

**Civil society and public health research
in the European Union new member states**

Mark McCarthy, Faculty of Population Health Sciences, University College London.

Agnese Knabe, Association Skalbes, Riga, Latvia.

Accepted for publication in Scandinavian Journal of Public Health, March 2012.

Correspondence to MM:

Faculty of Population Health Sciences, University College London, London WC1E 6BT, UK.

Email, m.mccarthy@ucl.ac.uk

Summary

Introduction

Civil society organisations (CSOs) are not-for-profit organisations working for the public interest with concerns complementary to public health. We investigated the contribution of CSOs in public health research.

Methods

Within a European project STEPS (Strengthening Engagement with Public Health Research), CSOs with interests in health were identified in the new member states of the European Union (Estonia, Latvia, Lithuania, Poland, Hungary, Slovakia, Czech Republic, Slovenia, Romania, Bulgaria, Malta and Cyprus) and workshops organised, held in their own languages. The reports of the workshops were translated into English, and drawn together through a framework analysis.

Results

CSOs can contribute in all stages of the research cycle, through championship, priority-setting, capacity building and generation of resources, sharing and application of the research results, and dissemination across their network of contacts. There have been successful CSO-researcher collaborations in public health fields. Funding is important, and ministries of health and public institutions should interact more with CSOs. Barriers include attitudes, technical understanding across public health fields.

Discussion

There is little European empirical literature linking health CSOs and research: our results indicate benefits and further opportunities. In contrast to biomedicine's link with industry, public health research can align with civil society in not-for-profit research. CSOs are important for European integration, and their contribution should be better recognised at international level.

Key words.

Europe

Social conditions

Public health

Research

Governance

Introduction

Following the 1998 UN Aarhus Convention on access to information and public participation in decision-making, the European Union has defined its policy for open consultation in all its fields with all 'interested parties', including contact with civil society [1, 2]. The European Union's Sixth and Seventh Framework Research Programmes have created links with civil society through the Science in Society programme, and reports from this programme have considered the value public understanding of science [3], 'cooperative' research [4], and participation by civil society [5].

Community health researchers working in low and middle income countries have promoted engagement with civil society organisations by governments, academia, funding agencies and technology councils [6, 7]. At the Ministerial Forum on Research for Health held in Bamako, Mali, in 2008, a Ministerial declaration called for civil society and community participation 'in the entire research process, from priority setting to the implementation and evaluation of policies, programmes, and interventions' [7].

SPHERE, a study of public health research structures in European countries, assessed priorities for research from the perspective of NGOs and national public health professional associations [9, 10]. Bibliometric studies showed lower levels of public health research publications, and less development of social science disciplines, in the countries of central and Eastern Europe [11]. In parallel, the European Public Health Alliance, which speaks for health on behalf of not-for-profit organisations, undertook an action to identify CSOs concerned with health in the EU new member states, and held a conference in Bratislava, Slovakia in 2008 which presented CSO interests for activism, health promotion, and delivery of health services through the voluntary sector [12].

Drawing funding from the European Commission's Science in Society programme [13], STEPS (Strengthening Engagement in Public Health Research) was initiated in 2009 with a special focus on the twelve 'new' member states that joined the European Union in 2004 and 2007. STEPS partners held workshops in each of the 12 new member states, engaging civil society organisations in discussion with researchers and health officials. The definition of 'public health' by the US Library of Medicine is "the prevention, detection, and control of disease, and the protection and promotion of health on a community or population level" [14]. Thus, public health research included all health research at population level but excluded biomedical – clinical and laboratory – research. This paper describes the perspectives on CSO engagement in public health research of participants in the 12 workshops.

