

newsletter

Welcome to the INVOLVE newsletter. In it, we share with you some of the highlights of our conference in November 2010 and provide a snapshot of the issues that were raised. We also have information about two new INVOLVE publications that share examples of public involvement in social care research and user controlled research. As always, we want to hear about your experiences – please tell us about any examples of public involvement in research that you know of.

Report of the INVOLVE 2010 Conference – Public involvement in research: innovation and impact

By Ruth Stewart, Researcher, University of London

The number of people and range of presentations at INVOLVE's 7th Biennial Conference was unprecedented – over 430 delegates came from throughout the UK, as well as from overseas. They made full use of the two day conference in Nottingham in November 2010 to share and discuss activities, ideas and challenges around involving patients and the public in health, social care and public health research. [Continued →](#)

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INVOLVE's 7th Biennial Conference

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

The conference, which centred on the themes of innovation and impact, was opened with a keynote speech from the Department of Health's Director of Research and Development, Dr Russell Hamilton CBE. He spoke of the importance of patient and public involvement to him, and the fundamental role he believes it plays in facilitating the high quality research which is needed for a high quality health service. His account of the central importance of patient and public involvement, both to the National Institute of Health Research (NIHR) and to government, was both reassuring and inspiring for the many researchers, patients and members of the public in the audience.

What followed this opening was an impressive array of opportunities for delegates to contribute, learn, discuss and debate patient and public involvement in research with a further 48 papers presented and 47 posters displayed, as well as workshops, discussion and information sessions.

There were examples of involvement in research across health, social care and public health, including service-users' own accounts of their involvement. Reported activities spanned research designs and used a range of models for involvement, with examples from throughout the UK and further afield. In addition, delegates learned of a number of structural programmes to support and facilitate involvement, both within NIHR and across other institutions. There were presentations and workshops designed to inform and train participants in a range of topics. Presenters also focused on the cross-cutting principles of involvement and explored underlying theories. Last, but by no means least, was a focus on the impact of patient and public involvement in research – how and why it might be measured and what the state of the evidence base is thus far.

All of this activity was brought to a close with the second keynote speech, delivered by the Chief Executive of the Association of Medical Research Charities, Simon Denegri. Whilst Simon spoke of the challenging context in which we are working, with fundamental changes underway in health, social care and public health services and research, he also outlined the opportunities which we face. In particular he urged us to stick close to the people we seek to serve, continuing to listen to patients and the public and remain loyal to our principles. He spoke of the importance of making greater connections between the various patient and public involvement activities, and developing strategies for increasing partnership working. Lastly he encouraged us to remain positive, persistent and patient in providing sceptics with the evidence of how public involvement makes a difference and why it can make research better.

For further information see the conference report on:

www.invo.org.uk/INVOLVE_Publications.asp

The conference programme and presentations, as well as Russell Hamilton's PowerPoint slides and a transcript of Simon Denegri's speech, are available on www.invo.org.uk/Conference.asp



There were opportunities for delegates to contribute, learn, discuss and debate



The conference enabled the sharing of ideas and perspectives

A snapshot of the issues raised at the INVOLVE 2010 Conference

People attending the conference had several opportunities to raise issues for discussion. They were invited to note down 'burning issues' and post these on a specially provided noticeboard. A 'soap box' session, facilitated by Lester Firkins from the James Lind Alliance, gave delegates a further opportunity to take the floor for three minutes and have their say.

A few of the views expressed were:

- Calls from service-users for better feedback about the activities in which they take part, including research projects and even conferences such as this one
- Questions about payment for involvement and calls for clarity and guidance
- Calls for self-reflection about what works and promotion of sharing personal stories about impact to contribute to the growing body of evidence
- A question about the availability of and need for those with specialist research skills alongside and in addition to service-user researchers.

INVOLVE Coordinating Centre News



**People in Research website:
sign up to receive email alerts**

People in Research is a web based resource for members of the public who are looking for opportunities to get involved in research activities. Researchers and research organisations can advertise their opportunities on the website. From February 2011 you will be able to sign up to receive email alerts on your chosen topic or activity. You will be able to choose to receive daily or weekly alerts on any new opportunities registered on the website.

