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Tobacco harm reduction consumer advocacy organisations

What is consumer advocacy in tobacco harm reduction?

Tobacco harm reduction is a **potentially life-saving intervention for millions of people across the world.**ⁱ To those who use high-risk tobacco products, like cigarettes and some oral tobaccos, it offers the chance to switch to a range of safer nicotine products that pose fewer risks to their health. These include nicotine vapes (e-cigarettes), **snus**,ⁱⁱ **nicotine pouches**ⁱⁱⁱ and heated tobacco products. While some governments are encouraging people who smoke to switch to safer nicotine products, in many countries, access is being limited or even banned entirely.

There are **now about 82 million people who vape worldwide**,^{iv} and a total of around 112 million users of all harm reduction options. However, only a small fraction of this large group of consumers actively advocate for tobacco harm reduction. Most people who have switched to safer nicotine products are unaware that the future of the products they used to quit smoking is not assured. This is because national and international health experts, scientists and policymakers remain divided over whether they offer a net benefit to public health by supporting smoking cessation.

Consumer advocates in tobacco harm reduction want to ensure that safer nicotine products are available as an alternative for all people who smoke, wherever they live in the world. Their approach and activities depend on the situation in their country and region, but they are all working to raise awareness of tobacco harm reduction. If regulatory proposals threaten to restrict access to products, it is often consumer advocates who step in to voice opposition, and to campaign for appropriate regulation.

Consumer advocacy is varied, ranging from individuals using social media or blogs, to more formal organisations and groups. To date, little has been written about these organisations. **Research conducted by the Global State of Tobacco Harm Reduction indicates that most of these groups are loosely organised**,^v run by volunteers, with little formal make up, and with no previous experience of advocacy.

Why does the consumer voice matter?

Consumers of safer nicotine products **have the right to health and the right to tobacco harm reduction.**^{vi} This means that they have the right to choose to use products which improve their health if they cannot or do not want to stop using nicotine. People who use safer nicotine products and people who smoke are significantly affected by policy responses to tobacco and nicotine, broadly described as 'tobacco control'. They are also those who would most benefit by tobacco harm reduction.

People who use safer nicotine products have key insights into how the smoking problem might be fixed, rooted in their own experiences. They know what consumers need, they know how the products work, and they know how consumers use the products. This knowledge and expertise is invaluable to scientists, regulators, politicians and people who smoke. The views and needs of people who use safer nicotine products should be central to discussions at national or international level about the products' future availability and regulation. This can be summed up by the phrase 'nothing about us without us', a mantra borrowed from earlier harm reduction movements.

Why did consumer activism for safer nicotine products start?

The Consumer Advocates for Smoke-free Alternatives Association (CASAA), founded in 2009 in the USA, was one of the first organisations to be set up. Over the next few years, a number of other consumer groups and associations began to emerge, initially mainly in Europe and Australasia.

One of the first major instances of consumers advocating for access to safer nicotine products took place in the UK in 2010, when the UK's Medicines and Healthcare Products Regulatory Agency (MHRA) opened a consultation on bringing vaping devices within the medicines licensing regime.^{vii}

Although not subject to targeted legislation, vaping devices on sale in the UK were already regulated under product safety laws. Many vapers were concerned that with the move to licensing as medicines, the UK government was about to make it difficult for them to access their preferred products, which they saw as essential in helping them remain free of smoking.

More than one thousand responses were submitted to the MHRA's open consultation.^{viii} The vast majority were from individuals, most of whom shared their personal experiences of quitting smoking by using vaping products. Many expressed their fear that licensing vaping products as medicines would effectively remove them from the market, while leaving combustible cigarettes legally available. Others wrote that a return to smoking would be inevitable. Those efforts were successful and in March 2011, the MHRA announced its intention to take no action regarding the status of vaping products, while committing to further research and assessment.

In Europe, consumer activists were further spurred into action in 2013 when proposals to regulate vaping devices as medicines emerged again, this time in the draft EU Tobacco Products Directive (EU TPD). There were also discussions in the EU about limiting the nicotine content of e-cigarettes to levels so low that they would be unlikely to satisfy smokers looking to switch. This move would have effectively removed nicotine vapes as a viable alternative to combustible cigarettes.

A grassroots campaign formed across Europe in response to the EU TPD proposals. Worried that their 'miracle cure' for smoking was going to be effectively taken away, some of the people who had successfully stopped smoking by switching to vaping products were forced into becoming first-time activists in support of tobacco harm reduction. The campaign was not orchestrated by any one individual or organisation, but the shared focus was to galvanise people to write to their elected representatives at the European Parliament and national parliaments, to share their experiences, and to give their views.

