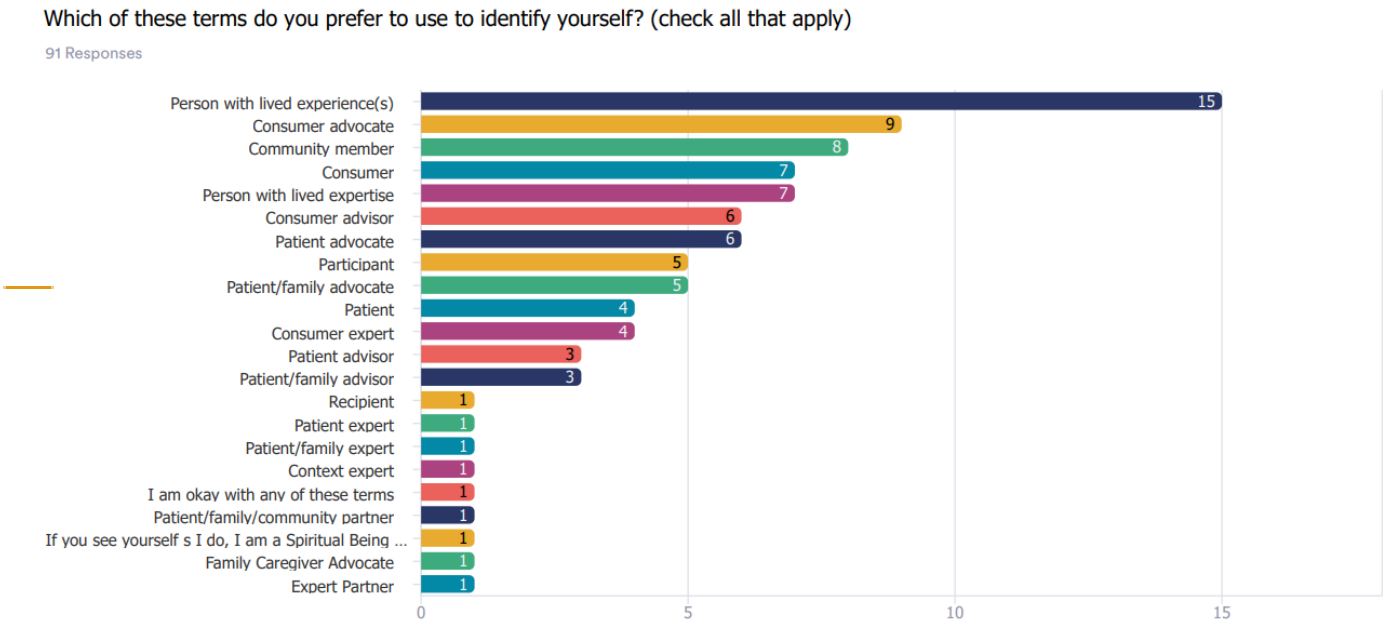
October 2022

Survey results: Preferred language for ‘people with lived experience’

- *This is an appendix to the blog post that can be found at https://camdenhealth.org/understanding-preferred-language-for-people-with-lived-experience*
- *Some responses lightly edited for clarity or relevance.*

Which of these terms do you prefer to use to identify yourself? (check all that apply)

