



DIVERSE COMMUNITIES

Consultation to Explore Peoples' Views on Organ and Tissue Donation

Discussion with Chinese Canadians

Toronto: 2005

SUMMARY REPORT TO PARTICIPANTS



Who is this report for?

This report is for the people who participated in the Diverse Communities Consultation. It is also for their families, their neighbours, and members of their communities. The Canadian Council for Donation and Transplantation and the other organizations that participated in the consultation are grateful to all the individuals who so generously opened their hearts and minds to share their beliefs, values, and opinions. This report honours CCDT's commitment to share the results of the consultation with its participants.

About the Canadian Council for Donation and Transplantation

In 2001, the Canadian Council for Donation and Transplantation was established to advise the Federal, Provincial, and Territorial Conference of Deputy Ministers of Health about the shortage of organs and tissues for transplantation. The CCDT helps coordinate federal, provincial, and territorial activities to develop standards, policies, and best practices for organ and tissue donation and transplantation.

Why were the consultations held?

In 2005, 4025 Canadians were on waiting lists for organ transplants. Over half of these people—2758—needed kidney transplants. This includes a large number of Chinese-Canadians. Successful transplants depend on finding a suitable match. A suitable match usually means that the donor and recipient must have similar biological traits—like matching blood types. That is why suitable matches are usually found among family members and among people from the same racial or ethnocultural background.

Sometimes people stay on waiting lists for up to a year or longer. Of course, the longer they wait, the more likely it is that their health will get worse. In the Chinese community in Toronto, the waiting time for a kidney transplant can be as long as eight years because the donation rate is low. It is this gap between the need for organ and tissue donations and the supply that prompted the CCDT to organize the Diverse Communities Consultation.

What do we mean by organ and tissue donation?

A **living donation** takes place when someone donates an organ or part of an organ to another person. This would usually be a kidney or a portion of a liver. Everyone has two kidneys and someone can live well with only one. A person can donate a portion of their liver and the remaining portion of liver will regrow to a normal size.

A **deceased organ donation** takes place when someone dies suddenly and loved ones agree to donate organs of the person who has died. The heart, liver, kidneys, pancreas, lungs, small bowel, or stomach are organs that can be donated.

Tissue donation takes place when someone has died. Tissues that can be donated include corneas, heart valves, bones, and skin.

Someone can receive an organ or tissue transplant in any of these three ways. These are all called “transplantation.”

Why were these communities chosen?

Canada's population is already very diverse. We represent many races, ethnic groups, cultures, and religions. But by 2017 it is likely that 23% of Canadians will identify themselves as "racially visible" and 4% will call themselves Aboriginal. The largest racially visible communities will be Chinese, South Asian, and black. In cities such as Toronto and Vancouver, certain ethnocultural communities will form the majority of the population.

These are some of the reasons why the CCDT chose to consult members of the South Asian communities of Vancouver and the Lower Mainland, members of Toronto's Chinese community, and Aboriginal peoples in Winnipeg and Saskatoon.

Other participants

In each community, a local donation and transplantation organization contributed to and participated in the consultation. These organizations were: **The British Columbia Transplant Society, Manitoba Gift of Life, Saskatchewan Transplant**, and the **Trillium Gift of Life Network** (Ontario).

What were the goals of the consultation?

The general goal of the consultation was to learn more about the beliefs and views of people from these communities and how those influence what they think about organ and tissue donation and transplantation. The goal was not to change people's views, but to try and understand them. In the end, the CCDT hopes that every Canadian will have the chance to consider donation and transplantation in a culturally sensitive and respectful way.

The consultation had three specific goals.

- To find an appropriate and respectful way to discuss donation and transplantation with each community.
- To learn about participants' beliefs and views about organ and tissue donation.
- To help create partnerships between these communities and their local donation and transplantation programs.

From the first planning stages, the consultation was guided by six values.

Appreciation of Diversity. To understand, not judge. To listen, not teach. To truly admire the cultural views being shared.

Collaboration. To build on existing local activities. To share results with participants.

Integrity. To be completely open about the purpose of the consultation, its guiding values, the processes used, and the use of the results.

Excellence. To plan the consultation using available evidence and the advice of local people. To learn from each session and apply what was learned to the next one.

