siyam'kela

measuring HIV/AIDS stigma

TACKLING HIV/AIDS STIGMA:
Guidelines for the workplace
Siyam’kela

Siyam’kela [SI-YUH-MU-GE-LAR] is an African word from the Nguni language. Translated it means “We Are Accepting” expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as “Together We Stand” for this project.

The Project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam’kela denotes a collective approach in working towards reducing HIV/AIDS related stigma and discrimination.
Tackling HIV/AIDS stigma: Guidelines for the workplace

December 2003

A joint project of the:

- POLICY Project, South Africa;
- Centre for the Study of AIDS, University of Pretoria;
- United States Agency for International Development (USAID); and
- Chief Directorate: HIV, AIDS & TB, Department of Health

Researched by:
- Insideout Research

Supported by:
- Representatives from the Siyam’kela Reference Groups
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1. Background

1.1 The Siyam’kela Project

The Siyam’kela Project is a joint endeavour of the POLICY Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV, AIDS and TB, National Department of Health. Siyam’kela is an African word meaning ‘we are accepting’, expressing a collective embracing. The project has interpreted the word as ‘together we stand’ to symbolise unity in challenging HIV/AIDS stigma.

Stigma, ‘a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons’, can be felt (internal stigma), leading to an unwillingness to seek help and access resources, or enacted (external stigma), leading to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS.

Because stigma has an impact on prevention and care it is important to address it directly. However stigma-mitigation practice has not been well informed by theory and research. An urgent need was identified for indicators of stigma, which can be used to develop interventions and measure their success.

The Siyam’kela Project thus aims to pave the way for a stigma-mitigation process by developing well-researched indicators of HIV/AIDS stigma and discrimination. The project has focused on three key areas essential to South Africa’s response to HIV/AIDS:

- faith-based organisations and communities as important sources of support to people living with HIV/AIDS (PLHAs)
- government departments as workplaces committed to dealing with stigma through good policy and practice
- the relationship between PLHAs and the media as an example of how empowered individuals can impact positively on perceptions and attitudes towards HIV/AIDS.

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A comprehensive literature review, two consultative workshops and the establishment of reference groups in the focus areas of the project ensured that a diverse range of opinions and experiences were reflected. The use of an independent research organisation, Insideout, for the fieldwork, also brought in a fresh perspective.

The project consists of six aspects:

- a literature review to provide a theoretical understanding of stigma
- a qualitative exploration of stigma experiences and perspectives through focus-group discussions and key-informant interviews across South Africa
- the development of indicators of internal and external stigma through this fieldwork and in consultation with experts in the field
- a media scan to contextualise and locate the fieldwork in a particular time and place
- the documentation of ‘promising practices’ which mitigate HIV/AIDS stigma
- the development of guidelines to assist those who wish to develop interventions to impact positively on HIV/AIDS stigma.

1.2 Accepting environments

It has been widely recognised that it is very important to address HIV/AIDS stigma in order to improve the quality of the lives of people living with HIV/AIDS and to address prevention effectively.

Powerful metaphors related to HIV/AIDS reinforce stigma and create a sense of otherness. Othering occurs when blame and shame are assigned to people living with HIV/AIDS. This sets a moral tone that contributes towards people conceptualising PLHAs as different, and guides thinking toward a ‘them’ and ‘us’ division. When this division occurs, a person is less likely to identify with the other group, in this case PLHAs.

For example, metaphors that refer to HIV/AIDS as a plague – and PLHAs by association as the carriers – presents PLHAs in a dehumanising and alien light.

The consequence of othering is that certain groups may feel that they are immune to the risk HIV infection. Stigma also influences how we respond to the HIV/AIDS epidemic. PLHAs, people representing certain risk groups, and people affected by HIV/AIDS have become targets for blame and punishment. This has only heightened their vulnerability to HIV/AIDS and pushed them into a vicious cycle of stigmatisation and discrimination.
As part of the qualitative exploration of HIV/AIDS, the Siyam’kela study collected many personal experiences of PLHAs who had started to heal emotionally because of supportive and non-stigmatising environments. Particularly, they mentioned the value of proper pre- and post-test HIV counselling, the provision of factual information about the virus and opportunistic diseases and counselling about disclosure. PLHAs highlighted the importance of acceptance by their family, faith group, friends and colleagues in helping them to overcome the initial shock of discovering their status, eventually learning to accept it and live positively. Where PLHAs have not been able to find such support, they have also been more likely to internalise societal stigma.

