Mental health lived experience narratives; recommendations for avoiding misuses and adopting good practice

Authors: Caroline Yeo, Stefan Rennick-Egglestone, Yasmin Ali, Victoria Armstrong, Marit Borg, Simon Bradstreet, Alison Faulkner, Donna Franklin, Trude Klevan, Joy Llewellyn-Beardsley, Katie Mottram, Fiona Ng, Julie Repper, Mike Slade, Jijian Voronka, James Wooldridge.

the institute of mental health
Nottingham

In memory of James Wooldridge, who lent his expertise to this document, and who has been a valued collaborator and friend of our work.

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Summary

This document explores how mental health lived experience narratives are used in healthcare and community settings (including by charities).

It highlights common misuses of narratives, including the dangers of narratives becoming commodified, co-opted or used for different purposes other than the author intended. It also highlights dangers for narrators (by which we mean those people who have chosen to share their story); of being subject to coercion or unethical editing practices.

Lived experience narratives bring huge value in the unique knowledge they can bring to the understanding of mental distress, and it is important not to see the challenges of using them ethically and appropriately as a barrier to using them at all.

Hence we also set out seven recommendations for those who use mental health lived experience narratives to avoid misuses and adopt good practices which are:

1. Narratives should be experientially and representationally diverse.
2. Consider ways of interpreting narratives and build pathways for ethical listening or visual appreciation and understanding.
3. Mitigate harm, promote safety for the narrator and recipient.
4. Recognize the value of narratives and offer appropriate compensation to narrators.
5. Integrate lived experience researchers into research processes using narratives.
6. Consider imbalances of power whenever using lived experience narratives.
7. When people publish lived experience narratives they should have guidelines which include a description of how misuses can be avoided.

Introduction

What are mental health lived experience narratives?

Mental health lived experience narratives are first-person accounts of the experience of mental and emotional distress. They can be presented in different formats such as audio, video or written accounts and can be published across a wide range of sources such as academic journals, books and online. Some examples can be found here:

- Emerging Proud - collections of stories of mental distress and spirituality - emergingproud.com
- Recovery Devon: Beyond the Storms and Riding the Storms - recoverydevon.co.uk/book-shop
- Exploring Experience - sites.google.com/view/exploring-experience/about
- Taraki men's mental health - www.taraki.co.uk/projects/mens-mental-health
- Sheffield Flourish - sheffieldflourish.co.uk/stories
- OC87 Recovery Diaries - oc87recoverydiaries.com/mental-health-first-person-essays
- Soul Relics - soulrelicsmuseum.me/home
- The Colour of Madness - Book exploring BAME mental health in the UK (Linton & Walcott, 2018)

> The NEON (Narratives Experiences Online) study (led by the Recovery Research Team) has been learning about the uses and misuses of lived experience narratives.

The NEON Lived Experience Advisory Panel (LEAP) wrote a 'telling your story' guide with McPin for people who plan to share their narratives (Narrative Experiences Online (NEON) Lived Experience Advisory Panel (LEAP), 2020).

Who uses lived experience narratives and why?

A recent piece of research (Caroline Yeo et al., 2021) identified 27 different uses of lived experience narratives, which included individual uses, such as promoting the recovery of the narrator or its intended audience, and as a therapeutic tool in online interventions. Lived experience narratives can also assist with aims such as: fundraising, helping in the reduction of stigma through their use in anti-stigma campaigns (e.g. Time to Change) or as data for research activities. This piece of research was the basis for this good practice guide.

Uses of Mental Health Lived Experience Narratives

Political

- Assisting with achieving policy change aims
- Using the voices of recovery or madness as agents of change
- Building a narrative collection to act as an evidence base
- Emancipation through having a voice
- Recruiting people to a cause

Societal

- Reconceptualising definitions of mental illness
- Reducing stigma such as in anti-stigma campaigns or apps
- Encouraging people to seek mental health treatment
- Using in research activities such as data for analysis
- Encouraging others to share their story

Community

- Organising, peer support and solidarity
- Opening dialogue between different perspectives
- Promoting fundraising activities
- Community participation
- Using in support groups for shared reading and analysis
- Increasing visibility for a specific group, for example the Black and Minority Ethnic community