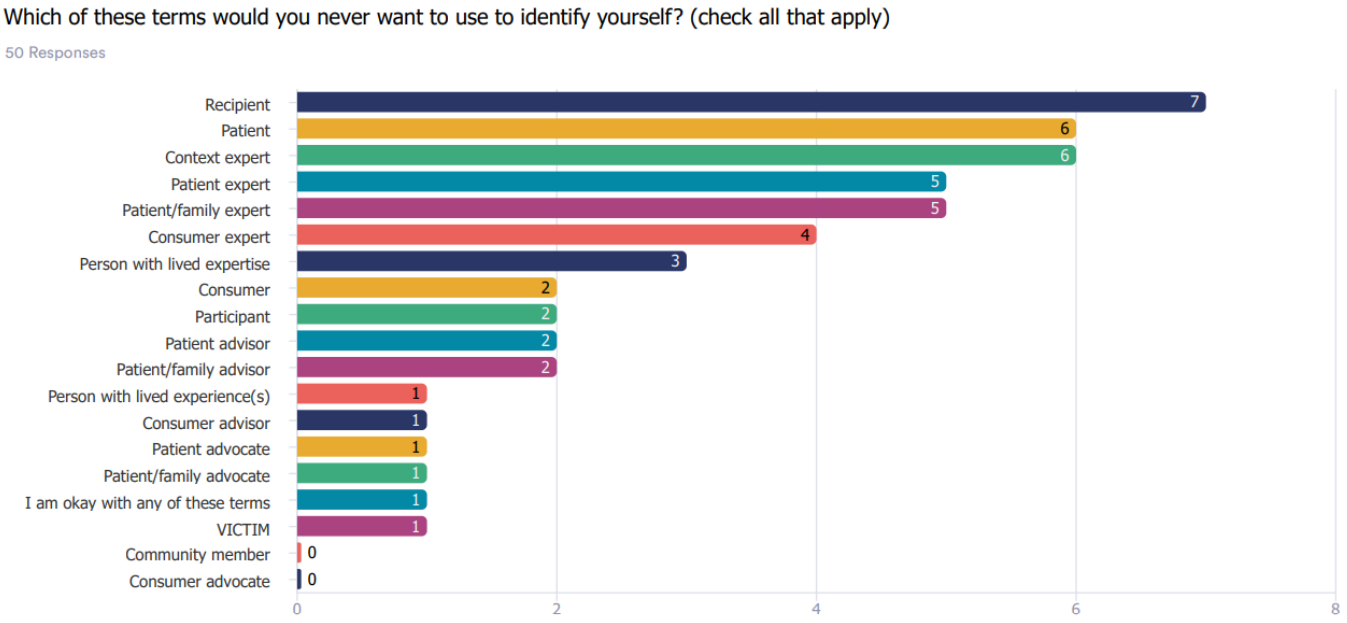


Camden Coalition

Please tell us WHY you prefer the term(s) that you use to identify yourself?

I chose terms that reflect respect and both the experience of consumers giving back and whether the consumer found adequate health support or had frustrating experiences, they are willing to offer time and thoughts of what is needed or needing improvement. These also reflect the possibility that the consumer comes with some medical navigation knowledge and perhaps even some considerable education derived from sitting on boards, speaking to multiple stakeholders, attending conferences, and continued education and valuable networking.
These are the terms I prefer, which can vary by setting
It simply identifies my journey over the last decade. Although it is not the sum of me, nor my life experience(s), it in a nutshell, opens the door for further conversation(s).
I most often used for myself (and my peers) "a person with lived experience/expertise" as I believe it is anything as simple as a "consumer" of a service. It means I have a say. It acknowledges me as an expert in my own body and mind, and capable of maintaining my wellness. As someone who wants to be an active "participant" in my health care, I would gladly accept being referred to as such. This word would make me feel included in my circle of care.
I don't think even professionals should refer to themselves as EXPERT in human behavior or human nature. Of course, when modes of treatment can be readily understood by Colleagues. It is only expedient to use those TERMS. However, the multi-social definition of VICTIM may intimate persons struggling to heal from trauma.
These terms imply that the individual has done positive work on self and in the community.
I lived the life of addiction, and I found a way to live a sober life and I use my experience with both to inspire hope to those still struggling
I use the terms interchangeably based on who I'm talking to. A lot of the work I do is with family members who are providing care to their loved ones but don't see themselves as caregivers. Other times I'm talking to people about becoming their own advocate.
It identifies who I am in context to the role I assume
They each can be used for specific situations that lends to the type of services being rendered at the time.
I use these terms because they all describe what I try to do and also what I have been doing for many years.
It shows that I am a expert in Consumer movement and that I am dedicated to fight for the rights of consumers
Our expertise is equally valuable to academic skillset and language helps the brain connect to images that either equates our excellence or places it on a lower level. When considering the bravery that comes with the vulnerability shared, there is a must to actualize the value of our stories.

Which of these terms would you never want to use to identify yourself? (check all that apply)