Please visit the website and try it out and do let us know what you think – we welcome feedback on the website. www.peopleinresearch.org



Patient perspectives report

In March 2010 the Academy of Medical Sciences (AMS) was asked by the Department of Health to conduct an independent review of the regulation and governance of medical research. The review was chaired by Sir Michael Rawlins. The report 'A new pathway for the regulation and governance of health research' was published in January 2011 and is available on the AMS website:

www.acmedsci.ac.uk/index.php?pid=47&prid=88

In the course of its inquiry the panel invited the Association of Medical Research Charities (AMRC) and INVOLVE to hold a workshop which would provide an insight into patient perspectives on the conduct of research and associated regulatory issues.

Continued →

It was agreed the conclusions of the workshop would be fed into the review and that AMRC and INVOLVE would separately produce an independent report of the event. This report – ‘Patient perspectives on the regulation and governance of medical research December 2010’ – is now available on the publications area of the INVOLVE website:

www.invo.org.uk/INVOLVE_Publications.asp



Putting it into Practice

Putting it into Practice is a new database on the INVOLVE website. It provides useful information on ‘how to do it’ including:

- guidance on good practice
- reports of the lessons learnt from direct experience of involvement
- descriptions of involvement in research projects.

The database can be found on the resources area of the INVOLVE website:

www.invo.org.uk/Resources.asp

Please let Helen Hayes know of any resources you have found useful, so we can look at including them in the database.

Contact: hhayes@invo.org.uk



Coming up in the next few months...

We’re have some exciting plans for the first half of the year, including:

- a new look for the INVOLVE website – all the current information will be there but it will be easier to find and search for in our new resource centre
- a new online resource for researchers to replace the current Briefing Notes for researchers
- a web based directory of approaches to training and support.

Interesting articles and publications

• Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives

Janneke E. Elberse, J. Francisca Caron-Flinterman, Jacqueline E. W. Broerse

Health Expectations, published online 22 December 2010

The objective of this research was to gain more insight into exclusion mechanisms and inclusion strategies in patient–expert partnerships.

• Developing Consumer Involvement in Primary Care Research – Final report of a development evaluation

Rachel Nickeas, Evaluator and Jane Stewart, Research Fellow/Project Lead on behalf of Nottingham Primary Care Research Partnership. A report of a project to develop a model of consumer involvement in research activities in primary care in Nottingham. To evaluate the process and outcome of implementing the model within Nottingham Primary Care Research Partnership.

Can be downloaded from www.rdnottspct.nhs.uk

• Critical appraisal guidelines for assessing the quality and impact of user involvement in research

David Wright, Claire Foster, Ziv Amir, Jim Elliott, Roger Wilson

Health Expectations, Volume 13, Issue 4, pages 359-368

This study offers guidelines for appraising the

quality and impact of user involvement in published papers and grant applications. Appraisal guidelines for user involvement have been developed on the basis of available literature and experiences from studies involving cancer patients and carers in the design and conduct of research.

• **Patients' and clinicians' research priorities**

Ruth J Stewart, Jenny Caird, Kathryn Oliver and Sandy Oliver

Health Expectations, published online 22 December 2010

A scope of the research literature available on initiatives that have engaged patients and clinicians in setting research agendas.

• **Patient and public involvement in translative healthcare research**

Clive Savory

Clinical Governance, Volume 15, Number 3, 2010, pages 191-199

This paper aims to set out a framework that can be used for locating strategies for incorporating patient and public involvement in the wider process of translative healthcare research.

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Coordinating Centre with details: hhayes@invo.org.uk



Looking to the Future: A peer education approach to end of life care planning

By Irene McGill, Jill Robinson, Gail Capstick, Oliver Coles, Deirdre Jacks, Susan Lockett, Janet Ross-Mills, Katherine Froggatt

The Lancaster End of Life Peer Education Group was formed in 2007 when eight older adults attended a Peer Education on End of Life Care training course. They meet monthly, led by Dr Katherine Froggatt, a senior lecturer in the International Observatory on End of Life Care. A research proposal submitted by the Group to NHS North Lancashire was awarded a grant to (1) develop a personal portfolio, which people could use to record their personal information, wishes and preferences regarding end of life care, and (2) to raise awareness on end of life issues locally. Using a participatory research approach, the group held two workshops, one for older people and the other for professionals, carers and advocates. The workshops were well attended and identified a need for more information on end of life care.