Capacity Building. To focus on each community's unique ability to contribute. To recognize and work from each community's assets and strengths.

Learning. To be open to new ways of doing things. To be willing to hear that individuals or groups have cultural reasons for not wanting to donate.

How was the consultation carried out?

Donation and transplantation are sensitive subjects. They are more than simply medical treatments for a disease. They touch people's deeply held beliefs about illness, death, care of the dying, and the body after death. Decisions about donation and transplantation must be made in the context of people's religious, cultural, political, and personal experiences involving health and health care.

The CCDT wanted to make sure that everything about the consultation was done ethically. The participants were all volunteers. Participants were asked to sign a consent form that outlined the purpose, context, and scope of the consultation. All consultation materials were reviewed to make sure that they were culturally sensitive and in agreement with the consultation values and principles.

Five principles were recognized in carrying out the consultations.

Heterogeneity of Populations. This means that there are differences to be acknowledged, even within an ethnocultural or Aboriginal community. There may be differences in languages, religions, traditions, and countries of origin. There are also differences between urban and rural residents, between individuals who live on- and off-reserve, between young and old, and between newcomers to Canada and long-time residents.

Individuality of Participants. Each participant must be recognized as an individual, not just as a member of a group.

Role of Local Community Representatives. Local community representatives must be invited to participate as partners, to help choose topics, to recruit participants, and to help make arrangements.

Flexibility. At all stages of the consultation, it was important to be willing to adapt to the community's needs and to be willing to make changes.

Relationships and Trust. It takes time to build relationships and trust. Because the consultation organizers were not members of the participants' communities, it was important to work with existing community organizations. It was also important to use interviewers and facilitators from the community.

For the consultation in Toronto, the CCDT asked representatives of Toronto's Chinese community to form a committee to advise us and to help us connect with community organizations. The committee suggested that we hold focus groups and conduct two surveys, one with Chinese Canadians and one with family physicians who care mainly for Chinese patients.

The committee was very helpful in advising us about appropriate cultural practices, such as giving gifts, and in finding people to take part in the surveys and the focus groups. Its members also reviewed the letters of invitation, consent forms, and surveys.

How was the Chinese community involved?

Focus Groups

Three focus groups were held with 44 people participating. Their ages ranged from the mid-20s to 92 years old. About two of every three participants were women. Most of the participants were not born in Canada. Many were born in Hong Kong, but had lived in Canada for 20 years or more.

Two of the focus groups were organized and hosted by the Yee Hong Centre for Geriatric Care and the third by the Chinese Cultural Centre of Greater Toronto. A facilitator led the groups. The main language spoken was Cantonese, and a translator provided translation in English, Cantonese, and Mandarin.

Survey of Chinese Canadians

A survey was developed that asked questions like the ones asked in the focus groups. It was written in English, simplified Chinese, and traditional Chinese characters. Most of the surveys were completed in English and/or traditional Chinese.

It was distributed through personal contacts, by word-of-mouth, and to these groups:

- a meeting of the Scarborough hospital Chinese Outreach Committee
- participants in recreation programs at the Chinese Cultural Centre of Greater Toronto
- staff, patients, and family members at the Scarborough hospital Hemodialysis Unit
- members of the Chinese Renal Association
- a youth group meeting at a Chinese Baptist Church

All together, 110 people completed the surveys. Just over half of them were completed by women. Most of the people who filled them out were between 45 and 54 years old. There were a few filled out by people over 75 and some completed by young people under 25. Almost two-thirds of the people were born in Hong Kong, 10% were born in Canada, and 10% were born in China. Over 70% of them had lived in Canada for 16 years or more. Over 80% of them had finished high school or had a post-secondary school education.

Survey of Physicians

There was also a survey of family physicians. They were not asked for their personal beliefs about organ and tissue donation and transplantation. The questions were directed to them as physicians. The survey had three themes:

- the physician's role in advising patients
- Toronto's Chinese community
- future possibilities for the role of physicians in organ and tissue donation

The survey was distributed at a dinner meeting of members of the Journal Club of Chinatown Physicians, to which the members of the Uptown Doctors Association were invited. The meeting was co-sponsored by the CCDT and the Trillium Gift of Life Network. There were two presentations on organ and tissue donation and transplantation, followed by a question and answer period.

