Civil Society and Health

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Case studies

- Tobacco control in Russia
- Pharmaceutical decision making EU-level
- Food banks in Cyprus
- Asylum seekers and refugees in Turkey
- HIV/AIDS in the Russian Federation
- Social partnership in Austria
- The Dutch 'whole-of-society' approach

Mini-case studies

- Tobacco control in Slovenia
- Corporal punishment in Finland
- Access to pharmaceuticals from Belgium
- Health research in the EU
- Maltese hospice movement
- Refugee crisis in Germany
- Obstetric care in Poland
- Fighting stigma and empowering disabled persons in Bosnia and Herzegovina
Why researching civil society?
**Our Mission:**

strengthening health systems – promoting evidence-informed policy making - bridging the gap between health research and policy making

**Our Role:**

informing policy makers - sharing international rigorous evidence and experience – building knowledge brokering partnerships and networks

**Our Functions:**

monitoring country health systems – analysing trends and health policy developments – assessing health systems performance – engaging with policy makers
Overview

• Why researching civil society organizations?

• What is civil society?  
Definitions, types, actions, benefits

• What are contexts conducive to civil society?

• How can civil society organizations strengthen themselves?  
Platforms and alliances

• What is the view of governments regarding civil society in the WHO European Regions?  
Great expectations, ambivalence and crack-down, does it exist at all?

• Concluding remarks
What is civil society?
Definitions, types, actions, benefits
What is Civil Society: definitions

• Negative definition: Neither state nor market (nor family)
  – However, civil Society Organizations working at the interface of states and markets

• Positive definition: Autonomy and constituency
  – Who has the power to choose and dismiss its leader
  – Who has the power to stipulate its statutes and operating by-laws?
  – What is its economic base?
  – Who has the power to determine its mandate?
Box 1.2 Non-governmental organizations and other non-state actors according to the WHO framework of engagement with non-state actors (FENSA)

8. For the purpose of this framework, non-State actors are nongovernmental organizations, private sector entities, philanthropic foundations and academic institutions.

9. **Nongovernmental organizations** are non-profit entities that operate independently of governments. They are usually membership-based, with non-profit entities or individuals as members exercising voting rights in relation to the policies of the nongovernmental organization, or are otherwise constituted with non-profit, public-interest goals. They are free from concerns which are primarily of a private, commercial or profit-making nature. They could include, for example, grassroots community organizations, civil society groups and networks, faith-based organizations, professional groups, disease-specific groups, and patient groups.

10. **Private sector entities** are commercial enterprises, that is to say businesses that are intended to make a profit for their owners. The term also refers to entities that represent, or are governed or controlled by, private sector entities. This group includes (but is not limited to) business associations representing commercial enterprises, entities not “at arm’s length” from their commercial sponsors, and partially or fully State-owned commercial enterprises acting like private sector entities.

**International business associations** are private sector entities that do not intend to make a profit for themselves but represent the interests of their members, which are commercial enterprises and/or national or other business associations. For the purposes of this framework, they shall have the authority to speak for their members through their authorized representatives. Their members shall exercise voting rights in relation to the policies of the international business association.

11. **Philanthropic foundations** are non-profit entities whose assets are provided by donors and whose income is spent on socially useful purposes. They shall be clearly independent from any private sector entity in their governance and decision-making.

12. **Academic institutions** are entities engaged in the pursuit and dissemination of knowledge through research, education and training.

Examples of civil society organizations:

Activist groups, charities, civic groups, campaigns, sports clubs, social clubs, community foundations, community/local associations, consumer organizations, cooperatives, churches, cultural groups, environmental groups, foundations, lobbies, men’s groups, policy institutions, political parties, private voluntary organizations, professional associations, religious organizations, social associations, social enterprises, support groups, trade unions, voluntary associations, women’s groups.
What actions do civil society organizations perform?

• Policy activities
  – Evidence, policy development, advocacy, consensus building, watchdog/ accountability

• Service work
  – Service to members, service to public

• Governance
  – Standards, self-regulation, social partnership
# Types and activities of Civils Society Organizations

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<th>Activity</th>
<th>Interest groups</th>
<th>Constituency</th>
<th>Communities</th>
<th>International</th>
<th>Other</th>
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<td>Causes</td>
<td>Economic</td>
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<td><strong>Policy</strong></td>
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<td>Consensus-building (ch4)</td>
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<td>Watchdog/ accountability (ch10)(ch4)</td>
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<td><strong>Service</strong></td>
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<td>Services to public (ch7)(ch8)</td>
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<td><strong>Governance</strong></td>
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<td>Self-regulation</td>
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<td>Social partnership</td>
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For civil society in policy

- Benefits of working together: information, representation of minority groups, political early warnings