Material and Methods

STEPS started as a partnership of three lead organisations: University College London as coordinator; European Public Health Association (EUPHA) with contact to national associations; and Association Skalbes in Latvia, which had previously been engaged with the Bratislava meeting of civil society health organisations in new member states [12]. In the first phase, the initial partners sought to identify relevant organisations to lead the 12 country workshops, using an iterative process: drawing from existing European networks (EU Health Policy Forum, European Public Health Alliance, the Social Platform), national level networks including the NGO support and information centres and the Open Society Institute, and field organisations including reproductive health and family planning, environment, anti-tobacco, patient's groups, health promotion agencies.

These activities identified suitable partners that were matched against possible partners from public health field identified by STEPS team members through country visits. The process drew on existing contacts from the partner organisations and internet searches and recommendations from contacts, as well as visits to ministries of health and research organisations. Agreeing an organisation to lead the workshop for each country was achieved over a period of a few months. A meeting of workshop leads was held in Lodz, Poland, in November 2009, and a template for the national workshop meetings was prepared. The template included guidance for the content and structure of the national workshops in order to keep the right directions and common character of the workshops. The leads also developed a questionnaire that was sent in eight countries to potential civil society organisations before the workshop.

The workshops were anticipated to be of about 30 people, drawn from a range of civil society, researchers and officials. Of four presentations expected in the workshop, one was to be on civil society organisations and one on health research. The workshops were held in the national language, and reports afterwards of about 15 pages, in both national language and English, were requested. The sections on civil society were abstracted from the English reports of the 12 workshops. The discussions in the reports were drawn together through a framework analysis, developed through reading and discussion of the workshop reports, made by three members of the STEPS partnership. The results section of the paper synthesises these findings.

Results

Identifying civil society

Civil society, in political thought, is the sphere of the natural association of people, separate from the governmental sector that promotes the shared goals, interests and values of the society at large. The European Commission's Science in Society programme has developed the definition that a CSO is 'a legal entity which is non governmental, non profit, not representing commercial interests and pursuing a common purpose in the public interest'.

In some countries there is a legal framework for these organizations to be consulted and then contribute to the drafting of legislation connected to their mission and objectives. There may also be a legislative framework so that governmental organizations can apply for non-reimbursable financial resources from public funds for non-profit general activities based on project competitions.

From a health perspective, categories of civil society organizations in new member states include organizations which promote specific health-related purposes (such as information, advocacy or policy-shaping), organizations aimed at self-support and protecting the rights of patients and vulnerable groups, organisations providing services, and organizations supporting the professions in their practice or employees' interests in their relation to their employers.

Civil participation in the health sector is growing, as a result of wider access to information through new information technologies, growing interest in transparency in public affairs for individual citizens and population groups, growing awareness that the state is constructed through its citizens (who should not be viewed merely as taxpayers and/or voters), and increasing formulation and implementation of evidence-based policy where the influence on the population, politics, economics and social environment is researched beforehand.

Value of CSOs

Public health reflects social needs as well as the choices of individuals. The promotion, implementation and evaluation of public health and welfare programs is difficult and requires the cooperation of state, private and non-government sector. People in civil society organisations hold

personal knowledge about health issues can support the development of practice to complement medical science, address social problems and achieve health promotion. Besides working on health projects, protecting citizens rights on local and national levels, and directly offering health services, CSOs may participate in formulating priorities and policies for public health as well as lobbying for politicians and the medical system.

Public health can create programs using a social health model within the community through the involvement of CSOs. Health and quality of life in communities is influenced both by the policies and practices of the national public health plan and services, as well as by the communities themselves. However, within this framework, while retaining their independence, the interests of civil society organisations need to be evident and transparent, especially if they are advocating for particular research priorities or public policies.

Research as the basis of knowledge society

In the 2000 Lisbon Agenda, the European Union set the objective of a 'knowledge society' to promote economic development and prosperity. Two models of the knowledge society and innovation have been suggested – expert knowledge and technological solutions of social problems on the one hand, compared with a 'collective' approach enabling concerned groups, promoting low-tech and social innovations, and putting emphasis on public accountability and utility.[3] Although research seems less valued if it is without an economic impact, or "hard" results, it is necessary also to emphasise other dimensions – social, environmental and cultural – where the public impacts can be presented. Public utility beyond economic notions should be a principal of research for civil society organisations, which can formulate the interests of groups of citizens in relation to science and academic institutions, and engage in research processes.