Service level

- Improving mental health and social care services
- Highlighting inhumane or oppressive psychiatric treatment
- Developing partnership and helpful relations in services
- Developing clinical theory and practice
- Evaluating mental health services

Individual

- Using as a therapeutic tool in a digital intervention
- Enhancing the personal recovery of curator, narrator and/or recipient
- Using in therapy sessions with a mental health worker
- Using for self-advocacy for narrators
- Using in meetings between peer support workers and service users

Lived experience narratives can be published individually or made into a collection by people we describe as curators, who may for example collect, select, edit and present narratives in different forms. Collections of narratives may present certain collective views and could be used for collective purposes such as fighting stigma, campaigning for change in service provision, educating about mental health and recovery, supporting others in their recovery journey, critiquing psychiatry, influencing policy, marketing health services, and reframing mental illness (C. Yeo et al., 2021).

Lived experience narratives bring huge value in the unique knowledge they can bring to the understanding of mental distress but their use comes with risks and possible negative impacts explored in this guide.

> It is important not to see the challenges of using them ethically and appropriately as a barrier to using them at all.

What is the purpose of this good practice guide?

The aim of this work is to offer a set of good practice guidelines for the use of mental health lived experience narratives in health care and community settings such as by charities. This guidance can also be used by curators, editors, activists, researchers, mental health workers, policy makers and anyone wishing to share their personal narrative to improve care practices or support the development of clinical interventions.

The intention of creating this guide is to promote good practice and to safeguard against lived experience narratives being misused, either intentionally or unintentionally.

How might mental health lived experience narratives be misused?

> The following possible misuses of lived experience narratives came from a review of published academic journals, online articles and magazines (Caroline Yeo et al., 2021).

1. Narratives may become patient 'porn'

Narratives are sometimes used by organisations in such a way that they become what can sometimes be referred to as patient 'porn': stories to be consumed, continually repeated and commodified. By this we mean that, **"while some people reveal their most intimate personal details, others achieve relief through passive watching, while still others profit from the collaboration of those on the front lines in compromised positions"** (Costa et al., 2012). Patient "porn" can also define an insatiable and unhealthy desire for information and details about distressing and traumatic experiences which can occur if lived experience narratives are shared around too readily without concern for the nature of their content. The term 'porn' can be used to refer to how stories are told, heard, performed, consumed, valued and how they might be commodified (Woods et al., 2019).

2. Narrator may be subject to coercion

In some circumstances, people may be coerced into sharing their narratives, such as by the mental health service they are using. One example of this was in Indian-controlled Kashmir where **"recovery narratives were treated as a requirement for discharge from inpatient care, creating conditions in which patients felt coerced into not only sharing a narrative but one with specific features"** (Kaiser et al., 2020).

Recovery in the Bin, a user-led group for mental health survivors and supporters, believe that **"being made to feel like you have to tell your 'story' to justify your experience is a form of disempowerment, under the guise of empowerment"** (Recovery In The Bin, 2014). Some believe that the imperative to narrate traumatic experiences is another form of oppression which can occur as a result of being a mental health service user (Woods et al., 2019).

3. Narratives may be used for different purposes other than an author intends

A narrative may be used for a different purpose other than the author may have intended, for example to advertise a specific mental health service or treatment. Once a narrative has been published, the author loses control of how it is used, (De Vecchi et al., 2017) meaning that it can be removed from its original purpose and intention (Carr, 2016). Once a narrative has been published it can be used without the narrator's consent, an increasingly common issue as more narratives are shared online (Carr, 2016). Whilst a narrator may agree in principle for their narrative to be used in, for example, a research project, the narrative may subsequently become used in other ways e.g. being published in a newspaper (Kaiser et al., 2020). It may not be easy for an author to withdraw their narrative once it is published (Kaiser et al., 2020).