These guidelines highlight the importance of such an accepting environment — not only for the healing of PLHAs, but also for creating an environment that allows open discussion and disclosure. It also reduces the sense that HIV/AIDS is somebody else’s problem.

1.3 Purpose of the guidelines

These guidelines were developed to provide PLHAs, HIV/AIDS co-ordinators and managers within a workplace setting with practical and user-friendly recommendations on how to create a HIV/AIDS-friendly environment in an appropriate and effective manner. Although the research was conducted in a government workplace, we believe that many of the recommendations are relevant in other workplace settings. Additional sets of guidelines are available for the faith and PLHA sectors. These guidelines are not exhaustive and should be read in conjunction with other guideline documents produced on HIV/AIDS and stigma within the three sectors (see the Appendix: Useful resources).

The purpose of these guidelines is:

- to share the findings of the Siyam’kela research project in a user-friendly way
- to increase awareness among decision-makers in the workplace of the importance of creating accepting environments to reduce HIV/AIDS stigma
- to provide recommendations on how to develop an HIV/AIDS-friendly environment.

“Acceptance is the key to many doors. And acceptance is probably one of the keys to the stigma door too.”

Male person living with HIV/AIDS
The guideline was developed through several phases:

- First, the findings of the 23 focus-groups and 11 key-informant interviews were analysed, with a special focus on enabling factors for stigma mitigation.

- Next, a broad consultation was then held with reference-group members and participants in a consultative workshop. All participants involved in these processes have a wealth of HIV/AIDS knowledge and experience. Participants were representatives of the three chosen sectors – the workplace, faith organisations and PLHAs with media experience.

- National government was selected as an example of a workplace setting. A total of 50 employees from 12 government departments participated in five workplace focus-groups. Three focus-groups were held with employees from different levels within the public sector, namely levels 1-5, levels 6-8 and levels 9-12 staff (See Appendix B).

Two groups were held with union representatives and with national government HIV/AIDS co-ordinators. An effort was made to include representatives from each of the participating departments in each focus-group, including Agriculture, National Treasury, the Presidency, the Public Service Commission, South African Police Service, Land Affairs, Correctional Services, Housing, Justice, Arts and Culture, Science and Technology, and Social Development.

In addition to the focus-groups, eight in-depth interviews were held with director-generals – or their nominated representatives – from the participating departments. Three key-informant interviews were conducted with PLHAs working in different government departments.

- After the draft guideline document was developed, the document was circulated amongst 7 selected key HIV/AIDS experts for comment. Their feedback is reflected in this final set of guidelines.

This guideline document is divided into the following sub-categories:

- policy
- leadership
- interventions.
2. Findings about the government workplace

2.1 Policy

Findings

HIV/AIDS workplace policies have recently been finalised within many government departments. Most participants were aware that there was an HIV/AIDS policy in place. However, there was often ignorance regarding the content of such policies and uncertainty about its implementation, resulting in low levels of confidence in these documents. As a result the content of these policies are not well known by employees, and there is little confidence and widespread skepticism regarding the policies since they have not yet been ‘tested’ by a sufficiently large number of PLHAs in the workplace.

According to the director-generals or their representatives interviewed for the Siyam’kela research project, the policies in the various departments focus on HIV/AIDS stigma education, awareness raising and prevention, and offering voluntary counselling and testing and referrals. No departmental representatives mentioned policies that formally deal with the issue of stigma. It is hoped that the HIV/AIDS education and support offered in departments would indirectly deal with stigma by challenging myths about HIV/AIDS and positively shaping attitudes towards PLHAs.