CSOs and research

- Contributions

Research as a concept includes a complete cycle of knowledge development – from its generation through information, analysis and trial, to its effective application. CSOs can participate in all stages of this cycle, through championship, priority-setting, capacity building and generation of resources, sharing and application of the research results, establishment of a network of contacts.

Civil society organisations can be involved at the very first stages of health research, by conducting

a needs assessment within civil society to determine which areas of concern are to be investigated. The experience of the public themselves, including those who live with a disease and those who care for sick people, is part of the health situation in the country, and reflects the needs, the problems and the policies that have to be developed. Volunteers may be involved in, and contribute to, designing research instruments for recording public perceptions, drawing on the expertise that volunteers have gained from working directly in the field, and contributing to a multidisciplinary approach. Civil society organisations are well placed to continue contact with surveyed populations after research fieldwork, and can disseminate the results produced by research. CSOs can identify the best methods for advocacy and for effective communication of research knowledge.

- Benefits

Involvement in research gives the opportunity for civil society organisations to widen their perspectives and to give an added dimension to their role. They can become more active, in community life and be able to defend the rights of the population groups they represent. Types of possible collaboration include research rooted in community, scientific workshops, civil juries and consensus conferences. Views reported on from this perspective in the Workshops included: “Civil society organizations are essential in gathering various research data, helping the quality, relevance and size of the gathered data and information.” “Research should be seen as a process that does not include only carrying out studies to gain new data, but also our ability to translate existing data into practice.” “All too often, the civil society organizations are not aware of the strategic importance and power of research for their work. Carefully considered use of research data can significantly contribute to achieving set goals of every organization and to help them be more successful with programmes, projects and future plans.”

Field level examples

Interested organizations usually have prior experience in research, in international projects and are part of the national and international networks. They would like to enhance their involvement in research, especially in setting the research priorities, but indicate the lack of a formal framework for the consultation of the civil society. They also understand the need of a closer collaboration and stronger involvement in research, both nationally and throughout Europe.

- Cyprus Alzheimer’s Association has branches in many towns of Cyprus, with goals to raise public awareness, to lobby for the patients’ rights, to offer social support for people with Alzheimer’s and their families, and to reinforce medical or social efforts for the prevention

and treatment of Alzheimer's disease. Day-centres offer daily care to their members, including educational lessons, and art, music and physical therapies. The Association participated in needs research in 2005 for both Greek and Turkish communities, funded by the UNDP. The Association attends international and European conferences. .

- Healthy Cities of the Czech Republic (HCCZ) has been functioning in the Czech Republic for more than 16 years and currently supports 90 cities, municipalities and regions. These members collaborate in the area of health with professional partners from state, academic and non-profit organisations and institutions and form a bridge for science knowledge, policy and practice. Healthy Cities is linked with WHO in health promotion in schools, runs thematic campaigns, and organises Healthy City Forums – public meetings where people identify the major problems of a city, municipality or region.
- DIA+LOGS is a Latvian association which works in the field of HIV/AIDS, providing direct services; for example needle exchange and other harm reduction services, social support groups, and advocacy and lobbying on the rights of people with HIV. These activities provide promote collaboration with different partners and provide a background for project proposals. DIA+LOGS has undertaken research on the needs of people living with HIV, employment facilities for socially vulnerable groups, and a prospective cohort study among drug injectors.
- In Slovenia, MOSA (Mobilizacija skupnosti za odgovornejši odnos do alkohola) is an information centre providing data and support to around 300 members of organizations working the field of alcohol control. The centre brings together strategic partners of national importance, encouraging long term connections, developing sources of data, identifying who is working on alcohol, and how and where problems and neglected questions can be highlighted.
- In Lithuania, three programmes of research engagement over the past five years were described. Global Initiative in Psychiatry initiated research on national public mental healthcare services, assessment of stigma in services, perceptions of disability, and public and employers' opinions on the integration of people with mental disorders into employment. The “I Can Live Coalition” undertook research on access to healthcare, social and education services for drug users, assessment of HIV prevention among people

