkron S, et al. Do words matter? Stigmatizing language and the transmission of bias in the medical record. Journal of general internal medicine. 2018;33(5):685-691.
10. Himmelstein G, Bates D, Zhou L. Examination of Stigmatizing Language in the Electronic Health Record. JAMA Network Open. 2022;5(1):e2144967-e2144967.
11. Sun M, Oliwa T, Peek ME, Tung EL. Negative Patient Descriptors: Documenting Racial Bias In The Electronic Health Record. Health Aff (Millwood). 02 2022;41(2):203-211. doi:10.1377/hlthaff.2021.01423
12. Hospital THTU. Community Health Needs 2019 Assessment. 2019. https://www.templehealth.org/sites/default/files/inline-files/tuh-chna-2019.pdf
13. Goodyear, K., Haass-Koffler, C. L., & Chavanne, D. (2018). Opioid use and stigma: The role of gender, language and precipitating events. Drug and Alcohol Dependence, 185, 339-346.
14. Stone, E. M., Kennedy-Hendricks, A., Barry, C. L., Bachhuber, M. A., & McGinty, E. E. (2021). The role of stigma in US primary care physicians' treatment of opioid use disorder. Drug and Alcohol Dependence, 221, 108627.
15. Puhl RM, Heuer CA. Obesity stigma: important considerations for public health. American journal of public health. 2010;100(6)
16. Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. BMJ Open 2013;3:e003384
17. Barry CL, McGinty EE, Pescosolido BA, Goldman HH. Stigma, Discrimination, Treatment Effectiveness, and Policy: Public Views About Drug Addiction and Mental Illness. Psychiatric Services. 2020/07/13 2014;65(10):1269-1272. doi:10.1176/appi.ps.201400140
18. Boston Medical Center. Words Matter. https://www.bmc.org/sites/default/files/Patient_Care/Specialty_Care/Addiction-Medicine/LANDING/ files/Words-Matter-Pledge.pdf
19. Michigan.gov. End the Stigma. [https://www.michigan.gov/opioids/09238-7-377-88140_96572-512727-00.html. 2021](https://www.michigan.gov/opioids/09238-7-377-88140_96572-512727-00.html).
20. Albury, C, Strain D. Canada O. Language Matters: Obesity. https:// obesitycanada.ca/wp-content/uploads/2020/10/Obesity-LanguageMatters-_FINAL-2.pdf. February 2020.
21. Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. Diabetes Care 2017;40(12):1790-1799. (In eng). https://doi.org/10.2337/dci17-0041.
22. Jain S. Let's stop talking about "battling cancer." Scientific American 2020.
23. Volkow ND, Gordon JA, Koob GF. Choosing appropriate language to reduce the stigma around mental illness and substance use disorders. Neuropsychopharmacology. 2021;46(13):2230-2232.
24. DesRoches CM, Leveille S, Bell SK, et al. The Views and Experiences of Clinicians Sharing Medical Record Notes With Patients. JAMA Netw Open. 03 02 2020;3(3):e201753. doi:10.1001/jamanetworkopen.2020.1753
25. Healy M, Richard A, Kidia K. How to Reduce Stigma and Bias in Clinical Communication: a Narrative Review. J Gen Intern Med. 2022 Aug;37(10):2533-2540. doi: 10.1007/s11606-022-07609-y. Epub 2022 May 6. PMID: 35524034; PMCID: PMC9360372.