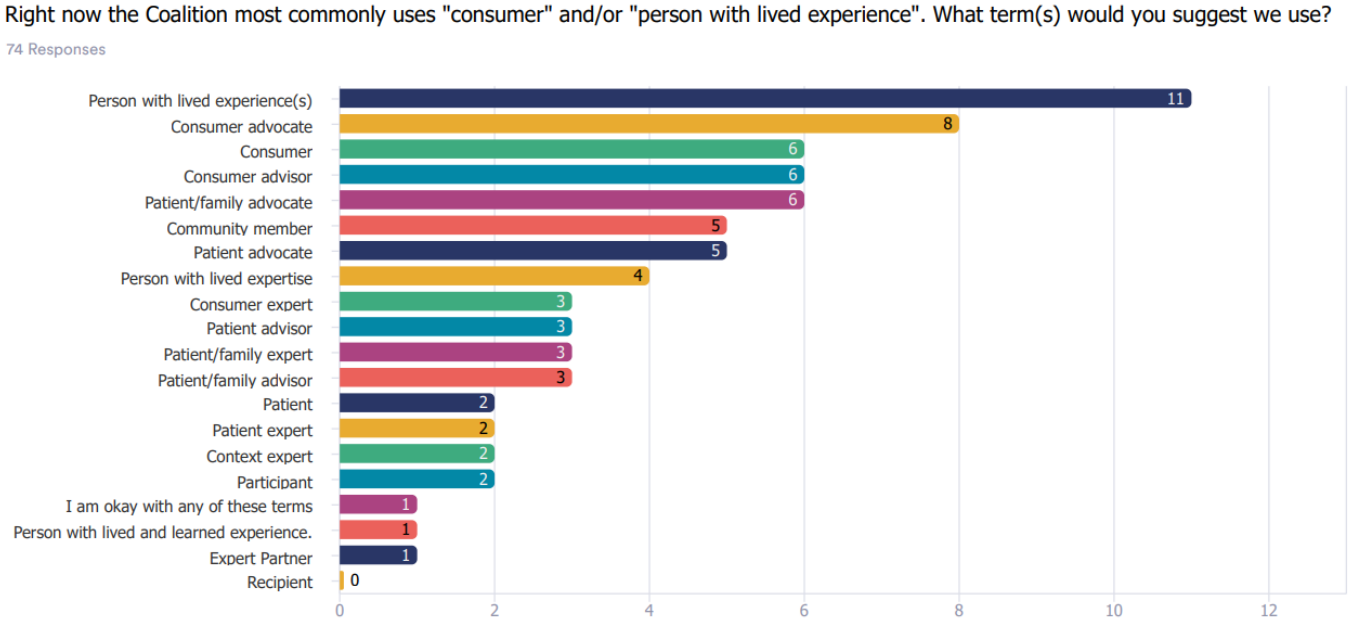
If there are any terms that you would never use to identify yourself, please tell us WHY you feel this way.

In order to get selected to support a certain facet of the medical system, one ought to have a title that reflects so. It need not be grandiose but empowering and signifying that their efforts are seen as a valued partnership by medical professionals.
I would never prefer to use the word "expert" because it feels too definitive. I feel as much as someone may know; they cannot possibly know everything- there's always more to learn. Additionally, it's impossible to see everyone's situation/life through their own lens, so there will always be variables in every situation. I also shy away from use of "consumer" when possible, because I feel it's often related to "business" which can be triggering and have a negative connotation especially for those with medical related traumas. Many individuals can feel "wronged" by healthcare systems, blaming "big pharma" or "the business of healthcare for profit and monetary gain" as the cause.
"Recipient". This term is triggering to me. It implies that I am beholden. That there is a quid pro quo.
While I was strongly inclined to check off "consumer" in the first part of the survey (due to my work in the field as a Mental Health Peer Specialist and from being addressed as such for so long) I feel that it doesn't seem to fit my individual/community progress and progressive language that we are striving to work towards. Checking it off on this survey is a very deliberate act for me and it has made me reconsider my position on the word. I feel that the word may denote a negative meaning in our modern world with how simply being a "consumer" means to take, to indulge, to consume greedily without giving back- though we know more than ever that those with lived expertise often want nothing more than to be participants in their wellness journey. I respect those that still feel comfortable using it. I know that the term has been used progressively in the past, but I understand that language matters and can change- there is a possibility this one has the power to evolve as well.
The term I don't wish to be identified with is VICTIM.
These terms above suggest that an individual has problems that haven't and need to be addressed. Also, to refer to an individual with such terms could have a negative impact on that individual.
While I have lived experience that may qualify me as an expert, I work to remain humble and actively on the same level as patients, clients or consumers to reduce or eliminate perceptions of arrogance that often is attached to our expertise.
I don't put myself out there as an advisor but someone who is sharing info that may be useful or helpful. I don't use the term expert but someone who has expertise in the area.
I don't like the words.
These two terms context expert and recipient seem non/specific and formal in their use with healthcare to me. Therefore, I recommend asking the person receiving the service or partnering with you for care... how do they want to be referred to in each instance or situation?
Because I'm not an expert, but I do have years of experience.
I do not have problems with using any of these terms

Are there any important differences that you see between some of these terms? Are there times that one/some apply and others do not?

