



RHD Action

United to End
Rheumatic Heart Disease

INTEGRATION, INTEGRATION, INTEGRATION:

**Why Rheumatic Heart Disease Must be
Incorporated into Universal Health Coverage**

INTRODUCTION

Rheumatic heart disease (RHD) – a disease of the world’s poorest and most vulnerable communities – has long been neglected by global and national health efforts. Now, at the dawn of the new sustainable development agenda, an opportunity has arisen to help the international community eliminate this preventable disease: all countries in the world have renewed their commitments to achieve **universal health coverage (UHC)**.

The year 2015 marked a decade since the World Health Organization first passed a Resolution on UHC, and also marked the inclusion of UHC into the 2030 Agenda for sustainable global development.¹ It is therefore urgent that countries take decisive steps to integrate RHD services into national UHC packages.

This paper sets out the compelling rationale for integration of RHD into UHC, and offers concrete actions to make this humanitarian vision a reality. Together, through our global quest towards UHC, let’s consign this preventable disease to the history books.

6 Key Messages

- 1** **Rheumatic heart disease (RHD) is a sentinel disease of poverty**, which can only be prevented, controlled and eliminated through robust universal health coverage (UHC) systems in endemic countries.
- 2** **All governments have already committed to establishing or furthering UHC**, however progress to date has been insufficient and uneven, with catastrophic results for human health and global development.
- 3** **In RHD-endemic countries, UHC systems should focus on inclusivity, coverage and financial protection**: these are the three dimensions of UHC most applicable to RHD.
- 4** **A human rights-based approach to UHC will empower people living with RHD** by mandating countries to fulfil existing commitments to health and social development.
- 5** **All RHD-endemic countries can make progress towards UHC** regardless of income level, however difficult choices and ‘trade-offs’ will have to be made, as every health system is resource-constrained.
- 6** **RHD services must be included in UHC coverage packages** in endemic countries for pressing epidemiological, humanitarian and economic reasons.

6 Key Actions



WHAT IS RHD?

Rheumatic heart disease (RHD) is a preventable disease that affects children and young people living in conditions of poverty and overcrowding.³

Practically eliminated in wealthy countries, RHD is still common in Africa, Asia, Latin America and the Pacific.⁴ Thirty two million people around the world suffer from the condition, which kills 275,000 people a year and is the most common acquired heart disease among children and young people in developing countries.⁵

RHD is preventable, but continues to cause significant levels of mortality and morbidity in countries with health systems too fragile to control it. Starting with an untreated strep throat, the disease progresses over time to inflict serious heart damage and death on some of the world's most vulnerable people.

Prevention of RHD in developed settings demonstrates that disease control is possible. The ongoing burden in developing settings indicates inadequate services for certain populations, contravening the universal human right to health.⁶ It is therefore urgent that sustainable, equitable measures are taken to eliminate this preventable disease from the world's poorest communities.



Photo: Mike Hill, Moonshine Movies for www.TakeHeart.tv

RHD in Numbers

80%

80% of people with RHD live in low- and middle-income countries, the remainder in vulnerable communities of wealthy countries.⁷

66%

Throughout Africa, the average age of people with severe RHD is 28 years, **66%** of patients are women.⁸

70%

In Ethiopia, **70%** of people with RHD die by 26 years of age.⁹

10%

In some Pacific Island States nearly **10%** of the total health budget is used on heart surgery for RHD.¹⁰

1977

Drugs to prevent and control RHD have been on the WHO Essential Medicines List since its inception in **1977**, but countries and regions are still experiencing stock-outs today.¹¹

222,000

The cost of the **222,000** deaths from RHD globally was estimated at USD 5.4 trillion based on data from 2010.¹²

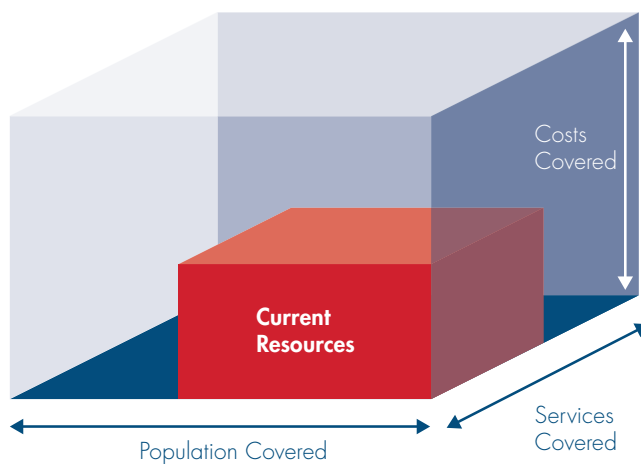
Preventable

Within a strong, comprehensive UHC package, RHD is almost entirely preventable in endemic regions across the world.