Following the workshops the group produced a portfolio 'Looking to the Future – creating a personal portfolio.' This was shared with the workshop participants and received a very favourable response, many requesting copies for their friends. We are now refining the portfolio, hoping to make it more widely available. Six further workshops are being planned, aimed at reaching the wider community within the Lancaster area and addressing topics identified in the earlier workshops.

Contact: Katherine Froggatt, Lancaster University
Email: peeredeol@lancaster.ac.uk

Turning the pyramid upside down: examples of public involvement in social care research

The second report published in our series of examples of public involvement in research was 'Turning the pyramid upside down: examples of public involvement in social care research.' Commissioned by INVOLVE this was researched and compiled by Hilary Blackburn, Bec Hanley and Kristina Staley from TwoCan Associates. This report provides real life examples of how service users and carers have been involved in social care research. Through these accounts, the researchers, service users and carers offer tips and advice based on their experience of involvement.

There are five examples outlined in the report:

- An assessment of the accommodation and health and social care needs of Gypsies and Travellers
- A survey of carers of people with heart disease
- A study of postural care for children with disability in mainstream schools
- An evaluation of a teenage pregnancy prevention strategy
- A study of adoption support services.

Some of the key messages from the examples of both the factors that ensure successful involvement and the benefits of involvement were:

Factors that ensure success

- Building relationships – working in partnership with service users, showing you respect and value their expertise – showing that you

are listening and making changes in response to their input

- Going the extra mile – making an extra effort to ensure service users can be involved in a way that meets their needs – for example holding meetings outside of office hours, printing out documents for people
- Honesty – being clear that research takes a long time and doesn't necessarily lead to change as well as being open and transparent about how you are working
- Being sensitive and aware – some topics are going to be very sensitive and emotional. You need to manage this and support people appropriately – at the same time as being clear about boundaries
- Clarity about roles – taking time at the start of a project to explain what you need from the people you involve and how they can help you
- Being mindful of the practical issues and minimising the costs for service users – the 'little things' really matter and can determine whether an individual can get involved
- Investing a lot of time – especially when planning involvement and supporting people during the project.

Benefits of involvement

Involving service users and carers ensures that you:

- stay focused on the useful outputs from your research – making it more likely that your research will make a difference to people's lives
- get the language and approach right throughout your project – in your recruitment material, research tools and reports – this is especially valuable when you are working with seldom heard groups or the topic is particularly sensitive or emotive

- get better quality data, a more-rounded and informed interpretation of the data and findings that have greater credibility with your funders and other key stakeholders
- gain personally from new relationships and a greater knowledge and understanding of the people you work with.

The full report is available to download from the publications section of the INVOLVE website www.invo.org.uk

Alternatively, please contact the Coordinating Centre and we will send you a copy.
Email: admin@invo.org.uk Tel: 02380 651088.

User involvement in research: a route map

The route map for user involvement in research is a resource for staff in health research charities and other organisations that commission research who wish to involve service users in their work. It was developed by Kristina Staley and Bec Hanley of TwoCan Associates with support from the Association of Medical Research Charities (AMRC).

There are three routes:

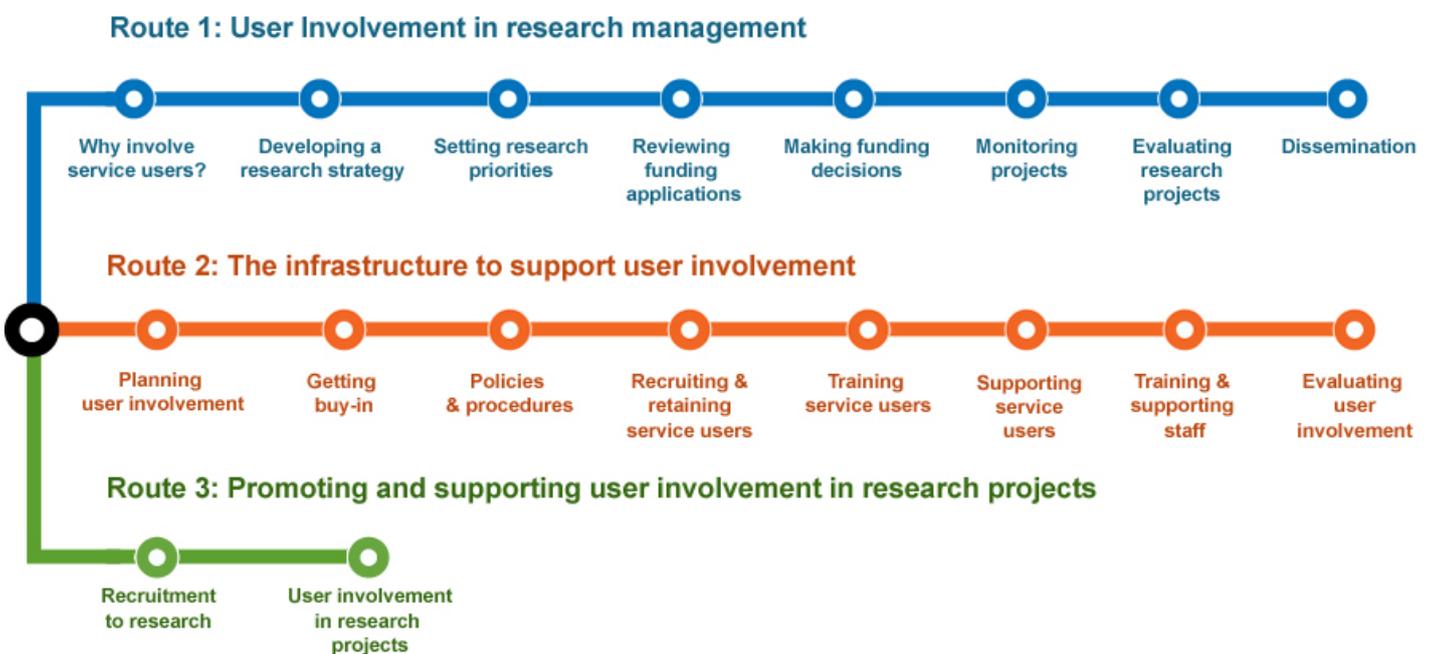
Route 1 (the blue route) takes you through the different stages of the research management process – e.g. developing a research strategy or setting research priorities.

Route 2 (the orange route) offers advice about how to develop the infrastructure for involvement – e.g. training service users.

Route 3 (the green route) focuses on how to support and promote user involvement in individual research projects - e.g. helping with recruitment.

Each 'station' on the route offers guidance on how to involve service users, lessons from other organisations and links to useful resources.

The route map is free to use. You can find it at www.twocanassociates.co.uk/routemap



Learning to improve the management of back pain in the community – involving patients can change practice

By **Steve Williams (Patient Representative)** and **Louise Worswick (Project Manager)**

Our project began in March 2008 when nine general practice teams came together for a series of eight workshops to learn about the principles and methods of quality improvement and evidence-based management of back pain. Each team included a patient representative who was selected by the team from their practice population and who engaged as an equal partner with their team in the workshops. The research project was called the LIMBIC project (Learning to Improve the Management of Back pain In the Community).

The aim of the project was to evaluate whether a series of interprofessional educational workshops made a difference to patient outcomes, practice teams and individual professionals. Previous studies had identified that GPs find the management of back pain frustrating and the implementation of national guidelines challenging. In spite of the existence of clear evidence-based guidelines sometimes the management or referral of people with back pain did not reflect best evidence-based practice.

Each practice team was requested to identify a patient from their practice to attend the eight workshops along with the practice team and to attend meetings at the practice in between the workshop sessions where the improvement project planning and implementation took place.