previously imprisoned, and a social tolerance study together with the National Health Council. The Centre for Civil Initiatives made a study of patients' rights, and followed with an analysis of the right to privacy and implementation of confidentiality in the healthcare system.

Funding

As well as donations and membership subscriptions, in most Central and Eastern Europe countries there are now further ways for financial support of CSOs, such as specialized foundations/funds for financing NGOs with initial capital, tax concessions for business activities related to the goals of the organizations, a “1%” mechanism, where the taxpayers has the right to determine the receiver as an CSO, or reduction the tax paid by them – as well as lotteries. Possible funding sources for CSO health research activities include state funds and programmes, international programmes, bilateral international projects, endowments (private and corporate), membership fees, and business activities (data bases sales, books and publications, trainings, etc.). Yet participation of CSOs is also impeded by the models and conditions for financing research. The scope and content of the information provided for the civil sector, and use of mean to transfer the information (internet and on-line means of communication) seems far from adequate. Moreover, funding sources remain limited and, for CSOs, tend to be oriented towards provision of services or implementation of more “tangible” projects rather than research or state-of-play analysis.

However, co-financing is usually not provided by the State (in contrast to public institutions). Although the European Commission makes initial advance payments, bridge financing is needed to continue the work during Commission's evaluation of the first phase reports, and months or years of waiting for final reimbursement can lead the CSO into liquidity difficulties. CSOs were concerned that funds for European projects and programmes funds are tending to be awarded to organisations with accumulated administrative capacity, yet without any significant contribution to the proposal field.

Capacity and environment challenges: CSO perspectives

- Attitudinal

Public health structures – both governmental and research institutes - can show reluctance to accept CSOs as partners and involve them in the shaping and planning of public health research policy.

Sometimes there is poor communication, including lack of openness, flexibility, sensibility and empathy; sometimes open public consultation, is done formally and ceremonially, through official round-tables and meetings, rather than within practical cooperation via projects, programmes and mixed working groups; and sometimes personal and organizational interests may significantly influence the allocation of resources, the content of the research projects and the readiness to invite CSOs to participate.

- Technical

There may be limited understanding of CSO competence for research, both on the part of the civil sector and the public health sector, while public health can also seem complex, and priorities on social matters or medical issues are challenging. There may simply be lack of information to encourage CSOs to participate. There may be insufficient knowledge about the research needs because of lack of contact with the academic community, insufficient information on content and technical aspects, and limited access to, or use of, databases on research knowledge and administration. Further, the experiences accumulated during the scientific co-operation between the civil sectors and one particular sector, for example, environmental protection, or managing issues of social inequalities, may be unknown to the public and civil actors elsewhere in the field of public health.

Specification of public health and public health research

A third issue is the lack of clarity for the field of public health. Many countries have had major political debates on the structures, provision and financing of health care (especially hospital care), but often without scientific technical discussion, nor a view of the broader objectives of a health system in controlling disease and promoting health. The problems of public health have been neglected and the transformation from the communicable disease control system to a modern public health system, including action on the determinants of health such as social behaviours, urban environments, housing, inequalities, and issues related to human rights, has been slow. Where there is a public health research strategy to address these fields, it is insufficiently known about; while some institutions and university research centres may have their own research strategies, these cannot be considered to be national.

Civil society response.