WHAT IS UHC?

The term 'universal health coverage (UHC)' first gained traction in 2005, when the World Health Organization (WHO) passed a resolution on 'sustainable health financing, universal health coverage and social health insurance'.¹³

In practice, countries as diverse as the UK, Italy, Bhutan, Brazil and New Zealand had already been striving towards UHC for many decades, with various degrees of success. Yet global progress so far has been insufficient and uneven: 400 million people today still live without access to essential health services.¹⁴



Population: who is covered?

Services: which services are covered?

Direct costs: proportion of costs covered

Inclusivity

Coverage

Protection

ACCORDING TO THE WHO:

*'Universal health coverage (UHC), is defined as ensuring that all people can use [the] health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.'*¹⁵

This concept involves three significant factors: **coverage** of good-quality essential health services according to need, financial **protection** for the individuals seeking care, and whole-of-society **inclusivity**.

The co-dependent relationship between **coverage** and **protection** and **inclusivity** is constrained by the limited resources of any health system, however developed. No country in the world can cover all good-quality health services for an entire population with no financial risk incurred by any care-seeker. The road to UHC demands that difficult choices are made by each country to mitigate the specific health priorities that they have identified on the ground.

This diagram demonstrates the three dimensions of UHC that need to be prioritised by countries with limited resources:¹⁶

We recommend that health systems dealing with a high burden of rheumatic heart disease structure themselves to prioritise **inclusivity, coverage** and **financial protection**. **Coverage** of good-quality health services for people with RHD is already included in some basic packages at the primary care level, but more should be done to make sure this coverage is effective and extends to tertiary care for RHD. Additionally, the populations most at risk of RHD are typically the least likely to access their national health services, or be able to afford them. Only through UHC can these gaps in **inclusivity** and **financial protection** be remedied in a sustainable and equitable way.

WHY INTEGRATE RHD INTO UHC?

Countries with weak or fledgling UHC packages often have an endemic burden of RHD. Now is a ripe opportunity to integrate services for prevention and control into fledgling or prospective UHC packages. RHD can be seen as a 'sentinel disease': one which indicates the extent of the gaps experienced in equity, coverage, access to healthcare and – in many cases – the wider socio-economic development of any country.

There is a compelling correlation between RHD and UHC: the existence of RHD is indicative of both the need for and the lack of UHC, while implementation of UHC packages in endemic regions will lower the burden of RHD significantly and position the disease as an indicator of UHC effectiveness.

Plainly put: without progression towards UHC, countries struggling with the burden of RHD will fail to prevent and control the disease sustainably or equitably, causing untold social, economic, and human suffering.

INTEGRATION TO SAVE LIVES

CVD currently claims over 17.3 million lives per year,¹⁷ while RHD currently claims 275,000 lives. Though dwarfed when set against the broader cardiovascular disease (CVD) epidemic, RHD makes up a vast percentage of CVD cases among vulnerable and marginalised communities – the very communities that UHC seeks to serve.

Moreover, the degree of suffering for those living with the disease is very high. People who live with RHD have lifetime morbidity, and many cannot fulfil their potential to contribute to society. When we account for the DALYs (Disability-Adjusted Life Years) and YLLs (Years of Life Loss) associated with RHD, the need to address the disease becomes particularly compelling.¹⁸

Deaths from RHD occur disproportionately in young people, particularly young women during childbearing. In Indigenous Australians, the average age of death from RHD is 40 years,¹⁹ which is approximately half the average life expectancy of the Australian population as a whole.²⁰ Heart health as a human right will be denied to these communities until country efforts to attain UHC adequately include coverage, inclusivity and financial protection measures to prevent and control RHD.