The workshops aimed to give everyone equal opportunity for participation and engagement and were structured to include content knowledge and improvement methodology. Workshops adopted an open and informal style and there was mutual respect between participants. Ground Rules were set whereby the importance of clear dialogue and guidelines were agreed, a glossary of terms was used and the agreement to avoid the use of jargon. This enabled patients to understand specialist perspectives and encouraged open debate and a sharing of the patients' experience of their back pain. Each team undertook an improvement project. The aim of the improvement project was for the team to look at an area of primary health care within the surgery that could be improved utilising the Plan-Do-Study-Act (PDSA) cycle. This was very much centred around the patient perception and patients enjoyed the entire process of being involved making positive changes in the primary health care system locally for back pain sufferers.

Using improvement tools, the teams identified an area of concern, implemented a solution, studied the impact and acted on data that was fed back to them. One practice focused on the referral process along with the information exchange around the initial GP appointment.

Example of a Practice improvement project:

Referral Process – The team looked into the timescales involved in patient referral for remedial physiotherapy or consultant referral using the experiences of their patient representative as a long term patient and identified quicker routes with follow up to ensure appointments were made and attended.

Initial Appointment – The team identified that patients were generally in pain and not confident about what questions to ask or symptoms to

describe to their GP. Their improvement project involved providing information in the surgery through the TV screen in the waiting room which offered advice to patients with back pain about what questions they might ask and to think about their symptoms. The GPs were also given information sheets with guidance notes and this led to a shared responsibility between patient and GP regarding the condition and its solution.

Outcome – The use of TV information about patient awareness and responsibility was seen to reduce valuable time in GPs surgery timescales with patients feeling more informed and taking responsibility in the partnership towards solving what was a joint concern. Another clear example of changes that were made as part of this process was the shortening of waiting time on referral from primary to secondary health care and other agencies working in the community purely by ensuring referrals were followed up with phone calls to chase up the referral.

The project evaluated a group of patients presenting to the GP before and after the workshops. The data analysis revealed positive changes or trends in these outcomes but not at a statistically significant level. Practice teams changed, not only in the way in which the individuals in the practice teams worked together to provide a service, but they also learned a great deal about working together with patients and recognised the value of patient engagement. The project demonstrated a shift in attitudes of practice teams towards the benefits and value of what we call user involvement, measured by focus groups with practice teams and their patients before and after the workshops took place.

During the course of the project, the patients had said to the health care professionals “Stop

trying to cure us and listen to us.” At the end of the series of workshops, the participants said that active patient involvement had helped them in:

- “Understanding the problem from patient’s perspective, sharing uncertainties and working together.” (A GP)
- “[Giving a] valuable viewpoint, a shared experience.”
- “Implementing outcomes from discussions.”

Conclusion

The project found that placing patients as service users at the heart of interprofessional learning is powerful in shifting attitudes and can lead to improvements in practice that enhance the patient experience.

The team and participants including the patient representatives made a film about their learning experience showing how the usual consultation with the GP can change from being a paternalistic encounter to become a two way discussion about people taking control of their condition. The lead parts in the film are played by patients from the LIMBIC project and the film, called ‘A Day at the Races’ can be seen at www.limbic.org.uk

The LIMBIC project was led by a research team from the School of Health and Social Care at Bournemouth University and funded by an award from the Health Foundation.



Participants of the LIMBIC project filming their story.

Changing Our Worlds: examples of user- controlled research in action

Autumn 2010 saw the publication of Changing Our Worlds, the report of a project exploring the role and value of user-controlled research through the use of seven example projects. Commissioned by INVOLVE, it was researched and written by Alison Faulkner, a mental health service user and researcher. The report is published along with a DVD, which was screened at the INVOLVE Conference in November 2010. The DVD features four of the seven projects, with British Sign Language (BSL) interpretation and subtitles available. There is also an easy read summary of the 'Connect Works' project

for people with learning difficulties, prepared with the help of Connect in the North.

The aim of the project was to increase understanding and awareness of the role and value of user-controlled research. Seven projects (see table below) where service users or disabled people controlled the research process were selected for exploration by the project advisory group. For each project, interviews were carried out with researchers, service users and other key people. Questions covered the origins of the research, the methods used, the nature and extent of user control over the research, and the dissemination and impact of the research findings.