Twenty-one physicians completed the survey. They were all Chinese family doctors, whose patients were mainly from the Chinese community in Toronto.

What did Chinese participants say?

*... from **Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation***

“All consultation participants shared their ideas and feelings openly and generously. This Summary Report cannot begin to encompass the rich details they provided about their personal experience with organ and tissue donation and about the impact of the beliefs embedded in their cultures and faith traditions.”

In all consultations, five topics were discussed.

1. The participants' awareness of and experience with organ and tissue donation and transplantation
2. The participants' views on organ and tissue donation
3. The traditional values and beliefs that influence donation and transplantation
4. Suggestions about support for making a decision about donation
5. Relationship building within families and communities

1. What is your personal awareness of and experience with organ and tissue donation and transplantation?

Most participants in the focus groups said that they did not know very much about donations:

I'm in a nursing program. I've been in the program for three years. But today is the first time I've heard about the three kinds of donations. I'm happy to hear about it.

I've worked as a volunteer for a senior centre since 1992, and this is the first time I've heard about organ donation and transplantation. Even kidney transplant, I have not heard about before.

Those who completed the survey also did not know a lot about organ donation, and some of them calling for more public education:

I think more awareness is necessary, especially towards youth.

There needs to be more promotion to encourage people to give.

Only a few participants in the focus groups personally knew someone who had received a transplant or given a donation. Two groups mentioned a pastor who had received a kidney transplant from a member of his congregation and spoke publicly about the value of donation and transplantation. In the survey, four out of ten respondents said they knew someone who had received a transplant in Canada, while almost one out of three respondents knew someone who had donated an organ or tissue. Several participants in the focus groups had signed a donor card themselves and/or knew of people who had signed a donor card.

There were many questions about donation and transplantation during the focus groups. These are some of the questions that were asked.

- Does age or illness keep someone from donating?
- How is the health of the donor affected?
- Can donations be directed to family members?
- How do donor cards work?
- What part does the family play? Must they approve, even if I've signed a donor card? What happens if the family doesn't approve? Who in the family has to approve?
- How do health care professionals and the health care system keep track of donors?

2. How do you feel about organ donation and transplantation?

General views

In the focus groups most people believed that people do not think very much about donation and transplantation. In the focus groups and in the survey, people said that there is a lack of information and education about the issue. They also said that some traditional beliefs (mostly, the belief that one should be buried whole) worked against donations.

What I hear mostly is that people are scared of it as there is still the old concept of being buried whole.

Most comments I hear are negative. People worry that you lose something, when something is cut off.

In the survey, most of the responses were positive, with some comments showing respect for those who had made a donation:

I think that organ transplantation is one of the greatest progresses in life-saving medical science. I am expecting that it will save many more human lives.

I honestly believe that all organ donors are angels.

I think donors are very compassionate, generous, and courageous.

Some participants, however, were concerned about the health and safety of the donor and about how difficult it was to make such a decision (particularly for family members).

Views in favour of donation

People in the focus groups who were in favour of donation seemed to be expressing evolving views rather than the more traditional beliefs.

I've been dealing with science and engineering my whole life. So for me, after death, the body returns to nature. It's part of a natural cycle. . . . It's better to donate as the body will just disintegrate.

More people are now being cremated. So after death, the organs are useless unless donated.

Many participants in the focus groups talked about the importance of donating in the Chinese culture. They spoke about the value of donating money and time, and believed that organ and tissue donation could be seen as another form of donating—of contributing to others.

You give your time as a volunteer or you give out money because you have an excess that you can share with others. But now you can do something more, which is that a donation can be an organ, can be your living tissue.

Giving is more than gifts and flowers.

Yes to donation, but with limitations

About one-quarter of the survey respondents who were willing to donate an organ said that they would place some limits on their donation. Some mentioned that they did not want to donate particular body parts. Most did not want to see their bodies used for experiments or medical research. Others placed limits on those who might receive their donation:

I don't want my organ given to criminals, terrorists, etc.

If it is a lung, that the person doesn't smoke. If it's a kidney, that the person doesn't drink.

I would like my organs to be donated to kids first.

Over half of the survey respondents were willing to make a living donation, for example, to donate a kidney while they were still alive.