4. Narratives may be co-opted

Co-option in this context refers to narratives being used as a commodity, (Sapouna, 2020) for instance to promote certain agendas (Fisher & Lees, 2016). Mental health service systems can take people's accounts of resistance to oppressive mental health treatment, sanitize them and make them less critical or negative and use them in ways that do not change the system's own embedded practices (Costa et al., 2012). Co-opted narratives can be depoliticised (McWade, 2020), edited and censored and used by mental health systems to promote or justify their practices or services (Kaiser et al., 2020). The sharing of co-opted narratives can also promote an incomplete approach to mental health, which focuses on an individual's responsibility to recover whilst ignoring the contribution of the wider systemic, social, political, cultural and economic factors and other interpretations of the experience (Sapouna, 2020; Woods et al., 2019).

5. Narratives may be used against the author

Stories have power. In some instances, they have been used against the author, and used to determine the worth of the narrator as a human commodity. For example, narratives may be used by mental health workers or other professionals in order to make decisions about a person's treatment, access to services or benefits. When those in power fail to acknowledge the experiences of marginalized groups, storytelling can serve as a weapon that disguises other perspectives which can promote and exacerbate social injustices (Davidow, 2019).

6. Narratives may be reinterpreted by others

Once a narrative is in the public domain, the narrator no longer has control of their own interpretation of their narrative (Russo, 2016a). Narratives can be used as data by researchers, who may fail to engage with the author of the narrative; as they seek to uncover 'deeper' meanings, they can run the risk of reinterpreting the narrator's voice, whilst the researcher assumes the power of translation and interpretation, (Church, 2013). This may result in researchers and mental health workers imposing a narrative template on the narrative that removes its nuances and complexities, in this way perpetuating the oppression of voices of lived experience (Fisher & Freshwater, 2014).

There is currently very little survivor-led analysis of individual and collective histories and narratives (Russo, 2012). Lived experience researchers are often called upon to share their narrative, but are rarely involved in the analysis of their narratives (McWade, 2020). Assigning the tasks of making meaning of others' experiences to researchers without lived experience, rather than to those with lived experience, can result in analyses perpetuating role and power divisions that are problematic within the psychiatric system (Russo, 2016b). Survivor-led research has the expressed aim of minimising this tendency for researchers to re-interpret personal narratives and to take control of the research process (Russo, 2016b).

7. Narratives may lack diversity

There is a risk of over-generalisation when narratives are shared which could give rise to unhelpful assumptions and harmful stereotypes; (Bortolotti & Jefferson, 2019) for example, national mental health campaigns tend to use the narratives of young people, celebrities and photogenic faces; often white, middle-class, non-LGBTQ2S+ women and men (Woods et al., 2019). The issue of intersectional narratives is a challenge to be addressed, where the effects of overlapping discrimination and disadvantage due to racial identity, class, gender, sexuality and disability as well as mental health status, may be overlooked (Carr, 2016; Kelly, 2016).

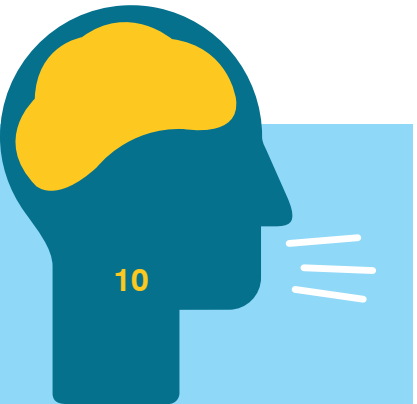
Whilst there are many narratives of healing and recovery, there also needs to be more space for stories of resistance and opposition, collective action and social change (Church, 2013) and narratives that critique the mental health system (Davidow, 2019). Narratives promoted by mental health services tend to be neutral or positive and 'risk free' and are often shared in a way that seeks to avoid causing distress to recipients (Kaiser et al., 2020). Narratives can be moulded to fit templates that show gratitude to mental health services and mask complexities or systemic problems (Sapouna, 2020). Narratives which are 'inspirational' or 'insightful' are given space over those that confuse or challenge, (Sapouna, 2020) or speak of non-recovery or non-compliance (Pascal & Sagan, 2018).

8. Narrator may be subject to unethical editing practices

The process of editing narratives may be ethically questionable if narrators are required by curators or organisations to include or exclude certain details, or to convey a certain message. One example of this is where narrators were given rules regarding what to include in their narrative such as needing to show gratitude to the police or other services and professionals (Kaiser et al., 2020). The curator may also edit the narrative through their own interpretive lens, which may differ from the narrator's and could change the intended message, especially if they have limited understanding of the subject matter.