The responsibility for implementing HIV/AIDS programmes usually lies with committees consisting of mid-level officials, with varying emphasis on the involvement of line managers. In some departments, the responsibility for implementing HIV/AIDS policies is the responsibility of a single official, presenting obvious capacity problems. Human resources and related staff (for example, Social Work Services and Special Programme Officers/ Employment Assistance Programme staff) are responsible for co-ordinating HIV/AIDS programmes within the departments. These staff members, however, lack the support of management and resources to implement a comprehensive, sustainable service.

“The policy is just there in name only. It’s there but nobody bothers to read it, and it is not enforced. So it’s like the policy is not really there.”

Level 9-12 government employee

“It is somehow shuffled into the human resources unit and no one wants to be the face behind [HIV/AIDS].”

HIV/AIDS coordinator
The study found that, irrespective of what the formal policy stated, the lack of confidentiality was a concern in the workplace. Specifically, it resulted in:

- gossiping among colleagues
- distrust of EAP staff (and in other settings of medical professionals)
- distrust of managers and supervisors, who were considered to have access to private files, including medical records.

**Recommendations**

a) **Conduct an HIV/AIDS policy analysis**

It is recommended that an HIV/AIDS policy analysis is conducted by all government departments. Such an analysis should focus specifically on the extent to which they address HIV/AIDS stigma. The analysis should also assess whether policies either produce or reinforce HIV/AIDS stigma. The analysis can be guided by tools such as those listed in the Appendix. Other resources. Once this has been conducted policies should be amended or sections added to existing policies to address HIV/AIDS stigma.

b) **Inform employees of HIV/AIDS stigma-mitigation policies**

The policy relating to stigma should be brought to life through presentations and workshops. Employees need to be aware of the policies in place in order to feel supported and in order to understand the consequences of discriminatory behaviour.

c) **Mainstream HIV/AIDS stigma-mitigation policies**

Just as all other aspects of HIV/AIDS policies should be mainstreamed, so should those related to stigma. Stigma-mitigation policies should be reflected in, for example, the content of communication strategies and strategic plans. This will ensure that stigma-mitigation is taken seriously and is addressed within the workplace.

d) **Monitor the implementation of policies**

All HIV/AIDS policies, and especially those relating to stigma-mitigation, should be monitored so that the policy does not only exist on paper but is put into action. This will also give the policy the necessary credibility.
2.2 Leadership

Findings

According to the participants in the focus-groups (representing various levels of employees), there was an erosion of employees’ confidence in senior management’s leadership and the proper management of HIV/AIDS. Specifically, employees felt that senior management was merely interested in keeping up appearances, rather than trying to effect genuine change, and rarely supported employees living with HIV/AIDS. Employees expressed a generalised sense of alienation from senior management.

These perceptions were considered to be as a result of:

- **insufficient support and commitment** from senior managers to HIV/AIDS issues
- a **perceived ignorance** of and **lack of interest** in HIV/AIDS issues by senior management
- the **responsibility** for management of HIV/AIDS strategy has often been **shifted** to the Human Resources Directorate with limited or no involvement of other business units
- **insufficient communication** between HIV/AIDS co-ordinators and senior management, which has led to the questioning of the source of information on HIV/AIDS by employees.

Recommendations

a) **Mainstream HIV/AIDS stigma mitigation interventions**

It is recommended that senior management take the lead for HIV/AIDS stigma-mitigation specifically and for HIV/AIDS as a whole. This would include both actively **supporting** non-stigmatising messages and interventions, while also **monitoring** the implementation of various HIV/AIDS and stigma-mitigation policies and programmes.

By actively taking responsibility, leaders may be able to bridge the perceived divide between staff and themselves. Visible management involvement has the potential to dispel the myth that the higher ranks of staff are themselves immune to HIV/AIDS, and sends out an important stigma-mitigation message that HIV/AIDS affects all.
The participants of the study recommended that a **programme manager** for HIV/AIDS should be located within each director-general’s office in order for it to be mainstreamed, prioritised and well resourced.

b) **Involve leadership directly**

It is crucial that management is committed to creating an environment that is free of HIV/AIDS stigma within their departments. One way this commitment could be demonstrated is through direct leadership involvement. This would not only involve **visible** leadership, but also **active participation** in HIV/AIDS stigma mitigation interventions at various levels. Leaders need to be the **face of the campaign** and to **lead by example**.