Across Europe thousands of vapers emailed their MEPs and MPs, telling them how they had quit smoking by switching to vaping, and demanding that vapes remained a consumer product. This was mostly organised via online vaping forums, as there were no European consumer groups at that time and few people leading the campaigns. A number of initiatives, including petitions and protests, were started too and, after a successful campaign, vaping products remained available as consumer products under the EU TPD.

What happened next?

It was becoming clear that vaping communities would mobilise to advocate for their right to continue accessing products that they felt were benefiting them. But the experience with the EU showed consumer advocates that they needed to get more organised. Consumers began to come together to form national consumer groups. The existence of these groups meant that consumers could establish

channels to communicate with the media, politicians, scientists and regulators, though this was not always easy. Having started as a true grassroots movement, most of the consumers who were advocating for tobacco harm reduction had no experience of organising, nor did many of them want to take charge. But, as happened in the case of vaping in the EU, consumer mobilisation grew around the world in response to regulatory threats in other regions.

What do we know about the consumer advocacy organisations operating today?

In 2022, a study by the *Global State of Tobacco Harm Reduction*, published in *Public Health Challenges*, identified 54 consumer advocate organisations operating around the world. The study focused specifically on grassroots national and regional groups that were set up and organised by SNP consumers, and answers to a questionnaire were obtained from 52 of them.

Many of these groups were affiliated with four regional umbrella organisations covering Latin America (*ARDT Iberoamerica*), Africa (*CASA*), Europe (*ETHRA*), and Asia-Pacific (*CAPHRA*).

Most began informally, often online, as people who had switched from smoking to vaping or other safer nicotine products connected with one another, before developing into grassroots groups. None of the groups the GSTHR surveyed were founded by professionals. Most of the people involved did not set out to become advocates or to set up organisations but took action in response to proposed regulatory or legislative changes in their countries.

The objectives of most of the groups are to raise awareness among people who smoke, the public, government and media about safer alternatives to smoking, as well as advocating for a legal and regulatory environment in which the products are available. A key activity of almost all organisations is to provide information to their supporters and the general public, especially those who still smoke.

How are the groups organised and funded?

Of the 52 grassroots consumer advocate organisations that answered the survey, 13 were operating in Latin America, eight in Africa, 24 in Europe, five in the Asia-Pacific region and two in North America but there were none in Eastern Europe and Central Asia, or the Middle East. The groups operated in 27 languages and 36 started from 2016 onwards.

The vast majority (42 organisations) operated with volunteers, with only seven having any contracted or paid staff. The maximum number of staff was three (for two groups). Another two organisations had two employees each, and three had just one person each. Taking the survey sample as a whole, this equates to only 13 people in paid positions among all the organisations surveyed.

The lack of operational resources is reflected in the low level of funding. A total of 31 groups had not received any financial support. For the 21 organisations with some funding, this ranged from US\$250 to US\$173,500 for the last full year.

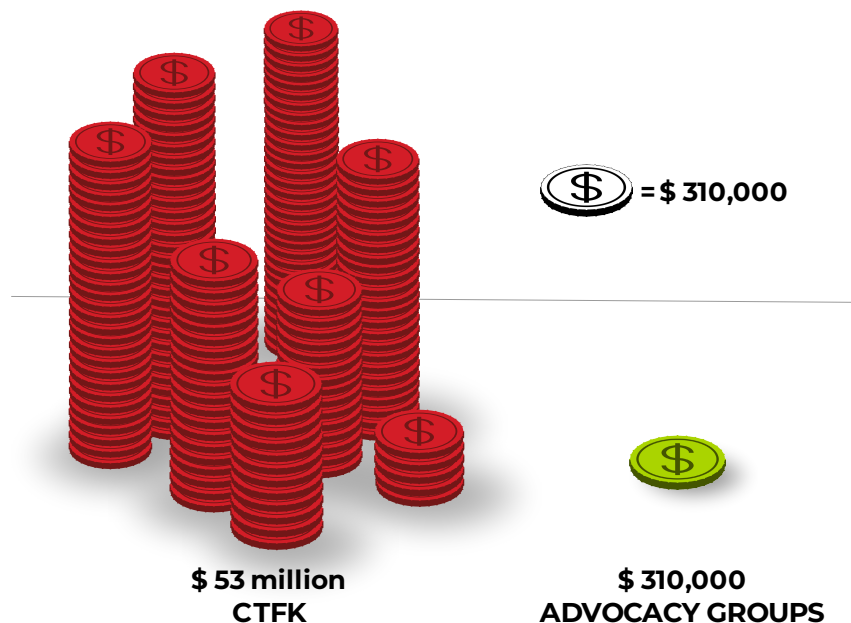
Overall, for the previous 12 months, the total funding for all groups surveyed was only US\$309,810. Funding was sourced from donations (for ten of them) and membership fees (for nine of them). Three groups received donations from vaping companies. None of the 52 groups had funding from tobacco or pharmaceutical companies.