9. Narrator may be harmed

The process of sharing one's experiences of mental distress may cause distress for the narrator as they tell stories which may be emotionally difficult, and may involve discussing pain and trauma (Woods et al., 2019). There is a potential for re-traumatisation during the process of sharing of a personal narrative through the reliving of traumatic experiences (Jackson, 2002). Furthermore, in the process of selecting narratives, certain stories may be rejected, which may be experienced as a harmful rejection of the validity of their own experiences by the narrator (Kaiser et al., 2020).



10. Audience may be triggered

Narratives can potentially cause distress to the audience or reader (Carr, 2016). For example, some narratives might be triggering or cause some people to experience re-traumatisation. Narratives that can be triggering include those describing self-injury including eating disorders (Dawson et al., 2018; McAllister et al., 2014; Roe et al., 2020). Accessing a narrative with which a reader resonates may also catalyse a crisis for them if it triggers previously suppressed memories.

11. Audience may misunderstand and wrongfully label experiences

Hearing and interpreting narratives through an institutional (McWade, 2020) or medicalised perspective can cloud the way a narrative is heard and understood, making its lasting memory very different from the narrator's original intention (Voronka, 2019). The process of listening to and learning from a narrative in order to derive meaning may lead to audience misunderstanding and the wrongful labelling of experiences, for example with medical diagnostic categories (Matthews & Sunderland, 2013). Lived experience narratives require the audience to be able to reflect, as they demonstrate a willingness to enter into dialogue with the narrator and their story, and to maintain an open mind (Grant et al., 2012).

> Finally, if you read this guide and consider that your narrative has been misused we hope you can seek support from a trusted source should you feel this way.

What are our recommendations for good practice use of mental health lived experience narratives?

We used our awareness of possible misuses of narratives to create the following recommendations for adopting good practice.

Recommendation 1: Narratives should be experientially and representationally diverse

Those seeking to use lived experience narratives must make a concerted effort to privilege the narratives of people from Black, Asian and minority ethnic communities, LGBTQ2S+ and Disabled people, as well as other groups experiencing structural inequality, whose narratives are often less visible to mainstream populations. Narratives should be encouraged to be complex, to include those that express resistance, critique, and non-compliance with services. This means that those who hold power to solicit, curate, and shape these narratives should be prepared to reflect on and question their own practice, including their own interests, biases and potential blind spots to ensure that a diversity of the experiences of both mental health and mental health system encounters are as authentically reported as possible, whilst maintaining awareness that people from marginalised groups may also be more reluctant to come forward if those using the narratives are largely from mainstream populations.

Recommendation 2: Consider ways of interpreting narratives, and build pathways for ethical listening

As the intent of the storyteller is processed through an audience, content is always subject to reinterpretation. No two people interpret art and language alike. Yet, given the dominant mental health illness narrative focused on the medical model (and excluding psychological, social, cultural, political and spiritual elements) that is driven through, and by, psychiatric powers, and the lack of alternative counter-narratives circulating in mainstream culture, it is difficult to listen to and understand mental health narratives beyond the confines of such illness and recovery frameworks.

Fully addressing the issues identified in this review, including how mental health stories may be misunderstood or reinterpreted by others, requires a cultural shift. This entails long-term systemic socio-cultural change that has been advanced by other social movement activist groups (e.g. Black, Asian and Minority Ethnic communities, Indigenous, LGBTQ2S+) who have demanded their stories be heard on their own terms and through their own sets of cultural values (Haritaworn et al., 2018; Mbilishaka, 2018; Ruml, 2020). Change requires first identifying, then articulating and drawing attention to the issue.

To help move our listening practices forward, Baylosis (Baylosis, 2019) offers practical considerations and tools for those working in mental health systems to help us work towards an 'ethics of listening' that promotes reflexive listening and work towards honouring and valuing narratives on their own terms without unnecessary power dynamics clouding the message. Some of these considerations are:

- Maintaining openness and resisting the desire for control and certainty, while making oneself susceptible to persuasion.
- Appreciating differing perspectives without imposing or defending your own position.
- "Listening across difference" shifting from understanding each other's positions to consider the "relationships and complicities, issues and the working of privilege" (such as race, economic status or gender) and power.
- Listening should entail hearing multiple perspectives that describe how people with disabilities (this includes psychiatric disabilities) experience living in society.