Some appear to be more like passive labels. Others seem to be empowering titles.
I would not consider myself an advisor when directly helping a family/patient, but more so an advisor when asked for input from professionals (i.e- patient advisory council/board, etc.). When working directly with a patient or family, I do not feel it is my duty to "advise" but to stand beside them and gently help guide them to make the best decision for themselves.
Absolutely. I wear various grassroots advocacy hats. Some of these terms evoke a pathology that I do not care to always be characterized as, plus, it's not always aligned with whatever task is at hand and/or venue.
I feel very neutral about the term Patient, which only makes me more curious about it. I had deliberated on the word being used as I believed if a surgeon was working on my heart, this could apply easily. However, when my brain or complex needs are what is being discussed/cared for, I wonder why there is so much extra thought put into the nuance of certain words? Just as easily we could use "participant" in physical care, as the person is involved in their heart surgery by focusing on what they can also control in their care journey. I may not mind "patient" for physical care but would never want to be seen as that for my mental health care. Holistically focused, we may find better language. I find that to be very interesting!
I think an individual's title should reflect what is the motive of the interaction between the Coalition and that Individual. Clinicians need paperwork that validates the day. So, classification is obligatory for collaboration.
Yes, there are times when a term applies, and others don't. We should be careful to assess an individual's situation and mindset before we label a term.
Depending on who you're talking to, there are times that some of these terms are more appropriate.
Patient implies a sick person on need of help or maybe not sure of getting help
Yes, there are times when one is a patient but later learns to be an advocate. Participants are people with lived experiences who have agreed to participate in research, trials or surveys but may not be a patient instead a caregiver for a loved one. It is all about asking the person how they want to be referred to.
To be an expert you would have to know everything about the situation that is being discussed.
Considering the ways that the brain connects to images, there needs to be imagery of strengths! Not a need for saviors or having the position of being at the mercy of someone who has authority over, as opposed to the image of partnership!!
They all very important

Right now the Camden Coalition most commonly uses "consumer" and/or "person with lived experience". What term(s) would you suggest we use?



What advice would you give to health/social care agencies who are unsure how best to refer to people with lived experience/consumers/patients etc.?

Ask yourself the question, "Do you really need and want consumer input, feedback, and perspective? Or is the idea just a hook that looks good on grant proposals?"
As with anything, it is important to ask someone how they wish to be addressed. At times when this is not possible (such as outreach/publication), it may be good practice to list 2 or 3 titles in posting to appeal to those who may be turned off by one or the other.
Just refer to us as your "colleague".
Ask the person who is involved in their health care if the space allows. If not, "a person with lived experience" or "healthcare participant" seems self-explanatory.
Include the subject person with the alternatives and their meaning. Let them choose what TERMS best serve the assigned title.
My advice is that we should all want to treat each other with respect and dignity regardless of a person's current condition. Also, when using a term, we should remember to be kind and non-judgmental.
Ask them how they like to be addressed. I think it adds a level of respect.
Ask how they'd like to be recognized
Ask them what they or each person wants to be called.
Ask us individually how we prefer to be referred to.
That the consumers must be at the table to help with decision making when the agencies are deciding how to refer to the Consumer
Ask. Invite people into the partnership of working together towards healing... in this partnership how would you like to be identified/ referred to?
Be open and willing to learn

Is there anything else you would like to share with us on this topic?

Just know that WE ALL bring our expertise to this work. You are not monolithic. Nor am I. We cannot shift the paradigm, nor move steps forward, without the other. This implies that we are EQUAL. I was compelled to start my platform: "we can no longer talk about equality and empowerment while continuing to enforce inequities", after being involved with an initiative to improve the quality of life and wellness for women displaced to Skid Row. I was living on $221 per month, in the heart of Skid Row and struggling. Really bad. Other than the three two other community advocates in addition to myself, everyone else was an executive, professor, etc. I fought for myself and the other ladies because the inequities were egregious. This happens time and time again. It happens when someone does not see me. It happens when someone does not value me. In other words, it's more than just talking the talk, it's about walking the walk.
People are individually unique like Snowflakes, no two of us are alike. Though we all may have similar experiences we normally have different reactions to our experiences. Therefore, health providers should approach each person with a plan that is similar to washing hands. IT TAKES TWO HANDS TO WASH ONE.
Yes I would like to thank all health care providers for their hard work, time and effort. People with lived experiences will always need the support of health care workers. Thank you
We are in a time when people are often disrespected or feel disrespected. It's good when agencies can use terms to show respect.
Always ask those in partnership how they chose to be referred to, and what does not work for them.