Views on receiving a donation

In two focus groups, people were asked if they would accept a donation if they needed one. Most people said that if they were over age 70, they would not accept a donation—that the organ should go to someone younger:

I've already lived a full life. Death is a must, so whether I live a longer or shorter life doesn't matter to me.

I am 80 and I have had enough for this life.

In the survey, eight out of ten respondents said that they would accept an organ transplant if they needed one. They noted that the transplant would extend and improve the quality of their life, and would avoid leaving family behind.

Concerns about both receiving and donating organs

Both focus group participants and survey respondents were concerned about medical issues. Some feared the operation itself, while others wanted to know how successful transplants were. A number of people showed concern for the health of the (living) donor. It was clear that people were not willing to risk the health of others to receive a donation. Many believed it was important to educate people about the risks to the donor.

I would not accept, because, even if it doesn't affect their health immediately, it could affect the health of the donor later on in life. Who knows?

If it would not affect the health of the donor, then I would accept.

One participant shared a story of a man who had made a living donation to his sister. Becoming a living donor meant that he had to take time off work, which caused some tension in the workplace. Participants talked about how important it is to educate employers about living donation.

When my colleague donated his kidney to his sister, he had to take sick leave and the boss was not happy. . . . Most of his coworkers accepted it as it was for his sister—but some people had to do his work too and they complain. . . . Some people may not make a donation because they feel their boss may not like it.

There was also the view that the donation might go to people not worthy of the donation:

Can one have access to information about the receiver? The reason I ask is because I think everybody here would like their donated body parts to go to a good person, someone who had made a contribution to society. They don't want to donate to a prisoner or somebody who is very bad.

Most survey respondents said that it would be fine for a family member to accept a donation from someone who was not of Chinese descent. People believed that having a compatible match was more important than the ethnic origin of the donor:

Race doesn't matter as long as it matches.

Life is more important than ethnicity.

There were a few people who did not agree with accepting a donation from someone of non-Chinese descent:

I am very conservative about this matter.

Only if there isn't any other choice.

3. What are your views about traditional values and beliefs, and how do they influence what you think about donation and transplantation?

In the survey, two out of three respondents said that their decision to donate would not be influenced by their faith. The question did not ask what the respondents' faith was, but just whether or not their faith would affect their decision. Most survey respondents said that they would not talk to their religious or spiritual leader about organ and tissue donation and transplantation.

Five themes were identified in the responses to the survey question "What are the most important beliefs/concerns (religious or non-religious) that influence your perspective on organ donation and transplantation?"

The first and most common theme was about the good of giving:

It's a gift of humanity.

To give is better than to receive; everything is in God's hands.

I believe that the donation of organs is an act of kindness and shouldn't be in conflict with my Buddhist faith.

A second theme was that the body was of no use after death and so donation was acceptable:

"The body is useless after a person is dead."

The third theme was the traditional belief that the body must be buried whole. Only six survey respondents mentioned this, but it came up frequently in the focus groups as a barrier to donation. Most focus group participants said that this belief is changing and is not held by most younger Chinese Canadians. People thought that this belief should be addressed in an education campaign.

It is a traditional Chinese viewpoint that all parts of the body are given by the parents and we are not supposed to hurt any part of it. This is part of filial piety—a very old concept. Your parents have given you a complete body; you should be buried whole and complete.

In my father's generation, some people believe in the Buddhist concept of reincarnation of life. So they may have an unfounded belief about whether a person, if an organ has been removed from his body, can be reincarnated whole in the next circle.

For some survey respondents, the view of "wholeness" was based on tradition, while for others; it was based on the fear of having their bodies taken apart.

I could not imagine myself being dismembered and treated as some kind of material without respect. Sorry, I have such an impression because I have witnessed such a situation before.

My belief that I would feel the pain and would hate the person cutting me apart.

The fourth theme among survey respondents related to health concerns:

I am frightened by the thought of an organ transplant and the difficulty of undergoing such an operation.

[It] concerns me . . . that I smoke and drink. Will that make my organs unhealthy to donate?

A final theme that emerged from the survey related to family:

It is probably the decision of my family. Having a Chinese family background, I can imagine that it would take some time to get approval for my decision to donate.