Countering these harrowing statistics and human rights violations are simple and cost-effective services and interventions to prevent and control RHD. This table describes example interventions, how they fit within the UHC movement, and their optimal outcomes. The examples chosen – which are not exhaustive – are taken from the World Heart Federation/RhEACH **TIPS** Framework, which provides a comprehensive menu of health-systems-based RHD interventions.²¹

Stage of Intervention	Type of Intervention	UHC Approach
Primordial prevention	Disease notification	Make RHD legally 'notifiable' by doctors and health professionals to improve information about the burden and distribution of disease. This allows the health system to prioritise and allocate appropriate resources towards RHD services in an evidence-based way. It also provides evidence on the need for RHD drugs and treatments, which results in more proportional distribution to populations most in need.
Primary intervention	Community education and health worker education	Implement community education at a variety of levels (including children, parents, teachers and community groups) using country-appropriate locations and media, to integrate health messages into people's lives both within and beyond the health system. Community education lessens people's risk of RHD, and correspondingly reduces financial and operational burdens on the health system. Educate health workers to appropriately check for, diagnose, and treat people with RHD in order to optimize results when people with RHD access primary healthcare.
Secondary intervention	Administration of drugs to manage existing RHD	Adopt cost-effective, innovative measures to ensure that people receiving treatment to prevent or manage RHD receive penicillin and other drugs in time. This could involve investing in SMS or text services to remind people living with RHD when their next appointment is due. This mechanism could be integrated into a holistic wellness-based telecommunications system that covers other UHC areas.
Tertiary intervention	Heart valve replacement/repair surgery	Invest in surgical and tertiary care facilities within the national health system, as this is more sustainable than flying emergency RHD patients abroad for surgery. It also allows for increased post-operative followup, which improves patient outcomes, and encourages skilled health workers to remain in the country rather than contribute to a 'brain drain' of qualified health professionals.

If countries integrate these and other selected **TIPS**-based RHD interventions within their health systems, life-saving gains will be made – not only in RHD prevention and control, but also in related areas across the health and development landscape.

Simply providing these interventions within a traditional health system is not enough. The framework and ethos of UHC is needed to make sure that those who need care for RHD can access and afford it in a sustainable way.

UHC-Centred Approaches to RHD: An Example

The provision of drugs within UHC systems is a good example of health systems implementing multi-sectorial, multi-stakeholder strategies favoured by policymakers.

For **benzathine penicillin G (BPG)**, the antibiotic used to prevent and control RHD, this requires reaching out to several actors outside health, including:

- **Public health insurance schemes** – to include access to RHD drugs within coverage packages, so all people can afford medicine without experiencing financial hardship.
- **Pharmaceutical companies** – to develop high-quality, low-cost formulations of BPG, the antibiotic used to prevent and control RHD.
- **Transport/infrastructure bodies** – to make sure drugs are distributed safely and cost-effectively.
- **Primary health care workers** – to learn the skills needed to administer intramuscular injections of BPG for both prevention and control.
- **Community leaders** – to teach vulnerable populations about the risk factors of RHD and how to prevent it and control it through good adherence to BPG.
- **Scientific researchers** – to continue work on developing an RHD vaccine and optimise other drugs for RHD.
- **Funding bodies (including Ministries of Finance)** – to cover costs of those too poor to contribute to pooled health funds, to fund drug procurement and to support vaccine development.

This example shows that UHC implementation must involve commitments and collaboration from sectors outside of health. Given the multi-stakeholder complexity and humanitarian impetus behind RHD, the disease is well placed to become a sentinel of 'best practice' within the global UHC movement, and is a valuable example for advocates of integrated health systems strengthening.

Key Policies that Support RHD-UHC Integration

Transforming Our World; The 2030 Agenda for Sustainable Development (2015)³⁴

WHO NCD Global Monitoring Framework (2014)³⁵

WHO Global Action Plan for the Prevention and Control of NCDs (2011)³⁶

Beijing Declaration and Platform for Action (1995)³⁷

Article 24 of the Convention on the Rights of the Child (1989)³⁸

Articles 12 & 14 of the Convention on the Elimination of All Forms of Discrimination Against Women (1979)³⁹

Declaration of Alma Ata (1978)⁴⁰

Article 12 of the International Covenant on Economic, Social and Cultural Rights (1966)⁴¹

Article 5 of the Convention on the Elimination of All Forms of Racial Discrimination (1965)⁴²

Article 25 of the Universal Declaration of Human Rights (1948)⁴³

Original Constitution of the World Health Organization (1946)⁴⁴



INTEGRATION TO UPHOLD HUMAN RIGHTS AND DEVELOPMENT

The economic case for UHC is sound and supported by 267 leading international economists.²² But the humanitarian case is also irrefutable, given how many lives could be saved by countries adopting this innovative approach to diseases such as RHD.