c) **Provide leadership training**

There needs to be an effort to **build the capacity of the leadership** to effectively create anti-stigma messages and take responsibility for the HIV/AIDS stigma-mitigation process. Training should include:

- sensitising managers to HIV/AIDS stigma by focusing on how it develops and what the consequences of stigmatisation are for PLHAs in the workplace
- exploring their own attitudes and prejudices and linking them to HIV/AIDS stigma.

d) **Include PLHAs in positions of leadership**

It is recommended that qualified senior managers living openly with HIV/AIDS should be appointed. These **leaders could be positive role models** and advocates for an HIV/AIDS-friendly environment.

3. **Interventions**

**Findings**

The workplace is considered an ideal setting for HIV/AIDS prevention programmes, as well as for the provision of treatment, care and support to employees infected and affected by HIV/AIDS. According to the director-generals or their representatives and focus-group participants, their government departments are currently involved in the following programmes:
a) **Educational programmes**
   - this includes peer education programmes, distribution of HIV/AIDS leaflets and posters, and utilising the internet to emphasise the promotion of healthy lifestyles.

b) **Awareness raising programmes**
   - promoting awareness through the use of stationery with red ribbons
   - highlighting special events – for example candlelighting ceremony, World AIDS Day and condom week
   - external PLHA consultants giving talks on HIV/AIDS

c) **Counselling services**
   - voluntary pre- and post- HIV test counselling

d) **Prevention programmes**
   - for example an extensive condom distribution programme

e) **Support groups**
   - for those living with and affected by HIV/AIDS
   - managing the needs of staff living with HIV/AIDS – aligning jobs to the needs of ailing staff

f) **Formal HIV/AIDS messages promoted by the South African government include:**
   - ‘condomise’
   - ‘government departments provide support’
   - ‘you will not be discriminated against if you are HIV positive’
   - ‘support people living with HIV/AIDS’
   - ‘HIV/AIDS is real’
   - ‘we can do something if we know your status’.

**Challenges for HIV/AIDS workplace programmes**

Despite these interventions and messages, very few employees have openly disclosed their HIV status in the workplace. Some participants mentioned that partial or informal disclosure does, however, occur in smaller groups. Some people are perceived to be taking greater precautions against contracting HIV because they have been personally affected by HIV/AIDS.
According to the findings of the Siyam’kela research project, the programmes seem to be hampered by several key issues:

- **the apathy** amongst employees concerning HIV/AIDS-related issues, especially among white and/or middle class staff, is an example of the consequences of ‘othering’, which has made some groups feel that they are not at risk of HIV infection
- apathy can also be linked to the HIV/AIDS information fatigue of many employees
- a further challenge in running interventions has been employees’ fear of stigmatisation and discrimination. As a result, very few employees have disclosed their HIV/AIDS status
- many HIV/AIDS co-ordinators have limited resources and competing demands, since HIV/AIDS is only one of many other responsibilities they have to spearhead within an already challenged department
- many HIV/AIDS co-ordinators were critical of the present approach taken by departments, recognising that their current training does not enable them to change people’s attitudes or behaviour. Training is lecture-based and there seems to be a lack of creativity when presenting the training. Furthermore, only a selected group of people is sent to the training.

**Recommendations**

**a) Conduct a stigma audit**

Before planning an intervention to address stigma, it is suggested that each department conducts a stigma audit to assess the **extent of the problem**, as well as the **local barriers and enhancing factors** of stigma mitigation. It is suggested that the audit refers to and builds on the Siyam’kela HIV/AIDS stigma-indicators.

The audit may include a survey of employees to assess their perceptions of PLHAs and HIV/AIDS and how these perceptions have influenced their responses to PLHAs within their departments. The audit will allow managers to assess the levels of stigma and to identify critical issues within various departments that need to be addressed. After the audit has been completed the findings should be shared with department staff members. During this
feedback session staff, especially PLHAs, should be included in planning interventions that address stigma-mitigation.

b) **Involve PLHAs to a greater extent**

One key recommendation is that people living with HIV/AIDS should be involved in all HIV/AIDS-related policy development, implementation and monitoring of programmes. Currently, ten departments have involved people openly living with HIV in their HIV/AIDS programmes. People living with HIV/AIDS have unique experiences and expertise, which could be used as a resource. By **involving PLHAs**, workplace policies will be more likely to reflect the concerns of employees living with HIV, as well as give credibility to the HIV/AIDS programmes. PLHAs could also be effective spokespersons for stigma-mitigation.