A belief that was discussed in the focus groups was “predetermined destiny”. One participant used a Chinese proverb to explain the idea:

One’s riches are destined, by God or the sky, and one’s life is also destined or guided by the sky, or heaven, or God. . . . Whether one is rich or poor or dies early or dies old, one cannot control. It’s all to do with luck, or God, or heaven.

4. What kind of support do you think is required to help you make decisions regarding organ donation?

In thinking about who should make the decision about donating, about two-thirds of survey respondents believed the decision to donate was a personal one to be made by the individual alone. Among the third who thought it should involve others, most said that family (spouse, parents, and other close family members) should be consulted.

In the focus groups, there was great concern that a family could reverse a donor’s wishes after they had died. Several participants repeated the view noted in the survey, that the individual should make a decision about donation, and that their decision should be respected. Among survey respondents, three-quarters were very confident that their family would respect a family member’s decision to donate. There was strong support for respecting an individual’s decision.

Finally, participants suggested that it would be important to talk it over with one’s family members so that they were aware of the individual’s wishes.

Since the family has overriding power, whether a donor signs a card or not, it’s better that the donor, before signing the card, talk with the family members and get consensus and agreement before signing. Then there would be no problem and no argument after death.

In two focus groups, participants were asked for their advice on how a family could be respectfully approached to donate a deceased family member’s organs. Participants said that the request could come from a respected person such as a physician or a spiritual leader. The request should also be made in the language most comfortable for the family.

Most Chinese believe in doctors, and if they have been going to see the same doctor for a while then there is a bond. You believe in that person’s skill. If I take the medication the doctor prescribed, I will be healed—that kind of belief. So if it’s an old person who is chronically ill and been seeing the same doctor for while, there is respect and support.

If the family is Cantonese-speaking, you have a person of authority who is Cantonese asking the questions. If the person can explain things in Cantonese, it will be much easier.

There were a number of suggestions about the way a request could be made, and the types of messages that should be stressed. Many of these were about the privilege of donating—of helping another person.

Since the family is grieving about their dying relative, maybe one could alleviate the grieving of somebody else waiting for an organ to sustain or prolong life. Would you consider having other families not grieve about a family member dying?

Donating an organ helps that person live on in another person.

Participants in the focus group expressed the idea that donating brings honour to a family. This is based on a traditional idea that an individual's actions can bring honour to the family. Some suggested that the family could get a certificate or some sort of sign of respect when one of their family members donated. Many liked the approach used by the Trillium Gift for Life Network, of giving out medals to the families of donors. Not all agreed that recognition was required, though.

In China there is a very popular way of doing things like this. If you do something good, they say this honourable family. The whole family is happy about it.

Having a certificate would help to educate the offspring that it is a good idea to donate organs after death.

I am against the idea of recognition either monetarily, which is the worst kind of reward, or even a certificate—because the donor gave voluntarily and there is no need to publicize or advertise about the dead person.

As for messages, people suggested that it would be important to give practical and technical information, such as success rates.

Organ transplant is a technical solution . . . so family members should be made aware of the success rate of donating an organ. If they have this information it would be easier for them to make a decision.

Another way to encourage donation was raised in two focus groups. They believed that the family of the person donating could receive a “credit,” in case a family member needed a donation in the future.

What if I donate organs, would my relatives or my family members' offspring have a priority in the future? Could there be a credit for the family in case in the future someone in the family needs an organ transplant—they can move up the list in priority?

The family members may not need a donation at the time of the deceased, but one day a son or daughter may need one. It would be peace of mind [to know they would be more likely to get one].

This idea seemed popular with many participants, perhaps because it relates to the importance and duty of family, which seems to be a strong belief in Chinese culture.

5. How is it best to build relationships in this area?

Focus group participants believed that education and promotional campaigns to promote organ donation were very important in the Chinese community. People believed that lack of information was a key reason why people did not donate:

I think the major problem is that people lack information—where you can donate organs, where to get information, what institutions to contact. I think there is an education barrier between people that want to donate and people that accept donations.

Several participants gave examples of work already done in Hong Kong:

In Hong Kong, many people have signed donor cards because it was widely publicized and promoted by the British Hong Kong government. Movie stars were involved in the campaigns, for the younger generation; most of them signed the donor space on their driver's license.