What obstacles do tobacco harm reduction consumer advocacy organisations face?

One of the main issues reported by all of the surveyed organisations was the lack of funds and resources. Most of them also pointed to a lack of volunteers and community engagement, a lack of active and mobilised participation from safer nicotine product users and consumer membership, and difficulties in reaching interested individuals. Many also reported negative attitudes from the majority of the media, health professionals, doctors and individuals from tobacco control organisations.

The challenge grassroots consumer advocate groups face is illustrated by the amount of support and resources they receive when compared to the funding available to those organisations that campaign against tobacco harm reduction. This disparity can be demonstrated by the Campaign for Tobacco Free Kids, which received US\$160 million from Bloomberg Philanthropies in 2019 to campaign against flavours in nicotine vapes around the world over three years.^{ix} Groups like this cast doubt on the safety and effectiveness of safer nicotine products in smoking cessation, despite significant evidence to the contrary. Their significant funding and high profile ensures their views are widely represented in national and international media.

A comparison of one year's Bloomberg funding of the CTFK to fight flavoured nicotine vapes versus the total annual monies received by all consumer advocacy groups worldwide



Bloomberg Philanthropies also launched a US\$20 million global industry watchdog called STOP (Stopping Tobacco Organizations and Products) in 2018. Covering the first three years of this initiative, the University of Bath in the UK received US\$15 million from Bloomberg Philanthropies,^x plus a share of an additional \$420 million committed to STOP in February 2023 to fund the watchdog's work through to December 2024.^{xi}

In addition, the stigmatisation of people who smoke, and therefore, by extension, the stigmatisation of consumers of safer nicotine products, means there are few avenues of funding available. Most ordinary

people are reluctant to donate money to this cause. Consumer groups are therefore limited in what they can do, and it can be difficult for individuals to stay energised and engaged while campaigning.

Consumer advocates for tobacco harm reduction have never been admitted to meetings of the **Conference of the Parties (COP) to the Framework Convention on Tobacco Control (FCTC)**.^{xii} These biennial events are where government delegations from around the world meet to discuss tobacco and nicotine policy, before making decisions that affect the domestic implementation of the FCTC and other international tobacco control measures. No consumer groups have been admitted to view proceedings, let alone be invited to speak at COP. This is despite consumers being the people most affected by the decisions that come out of these meetings. It is also very different from the COP meetings held to discuss climate change, where a broad spectrum of civil society groups are invited to observe or take an active role in discussions.

Consumer groups are often falsely accused of acting on behalf of or being 'shills' of the tobacco industry. This association is principally due to the fact the tobacco industry now manufactures some of the safer nicotine products consumers are using to avoid smoking. These accusations can even come from professionals working in public health. It should be noted that vaping devices were not developed by the traditional tobacco industry, and the tobacco industry only began substantial investment in vaping products and companies after 2012. As of 2023, they only have a minor share of the global market.

What have tobacco harm reduction consumer advocacy organisations achieved?

Despite the poor organisational resource and funding base, all of the groups that took part in the Global State of Tobacco Harm Reduction's survey were able to showcase important actions and achievements. For example, engaging the media, gaining print and broadcast media coverage, making submissions to consultations by government and regulatory and advisory organisations, participation in public hearings, hosting webinars and face-to-face meetings, contacting parliamentarians, helping new groups to launch, running social media campaigns, organising protests, pursuing legal challenges, developing contacts with government ministries, and contributing to the development of national e-cigarette standards.

In recent years, advocates for SNP have achieved considerable outcomes for consumers. In India and Mexico, advocates challenged the government's planned prohibition of vaping devices through court actions. More recently, in both New Zealand and the Philippines, consumers have played an important role in ensuring regulated access to vaping products through a consultative process. The following short national case studies summarise the activities of these consumer groups.