The report suggests that user-controlled research often arises from within communities or groups of people frustrated by traditional research that overlooks or excludes them and

Project title	Organisation
Deaf People's Mental Health Pathways	Vision Sense
Comparison of urine and blood tests for thyroid function	Thyroid UK
Connect Works (what people with learning difficulties want from personal assistants)	Connect in the North
Disability Hate Crime	DITO (Disability Information Training Opportunity)
The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual (LGB) disabled people in Leeds)	Rainbow Ripples
The Young Researcher Network projects: 1. Get the life you want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	Supported by the National Youth Agency Young Researcher Network (YRN)
Relationship Matters	Shaping Our Lives

their concerns. All of the project groups were passionately committed to changing and improving the lives of their community of service users, whether directly or indirectly, locally or nationally. What is perhaps surprising is the degree to which they achieved this, given their scope and resources. Although all of the projects experienced challenges, such as limited budgets, direct discrimination, and dilemmas surrounding identity and power, nearly all of them achieved positive practical change.

Many of the projects resulted in tangible outputs which extended the impact of the research to their wider constituency of disabled people or service users. Examples of this included: changes to services, training programmes, information packs and DVDs.

One of the benefits of the research being user-controlled was the shared identity it established between the researcher and participants. Several people referred to the sense of trust that this enabled, leading to more open and honest accounts about the issues being researched.

“It’s people who know asking people who know.”

This ‘insider knowledge’ in turn enabled the research to address the right questions, and to be interpreted by people with an understanding of that lived experience, giving a unique richness to the findings.

Some people talked passionately about the opportunity their project had given them for developing new skills, gaining in confidence and a sense of empowerment. Empowerment has been identified as a key principle of user-controlled research. These projects help us to understand how user-controlled research can bring about empowerment for the service users involved.

“People take us more seriously. That’s what empowerment is. Empowerment: you know you can do it.”

Copies of the report and the summary are available to download from the INVOLVE website www.invo.org.uk or please contact the Coordinating Centre if you would like a copy of the report with the DVD.

Email: admin@invo.org.uk

Tel: 02380 651088

Can you help?

INVOLVE is building a collection of practical resources for researchers who are new to public involvement in research. Do you have examples of any of the following to help inform our new resource for researchers?

- Advertisements looking for members of the public to work with you
- Role descriptions for involving members of the public in your work
- Ground rules
- Terms of reference for an advisory group
- Information on writing lay summaries.

Would you be willing to share them with us so we can develop templates for people using the resource to download and adapt? If so, please send your examples to Helen Hayes at the Coordinating Centre hhayes@invo.org.uk or call 02380 651088 to discuss further.

Deadline for contributions for our next newsletter: **4th March 2011**

If you have any questions on contributing to the newsletter, please contact Helen Hayes Tel: 02380 651088 Email: hhayes@invo.org.uk

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in Research and Development. If you would like to put an article on our noticeboard please contact the Coordinating Centre.

Wanted – Lay Members for research ethics committees

The National Research Ethics Service is recruiting lay members to Research Ethics Committees in the London area. Committee members receive training in ethical review and have opportunities to debate challenging issues in the life sciences to help protect the rights and well-being of research participants and promote ethical research. Positions are voluntary but expenses are paid, including travel and childcare costs. Committees meet on average for half a day per month and applicants will need to be able to attend at least two thirds of meetings.

Please note there is no deadline for applications – the recruitment process is ongoing. To find out more contact Michael Fox on: Tel: 02077 940500 ext 31342 Email: michael.fox1@nhs.net

National Children's Bureau Conference Beyond tokenism: How to effectively involve children and young people in policy research

29 March 2011, Church House Conference Centre, Westminster London, SW1P 3NZ.

The conference is expected to attract delegates from the research, academic and policy communities, as well as young people with interest in research. Some key questions to be addressed at the conference include:

- Why and how should children and young people be involved in the research process?

- What methodological and ethical challenges does their involvement present?
- Are research standards compromised or enhanced by the involvement of children and young people in the research process?
- Does the Government value the involvement of children and young people in policy research?

For more information and to book your place for £25 see www.beyondtokenism.eventbrite.com

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INVOLVE is a national advisory body funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development. If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

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