There should be statistical information too: How many people are on the waiting list? In Ontario? In your community? Direct information.

On the other hand, among survey respondents, more than half believed that they had enough information to make a decision about being a donor. Of the remaining group, the type of information they wanted fell into three categories. The first focused on information about the medical process, including the operation itself and the impact on one's health:

How long does it take? How painful it is? How do they repair the body?

[What are the] risks, side effects and length of life after transplant?

The second type of information requested was about the donor process:

How do I know if my organs are healthy enough for other people? Or will someone check that?

How the match is made? [Is there] any obligation to get in touch between the two parties? Will the background of the donor be revealed?

The need—tell me why it's needed, what other options are available, the number of people in need.

The final area of information needed relates to how the body is left after the organ(s) have been removed.

I would like to know how they will treat the rest of my body. I still want my remains to look good and be in one piece, even if they take things out of me.

Which organs can I donate and still have an open casket?

Focus group participants believed that religious organizations and physicians could help educate people about donations. More than one-third of survey respondents said that they trusted their

spouse most in helping them make the decision to donate. For about one-quarter of respondents, their physician was trusted the most.

Finally, the survey asked respondents how they would like to receive information about donation. Most people – one in five – preferred printed materials, with television running a close second.

What did the physicians say in the survey?

Advising Patients

Of the 21 physicians who completed the survey, 20 said that it was important for physicians to discuss donation and transplantation with their patients. However, it seems that this subject is rarely, if ever, discussed with patients. Most of the physicians were willing to help educate patients if more educational resources were available for both the public and physicians. Some said that education material for patients should be available in Chinese.

When asked how they wanted to receive information, the physicians said:

- printed materials (This was the most requested format.)
- information sessions at regular physician meetings
- seminars
- email notices
- website alerts (This was the least requested format.)

Patient Perspectives

Since most of the physicians rarely had the chance to discuss donation and transplantation with their patients, many of them said that they were not sure if their patients would sign donor cards or would accept a donation. However, almost half of them thought that their patients would not be very willing to sign a donor card. And almost two-thirds of them believed that their patients would accept a donation.

Future Opportunities

Almost all of them agreed that family physicians can help their patients be more informed when considering donations. One way would be to talk to their patients.

Medicine is based on scientific knowledge. As a doctor, one knows donation/transplants are part of current medical treatments available to patients. Thus a family doctor can explain it to their patients in a rational way.

Tell the patients that there are many Chinese on the waiting list.

Tell the patients old organs are useful too. Make it a routine in patient registration to discuss donation.

They made suggestions about how to increase donations. These included public education through the media (e.g., newspaper, TV, talk radio shows), public meetings (including meetings with high-

school students), presentations by recipients, donor cards in Chinese. Finally, almost half of physicians suggested involving other associations of Chinese Canadian physicians.

What did we learn?

This consultation gave the CCDT the chance to hear the views of members of Toronto's Chinese community on this sensitive subject. We learned their views on traditional values and beliefs and how these may be changing, and how they influence people as they make decisions. This information is important to helping us deal with the growing gap between the need for and the supply of organs and tissues for transplantation among Chinese Canadians.

We learned that the Chinese community needs more information about donation, and that Chinese family physicians seem to be willing to help educate people. We also learned that public education messages about the value of giving, the generosity of the donor, and the good fortune of the recipient might be appropriate.

Where can I get more information?

The complete report on the Diverse Communities Consultation and all background reports are available on the Canadian Council for Donation and Transplantation website. Reprints of the report can also be obtained by contacting the CCDT.

If you want to know more about organ and tissue donation and transplantation, you can contact these organizations or visit their websites.

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(204) 787-1897
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http://www.health.gov.sk.ca/ph_br_ae_orga_n_donor.html

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Canadian Association of Transplantation

Transplant Programs

http://www.transplant.ca/cancon_transprogram.htm

Donor Programs

http://www.transplant.ca/cancon_donorprog.htm

Canadian Diabetes Association

www.diabetes.ca

Canadian Liver Foundation

www.liver.ca

Heart and Stroke Foundation of Canada

www.heartandstroke.ca

Kidney Foundation of Canada

www.kidney.ca

or

La Fondation canadienne du rein

www.rein.ca

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