**Positive role models** of employees living with HIV/AIDS within the workplace will demonstrate that the environment is supportive of PLHAs. Such role models will also begin to de-stigmatise the disease by, for example, proving HIV/AIDS myths as incorrect.

The principle of the *Greater Involvement of People living with HIV/AIDS (GIPA)* should be applied more widely in the government workplace. The **GIPA principle** encourages workplaces to involve PLHAs themselves in addressing the pandemic and to so enable PLHAs to act as HIV/AIDS advocates for positive living. PLHAs have unique experiences and expertise that should be used as a resource.

It is suggested that **PLHAs be trained** in:

- disclosure
- issues of stigma
- coping skills to assist with the discovery of, and acceptance of, their HIV-positive status
- advocacy
- presentation and public speaking skills
- peer counselling
- knowing their rights and the HIV/AIDS policies or policies that relate to HIV/AIDS within their departments
- making them aware of their redress possibilities
• referral services – being aware of the services and care offered by their department and partner organisations.

c) Provide training and awareness raising
Staff at all levels should participate in training, sensitising them to HIV/AIDS stigma, how it functions and its consequences for PLHAs, the workplace and society. Existing training should be participative and not lecture-based.

d) Commit to visible care and support of PLHAs
Staff who are living with HIV/AIDS need to know that if they disclose their status in the workplace, they do so in a caring environment. If care for and support of PLHAs is clearly visible, PLHAs will be more likely to make their HIV status known.

e) Move beyond information provision and condom distribution
Many studies have shown that information does not necessarily change behaviour. In addressing stigma, interventions should refer back to models that have rather focused on changing attitudes. Training should include unpacking underlying assumptions and beliefs, which are closely linked to HIV/AIDS stigma, such as diversity issues, racism, sexism, and classism. This training will require skilled facilitators.

f) Mainstream HIV/AIDS stigma-mitigation messages
It is important that the stigma mitigation messages are not only limited to annual events or to certain staff levels. It is suggested that the message should be integrated with other workplace HIV/AIDS messages and that creative opportunities to spread the stigma-mitigation message should be encouraged. HIV/AIDS stigma-mitigation training, for example, could be held during staff meetings so that it is integrated within daily routines.

g) Use non-stereotypical images and concepts of PLHAs
When sharing HIV/AIDS-prevention messages within the workplace, it is strongly advised that these messages are representative of the HIV/AIDS epidemic and not presented by stereotypical images or concepts, such as depicting PLHAs as frail and sickly, or HIV/AIDS as a gay men’s disease. Such images and concepts add to the feeling of hopelessness and the perception that PLHAs should be avoided. They also allow people who do not associate
themselves with the stereotypical images to feel immune to the disease and not respond to prevention messages.

Images and concepts that should be avoided include:

- those focusing on high risk groups (e.g. truck drivers, commercial sex workers, injecting drug users). Instead they should focus on risk behaviour (e.g. unprotected sex, sharing syringes)
- images of PLHAs as ‘promiscuous’ and ‘immoral’, and as a danger to colleagues
- images of PLHAs as being ‘on death’s door’ and unable to live fulfilling lives because of their HIV-positive status
- understanding of HIV/AIDS as a ‘scourge’ or plague
- understanding of some PLHAs as innocent, which implies that some PLHAs deserve to be infected
- ‘us and them’ talk.

HIV/AIDS prevention messages should rather:

- focus on risk behaviour and not risk groups
- show that HIV/AIDS does affect all people – all ages, cultures and genders
- use positive language that is inclusive and sensitive, for example, using the term people living with HIV/AIDS.

h) Monitor interventions for their sensitivity in relation to stigma

It is important that all HIV/AIDS interventions are monitored for their sensitivity in relation to stigma so that such interventions do not contradict other stigma-mitigation messages within the workplace.
Appendix A: Useful resources

Publications

- Department of Health. (2002). *HIV/AIDS in the Workplace.* (Pamphlet) Includes a brief overview of the basic rights of HIV-positive employees, information on the transmission of the virus, and a short checklist of good practice for employers.