Recommendation 3: Mitigate harm, promote safety

Rarely does an author have control over their own narration: it is almost always intervened upon by others such as curators or researchers. Yet, people describing mental distress have particular considerations to contend with when storytelling. These include the fact that people, including health and social care professionals, landlords, employers, family, friends, and the general public may hold discriminatory views towards people who discuss their mental health problems. Sharing their stories can lead to long-term consequences, including housing and employment insecurity and possible isolation. Service users are often encouraged by mental health service systems to share their narratives as a part of recovery or anti-stigma work. While this choice is presented as service user choice, often what isn't recognised is that many marginalized service users live with limited decision-making choices (Voronka & Grant, 2021), as exemplified by experiences of coercion where they may experience forced treatment. Further, many academic or service provider events are now filmed and posted online. Service user narratives might thus be consumed beyond the scope of the in-room audience, subject to viewing and comments by anyone in the public arena for a usually unlimited amount of time.

Given that stories are increasingly consumed and shared online, and likely easily accessible forever, these risks need to be carefully considered by curators and narrators. When approaching narrators to share narratives, it is important to empower them to choose to decline should they so wish, by discussing these risks. Then, if planning on recording an event, to inform the narrator when invited to tell their stories as this may influence their decision. Or, offer to not record their segment, and normalize this practice. Encourage them to use a pseudonym if they wish, and discuss why. Consider not tagging their name to videos posted online. However, forcing people to use pseudonym should be avoided and some people may profit from using their real name through publishing or from a career perspective.

It is important to ensure people have the opportunity to provide fully informed consent and the freedom to make decisions which are right for them, where there is no coercion (implicit or explicit). Ensure authors are fully informed about potential uses that may be uncontrollable after publication, and potential risks related to this. Discuss whether they feel able to deal with any potential negative reactions to their story and ensure appropriate support resources are in place to deal with any eventuality.

Recommendation 4: Recognise the value of narratives and offer appropriate compensation

In broader contexts, individual experiences and narratives can be turned into commodities for profit e.g. in a book for sale. As good practice, both those telling the story and those harnessing and giving the story need to recognise this and efforts for equal exchange/remuneration should be discussed. Frank and open discussions with narrators about how their personal narratives could be gathered for research, promotional, or public relation campaigns, and that there is a monetary value attached to narratives that benefits those soliciting them, needs to happen. The author should be encouraged to reflect whether the benefits of sharing their narrative would be greater than the risks to them. One way to address the issue of commodifying narratives is to actively and openly recognise the monetary value of these narratives, paying those who offer this commodity a fair and appropriate compensation in line with how much financial gain could be made from them. However there are some uses where there is no monetary gains for example, a community activist collecting narratives for a campaign.

Recommendation 5: Research processes into lived experience narratives should integrate lived experience researchers

Lived experience narratives can also be misused in research contexts (Caroline Yeo et al., 2021). If lived experience narratives are being utilised as data, it is vital that people with lived experience are engaged in the analysis and interpretation of the data. This means the employment and involvement of more researchers with lived experience at the level of analysis, not simply at data collection level.

Recommendation 6: Consider imbalances of power whenever using lived experience narratives

Power is a key issue relating to the uses and misuses of lived experience narratives. Foucault stated that **"instead of conceptualizing psychiatric power in terms of institutions, with their regularities and rules, one has to understand psychiatric practice in terms of "imbalances of power" with the tactical uses of "networks, currents, relays, points of support, differences of potential" that characterize a form of power"**(Foucault, 2008). In relation to the use of narratives one can consider different people and institutions involved in the process and the imbalances of power, with the narrator as service user or survivor typically having the least amount of power. This power imbalance extends to academic life, whereby service users are engaged by **"non-user academics motivated more by the exigencies of their own academic advancement than the deeper and more meaningful rebalancing of power and expertise"** (Kalathil & Jones, 2016). Non-user academics and others using lived experience narratives, need to contend then with their own power in these encounters with narratives, and how to use them in the interests of dispersing power to those who hold them.