India

In 2014, the Conference of the Parties to the WHO Framework Convention on Tobacco Control raised concerns over vaping products and in response, the Indian government decided to ban them. **The Association of Vapers India (AVI)**, a nonprofit organisation, was formally registered by consumers in 2016. With the support of pro bono lawyers, AVI moved courts across the country to challenge vape bans being imposed at the state level, and got major high courts to block key decisions by the central government. The court rulings delayed the ban by many years but ultimately, the government circumvented the normal legal processes and issued an executive order to ban the sale, manufacture and import of nicotine vapes in late 2019. This controversial move was rushed through Parliament by the majority government a few months later.

Following the 2019 ban, tobacco harm reduction consumer groups continued to generate significant media coverage in the country and in May 2023, the Indian government issued a media gag on the

publication of material considered to be ‘pro-vaping’. This move is seen by AVI and other groups as recognition of the success of consumer efforts to ensure the country’s 120 million smokers have access to safer alternatives.

Mexico

Set up in 2017, **Pro-Vapeo Mexico** is a non-profit association formed by consumers interested in promoting and raising awareness about the health benefits of switching from smoking to the use of safer nicotine products. It aims to help health authorities, politicians, the general public and the media better understand the need for open and inclusive debates regarding the implementation of policies in support of tobacco harm reduction.

Over the last six years, the group has been interviewed by various print and broadcast media outlets, while establishing strong links with consumers themselves. Its members have engaged with the country’s legislators, participating in forums organised by the Senate of the Mexican Federal Congress. They also submitted documentary evidence in a case that saw the Mexican Supreme Court of Justice declare the total prohibition of vaping products was unconstitutional. So, while the sale and promotion of vapes is now banned in the country, their use is legal at the time of writing.

New Zealand

Consumer advocacy organisations, including **Aotearoa Vapers Community Advocacy**, wanted to establish a regulated market for vapes in New Zealand. Consumer groups were concerned about the safety of these products, but wanted to maintain access to vapes for people who smoke.

Advocates worked closely with their elected and government officials, as well as healthcare providers. They presented evidence, including the latest scientific research and policy precedents from other countries, as well as the lived experiences of the consumers themselves. Relationships with politicians were built based on trust, respect and understanding.

Their successful advocacy helped to inform the Smokefree Environments and Regulated Products (Vaping) Amendment Act 2020.^{xiii} This legislation sought to strike a balance between ensuring vaping products were available for smokers who wanted to switch to a less harmful alternative, while making sure these products were not marketed or sold to young people.

The Philippines

In the Philippines, there were fears that vapes could be banned entirely due to the efforts of anti-vaping groups funded by Bloomberg Philanthropies. One of the groups that led the charge to keep vapes on the market was **The Vapers Philippines**. Their approach was informed by the work of their peers in New Zealand. They presented scientific evidence and consumer experience to a variety of stakeholders, and, using the recent example of the new regulatory framework in New Zealand, they helped to influence the Vaporised Nicotine Products Regulation Act, signed into law in 2022. The bill did impose restrictions on where vaping products could be sold, though it also lowered the legal age of purchase from 21 to 18. But in a part of the world where vaping had been banned in a number of nearby countries, this bill established vaping as a government-approved strategy to help people who smoked to reduce their health risks.

Conclusion

The ultimate goal of tobacco harm reduction consumer advocacy organisations is to ensure continued access for themselves and others to the safer nicotine products that have helped them quit smoking. They are fragile grassroots groups that are overstretched and under-resourced but have huge potential.

As this Briefing Paper demonstrates, there have been numerous examples of positive outcomes from active consumer engagement. In other comparable areas of public health, there is a recognition of the importance of the lived experience in decision-making. Consumers of safer nicotine products should similarly be recognised by governments around the world as important voices in collective efforts to bring an end to the smoking epidemic.

For further information about the Global State of Tobacco Harm Reduction's work, or the points raised in this GSTHR Briefing Paper, please contact info@gsthr.org

About us: **Knowledge•Action•Change (K•A•C)** promotes harm reduction as a key public health strategy grounded in human rights. The team has over forty years of experience of harm reduction work in drug use, HIV, smoking, sexual health, and prisons. K•A•C runs the *Global State of Tobacco Harm Reduction* (GSTHR) which maps the development of tobacco harm reduction and the use, availability and regulatory responses to safer nicotine products, as well as smoking prevalence and related mortality, in over 200 countries and regions around the world. For all publications and live data, visit <https://gsthr.org>

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