- Policy should thus:
  - Consult formally and clearly and not too onerously
  - Be transparent, so decision makers, decisions, and their grounds are clear
  - Strive to balance inequities in e.g. resources
Chapter 5

The governance of coverage in health systems: England’s National Institute for Health and Care Excellence (NICE)
Iestyn Williams

Example of the European Medicines Agency

Ilaria Passarani
Policy, politics and public health

Scott L. Greer¹,², Marleen Bekker³,⁴, Evelyne de Leeuw⁵, Matthias Wismar², Jan-Kees Helderman³, Sofia Ribeiro⁴,⁶, David Stuckler⁷

- Populism undermines evidence informed policy making
- Populism undermines equity, solidarity and inclusiveness
  - Nationalistic welfare state
  - Reduced welfare state

Box 1 Populism and public health

- The ‘populist radical right’ is nativist (believing that there is an ethnically united people with a territory, aka nationalism or ethnocentrism), authoritarian (believing in the value of obeying and valuing authority) and populist (preferring the ‘common sense’ of a unified people to elite knowledge).
- Populist politicians ‘infect’ regular party politics by showing the possible electoral rewards of adopting populist positions that might contradict evidence, norms or the law. This effect is visible in immigration policy in many countries, where mainstream parties adopted harsher policies as responses to populist radical right challengers.
- The populist radical right therefore challenges the checks and balances of the political democratic system and the protections that exist for minorities. Once in office, there is a risk of ‘democratic backsliding’ when ‘elections happen but without a realistic chance of them leading to a transfer of power’.
- Combined with a recent trend towards populist ‘welfare chauvinism’, populist policies could have very significant implications for unfair redistributive policies, unequal access to welfare benefits and increasing health inequalities.
- Whether they will, and how, depends on the political context that makes them more or less powerful and their agendas more or less practical.
Identification of conspiracies
• Fake experts
• Selectivity
• Impossible expectations of what research can deliver
• Misrepresentation
A meaningful discourse is impossible when one party rejects these rules. Yet it would be wrong to prevent the denialists having a voice. Instead, we argue, it is necessary to shift the debate from the subject under consideration, instead exposing to public scrutiny the tactics they employ and identifying them publicly for what they are.

Denialism (public debate) (Dietelhelm & McKee 2009)

Walter Ricciardi resigns as president of the Health Institute: "insufficient efforts"

Different views from the government on vaccines and assistance to migrants. "But no contrast with Minister Grillo." The last of the excellent exits in the health field
Service organizations

- Benefit is that they are cheaper, more flexible, and often more sensitive to emerging or niche problems
- Policies to work with them should include:
  - Clear and accessible criteria for grants and contracts
  - Grants and contracts that are not too large
  - Careful oversight (reporting requirements not too onerous but be alert to signs of fraud, financial instability, etc)
Governance

- Obviously a big concern in social partnership countries, but found everywhere, e.g. setting and professional regulation

- Such authority and responsibilities needs:
  - Particularly clear legal standing, transparency and participation
  - High level of organization, often monopoly
  - Power to deliver outcomes and institutions to enable both regulated conflict and real role in governance
What benefits have civil society organizations to offer?

• Empowerment
• Services
• Commitment
• Flexibility
• Participation in policy
• Credibility
What are contexts conducive to civil society?
Context: Legal status and registration

- Should be:
  - Non-political
  - Legally clear
  - Not onerous
  - Basic transparency

- Advantageous but not mandatory...advantages of incorporating and tax treatment, but no legal requirement
• Freedom of association
• Regulatory and legal issues
• effective, formal, transparent and efficient system for registering civil society organizations
• Political social context
• Social contexts
• Financing
  – Different civil society organizations need different kinds of support
  – Too much project funding too little core funding
  – Too much red tape for small entities
How can civil society organizations strengthen themselves?

*Platforms and alliances*
Cyprus – a civil society platform to address austerity induced poverty

- was particularly hard hit by rising unemployment and austerity policies as a consequence and response to the financial and economic crisis.
- setting up of social groceries to assist individuals and families, demonstrating how local civil society organizations can respond in delivering timely services to the public.
- existing organization such as the Pancyprian Federation of Patients’ Associations and Friends has taken a leading role in representing patient organizations
- strengthening resilience and participation of civil society (Joachim 2017)
EU – A civil society strategy to address the food industry

- EU Platform for Action on Diet, Physical Activity and Health
- Public Private Partnership
- Bridging the resources gap
- PPP as a lever for health changes and intersectoral action

- Programme Manager for Governance & Health Cities, WHO Regional Office for Europe (and formerly civil society leader)
Russia – a civil society alliance to curb the tobacco epidemic