Countries have already committed to act. Universal health coverage was included as a priority in Agenda 2030 for sustainable development, which was ratified by all 193 United Nations Member States in September 2015 under Goal 3: 'Promote healthy lives and ensure well-being for all at all ages'.²³ UHC is mentioned specifically in target 3.8 of the Agenda: 'Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all'.²⁴ With these commitments enshrined in global policy, national governments are duty-bound to make progress towards UHC.

Beyond these political mandates, there are 5 compelling humanitarian motives for stakeholders to advance the prevention and control of RHD within a UHC framework.

1. INEQUALITY

RHD remains endemic in areas of Africa, Asia, Latin America and the Pacific, despite being virtually eliminated in developed countries.

RHD is also prevalent in vulnerable communities living in countries with high levels of domestic inequity.²⁵ For example, South Africa is one of the most unequal countries in the world, and carries a correspondingly high burden of RHD.²⁶

Within most endemic countries, the demographic that carries the largest burden of RHD is women and young children, who are also less likely to receive equitable access to health services.²⁷

2. INCLUSION

All countries have committed to Agenda 2030, the most inclusive and integrative global development agenda to date.²⁸ Agenda 2030 makes explicit calls for inclusive and integrative measures – including universal health coverage and multi-stakeholder partnerships – to enable sustainable development.²⁹

Integration within the health sector is vital for both RHD and UHC. Successful UHC systems must be integrated within a wider socio-economic and political context in order to be sustainable, while the complexity of RHD requires buy-in from non-health stakeholders to scale-up interventions.

RHD can be effectively included and integrated into other health areas, such as maternal and child health, and HIV/AIDS interventions. This integration capitalises on resources, builds the capacity of the health workforce, and encourages sharing of best practice.

3. INDIGENOUS HEALTH

Indigenous people, even in high-income countries, experience a disproportionate burden of RHD. The impact of RHD on Indigenous communities in Australia³⁰, New Zealand³¹ and Canada³² is profound.

Social and economic inequality in many settings means that Indigenous people living with RHD are less likely to be able to afford and access the crucial health services they need to treat and prevent RHD.

Without integration of RHD services into UHC packages, Indigenous people living in poverty who access treatment for RHD are vulnerable to financial catastrophe and impoverishment through out-of-pocket upfront payments at the point of care.

4. PREVENTABILITY

RHD is almost entirely preventable, given the correct socio-economic and geo-political landscapes.

The main antibiotic drug to prevent and control RHD (BPG, or benzathine penicillin G) is available as a cheap generic drug, and has been on the WHO Essential Medicines List for nearly 40 years, yet efforts to improve access have failed and require UHC systems for sustainable scale-up.

Lack of awareness and education among vulnerable populations is a large barrier to prevention and control of RHD. Intervening here is a low-cost and high-impact way to improve RHD outcomes, and also improve health education in other related disease areas.

5. POVERTY

Although the drugs and interventions to prevent and control RHD are relatively inexpensive and cost-effective, their users are often among the poorest members of society.

A significant primordial cause of RHD is overcrowding and poor sanitation, which are central to the current global development agenda.

The poorest individuals are often the most socially marginalised, and the least likely to be covered by (or able to access) health services. This requires a broad and inclusive UHC approach to ensure that nobody at risk of RHD gets left behind.

These five areas, which span the global development agenda, are inextricably bound to existing policies on the universal human right to health.³³ Even without the sound epidemiological and economic arguments supporting the integration of RHD services into UHC, they alone should provoke countries to act on these issues today.

A CASE STUDY FROM THE PHILIPPINES

Anne Cristobel is 15. She has three siblings. Her father is a driver and her mother a laundrywoman. Anne was recently hospitalized with congestive heart failure: RHD has damaged her heart valves and her enlarged heart can no longer pump blood effectively.