  Provides practical tips on how to integrate HIV/AIDS response to existing social, financial and occupational systems.


  Provides guidelines relating to HIV/AIDS policy and planning, workplace HIV/AIDS programmes, and reporting, monitoring and evaluation. It also contains a list of references, contacts and useful websites.


  The media scan provides a context for the Siyam’kela fieldwork, so that the reader has a snapshot view of how HIV/AIDS was portrayed in the popular television, radio and print media in South Africa at the time that the field research was undertaken.


  Proposes indicators for measuring internal and external HIV/AIDS stigma. Highlighting the indicator’s relationship to existing stigma, suggesting methods for verification in different contexts and listing conditions for the use of indicators.


  Provides a theoretical understanding of the origin, and manifestation of HIV/AIDS stigma and highlights the challenge for a stigma-mitigation process.

Describes best practices in stigma mitigation identified during the *Siyam’kela* Research Project fieldwork from: the faith-based response to HIV/AIDS, media reporting on HIV/AIDS particularly, the relationship with people living with HIV/AIDS, and national government departments as workplace environments.


The document recognises ‘that people living with and affected by HIV/AIDS should share the lead and responsibility in responding to the epidemic, while encouraging society to create the space for them to play this role’. It emphasises empowerment and leadership and is a guiding principle that should be applied to all elements of the HIV/AIDS epidemic. It is based on the recognition that ‘no community, government or institution can alleviate the impact of HIV/AIDS without embracing those infected or affected’.

**Websites**

- [http://www.ilo.org](http://www.ilo.org)
  The website provides details of the International Labour Organisation’s *Code of Good Practice on HIV/AIDS and the World of Work* (including programme guidelines and a code of practice). It includes mitigation of the impact of HIV/AIDS on work, care and support of infected and affected workers, and elimination of stigma and discrimination. It also provides a clear argument as to why AIDS needs to be considered a workplace issue.

  The site provides access to the Department of Labour’s *Code of Good Practice on Key Aspects of HIV/AIDS and Employment*. The document includes a list of principles, and information on workplace policy, confidentiality of HIV status, disclosure issues, occupational benefits and managing risk.
http://www.doh.gov.za
The website, run by the Department of Health, provides access to *HIV/AIDS and Sexually Transmitted Diseases in the Workplace*, published in 2000. The document outlines policy on issues such as confidentiality, recruitment principles in relation to HIV/AIDS and workplace injuries.

http://www.dpsa.gov.za
The Department of Public Service and Administration website provides access to the comprehensive and exhaustive 158-page document entitled *Managing HIV/AIDS in the Workplace: A Guide for Government Departments* (see above).

http://www.undp.org
The website of the United Nations Development Programme outlines the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, and the unique contribution that PLHAs can make to workplace and other programmes. It provides contact details for organisations wishing to utilise the GIPA principle.
Appendix B: National government departments

Different staff levels

Level 1: Cleaners
Level 2: Cleaners 2 and clerks grade 1
Level 3: Secretaries, clerks grade 2
Level 4: Senior secretaries grade 1, senior clerks grade 1
Level 5: Senior secretaries grade 2, senior clerks grade 2
Level 6: Senior secretaries grade 3, senior clerks grade 3
Level 7: Administration officers, planners
Level 8: Senior administration officers, senior planners
Level 9: Assistant directors first leg, principal planners
Level 10: Assistant directors second leg, chief planners
Level 11: Deputy directors first leg
Level 12: Deputy directors second leg
Level 13: Directors
Level 14: Chief directors
Level 15: Deputy director-generals
Level 16: Director-generals

The terms grade and leg refer to experience, years of service and qualifications.
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<th>Departments</th>
<th>Director-generals or nominees</th>
<th>Level 9-12</th>
<th>Level 6-8</th>
<th>Level 1-5</th>
<th>HIV/AIDS co-ordinators</th>
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