Recommendation 7: Publication guidelines for lived experience narratives should include a description of how misuses can be avoided

Editors of journals or publishers who include lived experience narratives in their publications could provide guidelines and recommendations to prevent misuse and give guidance on, for example, improving the diversity of lived experience narratives selected for publication. Similarly, curators of books or online collections of lived experience narratives may be guided to avoid possible misuses such as unethical editing practices, as described above.

Whenever narratives are published a suggestion is that a foreword could be added offering the audience guidance in order to prevent audience misunderstanding, encourage ethical listening and state the value of keeping an open mind.

> A specific component to include in publication guidelines is the possible dangers of a published lived experience narrative being co-opted or used for purposes other than their authorial intent.

Potential approaches to reducing this danger include:

- Publishing the narrative using a Creative Commons Attribution Licence (Creative Commons) specifying the permitted amount of re-use or modification, ensuring (e.g. through a consent process) that narrators are aware of the potential for wider circulation of their narrative.
- Providing guidance on anonymising narratives.
- Having clear withdrawal processes prior to final publication.
- Signposting contributors to 'telling your story' guides, for example the NEON LEAP guide (Narrative Experiences Online Lived Experience Advisory Panel, 2020) which may offer them helpful information.

Some tips if you are planning to share your narrative

> We have prepared a few tips for those who may want to share their narrative, some of which come from some previous research (Costa et al., 2012).

- Remember that your participation is voluntary and you can always say no.
- Ask yourself, who profits from you telling your story in this way?
- Consider what purpose does sharing your personal story serve?
- Make sure you have an opportunity to proof-read and edit the final version of your story before it is published / broadcast / posted online.
- Ask about withdrawal and update procedures.
- Ask how large organisations use stories to make material change?
- Think of story-telling as an exercise of labour/work and ask if you get paid.
- Remember that the internet lasts forever and because of the technology available today, your interview or story will likely be accessible to the public for a very long time, including people you may not wish to see it in future, e.g. future employers or landlords.
- Consider that people you know might find out about your mental health experiences through your storytelling, and might treat you differently because of their own discriminatory beliefs.
- As part of their work role, those who are soliciting stories to fulfil their job obligations may not be considering, or may not be aware of, the long term consequences of your public story-telling.
- You do not have to share your real name and could use a pseudonym if you wish.

Conclusion

> The rapid rise in the use of lived experience narratives in the mental health field was mostly led by good intentions: to value and highlight the voices of those with personal expertise and experience of the conditions and treatments previously only narrated by professionals.

From the very beginning this has brought with it risks and exploitation, and the tendency within the mental health arena has been to hear the voice of 'service users' with little heed to the personal cost to those offering their stories.

Whilst there are an increasing number of guidelines informing the use of lived experience in practice, via peer support and other staff-service user relationships, there is little published guidance for the use of recorded narratives. This guide aims to offer some ideas for those who plan to use lived experience narratives and those thinking of telling them.

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Authors

Caroline Yeo
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Yasmin Ali
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Victoria Armstrong
Disability North, Newcastle, UK

Marit Borg
Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Norway

Simon Bradstreet
Institute of Health and Wellbeing, University of Glasgow, UK

Alison Faulkner
Independent Survivor Researcher, UK

Donna Franklin
NEON Lived Experience Advisory Panel

Trude Klevan
Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Norway

Joy Llewellyn-Beardsley
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Katie Mottram
Founder, Emerging Proud Campaign

Fiona Ng
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Stefan Rennick-Egglestone
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Julie Repper
Implementing Recovery for Organisational Change (ImROC), Nottingham, UK

Mike Slade
School of Health Sciences, Institute of Mental Health, University of Nottingham, UK

Jijian Voronka
School of Social Work, University of Windsor, Canada

James Wooldridge
Recovery Devon, UK

the institute of
mental health
Nottingham

www.institutemh.org.uk

@institutemh

Institute of Mental Health,
University of Nottingham
Innovation Park,
Triumph Road,
Nottingham, NG7 2TU

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