Anne discovered that she had rheumatic heart disease two years ago when she had palpitations and difficulty breathing. The clinic prescribed long-term use of penicillin to prevent the valve damage from advancing. Her family is enrolled in the National Health Insurance (PhilHealth), but it does not cover BPG penicillin for control of RHD. They had to pay for the medication themselves, and sometimes this was difficult.

Consequently, Anne took the penicillin, but not regularly enough to provide effective protection. Now she will need expensive heart surgery and afterwards, lifelong followup. Pregnancy may be risky and she will still need to take penicillin for many years to protect her from further valve damage.

The valve surgery is covered by PhilHealth, so Anne will be able to get the surgery she needs – even though this surgery will cost the health system far more than if it had provided penicillin when Anne was first diagnosed. The Philippine Heart Center is working to provide the information needed to include penicillin for RHD prevention and control in the package of services insured. This will mean that lack of affordability of the basic medications neither prevents parents from being able to protect their children from this debilitating and potentially fatal disease, nor increases need for more complicated, higher-cost services.

Although the government aims to provide universal health coverage (UHC), until recently it has been unable to provide sufficient funding for national health insurance to cover many disadvantaged families that are most affected by RHD. At the end of 2012, the government increased taxes on all tobacco and alcohol products and allocated 85% of the revenues generated to financing national health (80% of this allocation is for UHC, while 20% is for medical assistance and health enhancement facilities and programmes). In the first year, these taxes generated US \$1.2 billion. This amount enabled PhilHealth to extend coverage to an additional 45 million disadvantaged Filipinos as of June 2015.



A Healthy Dose of Pragmatism

Universal health coverage threatens to become an empty buzzword without understanding the reality of the world's resource-constrained and politically divisive health systems. No country can ever 'achieve' UHC in full, yet every country is obliged to work towards it, making difficult decisions and 'trade-offs' along the way.

In pursuing UHC, each health system must adopt a tailored approach to meet the needs of the populations it serves. Furthermore, health systems must distinguish between conceptual coverage and effective coverage. RHD should stand as a sentinel indicator in this regard. If people living with RHD – often the poorest and most vulnerable members of society – are accessing and affording health services to treat their condition, the system is successful. If they are not, progress to UHC remains insufficient and uneven.

This approach may sound ominous to even the best-resourced and most functional health system. But the cost of action towards furthering UHC in RHD-endemic countries is minuscule compared to the cost of inaction.

RECOMMENDATIONS: THE BEST WAY FORWARD

To start the crucial work of integrating RHD services into basic UHC packages, 6 Key Messages must be spread, and 6 Key Actions must be implemented (see first page). Actions speak louder than words, so here is more guidance to help you take the 'next steps' in this process.

6 KEY ACTIONS - REVISITED

1. INCLUDE selected RHD interventions from the TIPS Framework in basic UHC packages⁴⁵

Who? Policy-makers, health advocates, ministers of health, other government bodies, public and private insurance organizations.

How? Select UHC-appropriate interventions from the TIPS Framework that are relevant to your national setting and advocate your government to include them within a national UHC package.

'Low-hanging fruit' interventions already identified in this paper include:

- Disease notification (primordial intervention)
- Community and health worker education (primary intervention)
- Administration of drugs to manage existing RHD (secondary intervention)
- Heart valve replacement/repair surgery (tertiary intervention).

Why? Without progression towards UHC, endemic countries will fail to prevent and control RHD sustainably or equitably.

Use this briefing paper as an advocacy resource to convince decision-makers of the human and financial necessity to integrate RHD into UHC.

2. ORIENT UHC priorities towards inclusivity and financial protection

Who? Policy-makers, health advocates, ministers of health, ministers of finance, ministers of social affairs, public and private insurance organisations.

How? Encourage decision-makers to prioritise RHD as they make difficult choices and compromises when allocating resources to the health system.

Expand inclusivity and financial protection measures within the UHC framework.

Secure/maintain coverage of RHD drugs and services in basic UHC packages.

Why? The people most at risk of RHD are typically those who are least able to access and afford life-saving health services.