- The Russian AntiTobacco Advocacy Coalition (ATACa)
- after the collapse of the Soviet Union, the international tobacco industry was in a strong position
- ATACa established consensus among key civil society organizations.
  - bringing (international) evidence to the table,
  - provide advocacy
  - mobilization and
  - act as watchdog
- autonomy of civil society organization is, as all too often the tobacco industry tries to undermine the independence of institutions and officials
- transitional funding
- ...seems likely that the changing view on the tobacco industry has played a part in the substantial decline of smoking rates in Russia.
- (Danishevskiy & McKee 2017)

Box 4.2 Current members of the Coalition (as of 1 December 2008)
1. Open Health Institute
2. International Confederation of Consumers’ Societies
3. All-Russian non-governmental organization “The League of patients’ protection”
4. Regional non-governmental organization “Healthy Regions Association”
5. Union for struggle for public sobriety
6. All-Russian community movement “Sober Russia”
7. Russian philanthropic Foundation “No to Alcohol and Drug Abuse”
8. Foundation of Social Development and Public Health “FOCUS MEDIA”
9. Coalition “For Tatarstan free of tobacco smoke”
10. Russian Public Health Association
11. Cochrane Collaboration
12. Arkhangelsk International School of Public Health
13. Interregional non-governmental organization “Society of evidence-based medicine specialists”
14. Interregional non-governmental organization “Assistance to public health”
15. Non-profit partnership “Parental meeting”, city of Ulyanovsk
16. Philanthropic foundation “Open Medical Club”
17. Non-governmental organization for a sober and healthy lifestyle “The Nizhnekamsk optimalist”
18. Association of University Programmes in Healthcare Administration
Together for a tobacco free society

- Slovenia was one of the “five countries in Europe that were able to reduce smoking prevalence below 25% for the adult population”
- The initiative involved government, press, medical professionals and NGO representatives from Central and Eastern European countries developing a campaign, based on the Great American Smoke-out.
- The campaign aimed at building coalitions and strengthening in-country advocacy capacities.

The Slovenian Coalition for Public Health, Environment and Tobacco Control (SCTC), involving 26 NGOs, was founded in 2003.

The coalition took an active part in the public debate in 2007 when Slovenia was in the process of adopting a total smoking ban in public places and raising the smoking age limit to 18.

It remains active to date and in 2017 was significantly contributing to the adoption of a new tobacco law in Slovenia, introducing inter alia a total ban on advertising, donation and sponsorship; plain packaging; and licensing (Petric 2017)
What is the view of governments regarding civil society in the WHO European Regions?

*Great expectations, ambivalence and crackdown, does it exist at all?*
• Book launch, WHO Regional Committee, 12 Sept 2017, Budapest
• Better synergies for health – the role of civil society (with the EU Commissioner Vytenis Andriukaitis and Josep), EHFG, 06 Oct 2017, Gastein, Austria
• Brussels book launch (with Pedro Facon Director General for Health, Belgian Ministry of Health), 10 Oct 2017 Brussels
• Round table EUPHA: Civil Society governance for health, (together with Marleen Becker, President of the EUPHA Section Public Health Policy and Practice) EPH-conference, 04 Nov 2017 Stockholm.
• Civil Society and Health: partners symposium, 27 Nov 2017 Brussels
• Civil Society and Health: briefing for the European Commission, 06 Dec 2017 Brussels
• Civil society breakfast: at the Slovene Ministry of Health, 30 Nov 2018, Ljubljana.

Civil Society: great expectations
CPME Retweeted

**World Medical Association** @medwma · May 6

@CPME EUROPA and @medWMA condemn sentencing the members of the Council (2016-2018) of the Turkish Medical Association (TMA). Press release: bit.ly/2PMyndo

#supporttma @ttborgtr @_ttb

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**Chapter 7**

Syrians under Temporary Protection, health services and NGOs in Turkey: the Association for Solidarity with Asylum Seekers and Migrants and the Turkish Medical Association

*Saime Ozcurumez, Deniz Yildirim*

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**CPME STATEMENT ON THE OUTCOME OF THE TRIAL AGAINST THE TURKISH DOCTOR LEADERS**

The Standing Committee of European Doctors (CPME) joined by the World Medical Association (WMA) condemn the outcome of the trial against the members of the Council (2016-2018) of the Turkish Medical Association (TMA).

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Ambivalence towards civil society

- The room for civil society action is limited
- HIV/AIDS epidemic in Russia
  - People that inject drugs
  - Female sex-workers
  - Prison and pre-trial detention centers
- Russia’s HIV/AIDS strategy focuses on ‘family values’;
- No support for the affected
- Acceptance of foreign resources turn CSO into ‘foreign agents’ with consequences for the functioning of the organization
Some conclusions

- Having an active civil society and capable civil society organizations strengthens health and health systems
- To thrive civil society organizations need regulatory and financial back-up
- Civil society organizations need to be able to develop and use joint platforms and/or coalitions