Inclusivity and protection must be increased so these people are not left behind.

3. INTEGRATE RHD interventions into other established disease areas

Who? Country-level programme coordinators, development donors, health advocates, World Health Organization.

How? Identify existing well-resourced and successful programmes that overlap with RHD in terms of: primordial conditions, risk factors, use of medicines and technologies, and/or high-risk populations.

Work with these programmes to share skills, resources, staff and experience.

Use World Health Organization guidance on integration wherever available.⁴⁶

Why? Tackling RHD and improving UHC both require an integrative approach.

The RHD movement is chronically under-resourced, so would benefit from cost-effective integration into other programmes.

Integration avoids the inefficient 'silos' of disease, which threaten to undermine strong UHC systems.

5. SUPPORT effective health systems strengthening and promote an enabling policy environment

Who? Policy-makers, health advocates, politicians, technical experts, World Health Organization, the general public.

How? Advocate the United Nations and other decision-making bodies to adopt a horizontal systems-based approach to health, rather than supporting individual disease silos.

Support your national health system by avoiding use of competitive private health insurance schemes and undertaking 'health tourism' abroad.

Join campaigns such as 'Health For All' on Universal Health Coverage Day, to bring the benefits of UHC to policy-makers' attention.⁴⁷

Why? Governments have already made several global commitments to UHC, but will not deliver without the pressure of sustained advocacy.

Governments will continue to invest in UHC if they see good results.

This requires the general public using the national health system fairly and exclusively.

4. BUILD capacity of the national healthcare workforce

Who? Educators, ministers of health, international and national labour organizations, clinicians, nurses and other healthcare professionals

How? Include RHD prevention and control on educational curriculums in health-training institutes.

Empower nurses and family doctors to diagnose and treat RHD through regular training programmes.

Implement local and national RHD registers to help healthcare workers manage their caseloads.

Make sure healthcare workers have access to safe, high quality drugs and equipment to treat RHD.

Train non-specialist workers to check for RHD when people present with other complaints.

Why? A strong and well-resourced healthcare workforce is a cornerstone of UHC.

Building the capacity of local-level, down-stream health workers (e.g. nurses) helps more populations to access the care they need.

Training healthcare professionals specialising in other disease areas (e.g. maternal health) to recognise RHD can improve early diagnosis rates.

6. INVEST resources into building and sustaining UHC systems

Who? Governments (especially Health and Finance departments), development donors, country-level programme coordinators, public and private insurance organizations, the general public.

How? Commit resources (financial, human, intellectual, political) to the UHC movement, ear-marking some for integrative measures.

Ensure fair and well-monitored public taxation to fund national UHC systems.

Dedicate a portion of RHD programme resources (financial, human, intellectual, political) to health systems strengthening projects.

Why? For many countries, the main barrier to UHC is financial, yet health systems that do not integrate UHC are less cost-effective.

Grassroots investments in integrative UHC measures create an enabling environment for broader change, and can be used as 'best-practice' examples by advocates.

RHD is a sentinel disease of the poor, who cannot always afford the cost-effective services that could save their lives.

CONCLUSION

Integrating RHD services into UHC packages is a sustainable way to save both lives and money, and avoid the untold human suffering that those affected by the disease live with every day. The economic benefits of this approach are self-evident: the estimated economic cost of the 222,000 deaths from RHD in 2010 was USD 5.4 trillion dollars.⁴⁸

It is clear that the scale of the problem, both human and financial, threatens sustainable development as a whole and requires large-scale, country-led action.

By sharing the 6 Key Messages and implementing the 6 Key Actions recommended in this paper, we can begin to integrate RHD services into the UHC movement and consign this disease of poverty and inequity to the history books.

While the path to universal health coverage may be long and difficult, it is the only sustainable and equitable way to rid the world of rheumatic heart disease.



Photo: Mike Hill, Moonshine Movies for www.TakeHeart.tv

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RHD ACTION ALLIANCE

The **RHD Action Alliance** (RHDA) is a coalition of global organizations leading the global movement to reduce premature mortality from RHD. The founding partners of the Alliance include Medtronic Philanthropy, the World Heart Federation and RhEACH. Together, the Alliance is committed to work at local, national and global levels to end death and disability from this preventable disease in the world's most vulnerable communities.

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