Civil society also sometimes show a lack of initiative, determination, interest and assertiveness. Few health CSOs interact with other CSOs and thus limit their capacity for development and work

on projects. Cooperation with organizations working in the fields such as social policy, ecology or human rights, could provide new perspectives and support. Nevertheless, there are also practical factors limiting responsiveness, which include issues of finance discussed above, shortage of human resources, and the background lack of tradition for civil society engagement in the new member states.

Ministries' capacity for promoting research

At central government level, a framework for the Ministry of Health or the National Health Insurance Fund to support research projects and programmes, and to engage with structures of the civil society, may be lacking. CSOs projects related to the health sector may be financed by the ministry of labour and social affairs (eg including health information campaigns, provision of services, medical equipment deliveries), the ministry of regional development and public works (infrastructure projects, hospital development), the ministry of environment (environmental health), the ministry of justice (medical law, medical errors), the ministry of transport (accidents, active travel), the ministry for information technologies and communications (electronic health care) and the ministry of finance (Structural Funds). The ministry of health may be a passive observer of these policies and processes, and lack action to unify what's happening in neighbouring fields with the health care sector research projects and programmes.

How to cooperate

Principles of interaction between public institutions and CSOs in health research should be a pluralism of viewpoints; transparency in CSO governance, funding sources and accounts; transparency and public control over the procedures related to public health research projects; and building of understanding through accessible national databases with results from public health research and programmes, (these funded from the national budget and/or European funds). Public health policy is based on real experience and relates to the people it is made for. To improve their participation in the processes of decision making, and especially for public health research, CSOs need to establish a culture of cooperation.

While the current actors of the public health system can be broadly identified, it is less easy to determine which CSOs can be considered as competent actors for involvement in health research policy development and implementation. The public health system could assist CSOs in determining their own capabilities and limitations for involvement in research, assisted by CSO

support programmes of research education and training. Stakeholders in the civil sector should identify the points where the civil sector can join in, in a productive, efficient and sustainable way, propose incentives (e.g. application system) suitable for civil sector organisations, and improve information on willingness to participate through a survey and data-base.

Discussion

Our study contributes description and analysis to help understanding of the contribution of civil society organisations to health research within the framework of European integration theory [15]. Integration has promoted political institutions being responsive to their citizens, and also citizen-led approaches in social development. Citizen engagement with the state can promote legitimacy and accountability, influence policies, counter 'élite-capture' of resources, and implement effective services. On the other hand, negative outcomes may include disempowerment and loss of agency, a sense that participation is tokenistic or manipulated, or the use of skills and alliances for corrupt or malign ends. Effective change comes from positive alliances between champions inside the state and social actors on the outside [16]. CSOs can operate at several levels, and can thereby sometimes overcome bureaucratic blocks in ways that are politically appealing.

While civil society organisations in the western sense were subsumed into the state in the post-war communist societies, western interests after 1990 have sought to recreate civil society through internal organic structures such as the Open Society Institute in central Europe, as well as direct support in weaker states in south-east Europe. Early initiatives formed around environmental and rights issues, while health CSOs were more commonly contributed as welfare providers rather than action groups. Civil society organisations in the 'third sector' are part of the 'soft' institutions of shared European norms, principles and procedures [17].

CSO engagement in health research has been considered, through a literature review, in the developing world [18], described models for undertaking health science and framing evidence, the opportunities for CSO engagement in priorities, commissioning and communication, the use of research evidence for policy, and also the different methods that CSOs might bring to research – including documentary methods such as photography and individual narratives. A Canadian study [19] within an international health research system perspective described CSOs contributing in advocacy for research, promoting priorities, reviewing ethical frameworks, mobilisation of

resources and use of knowledge use. The study also found 'a lack of accessible and centralized information' and concluded by proposing an 'NGO network for global health research'. The Council on Health Research and Education for Development (COHRED) has promoted an action plan [20] for greater involvement of CSOs in research networks, planning and access to research funds, with a core group of 12 organisations giving support to the call.

This activity, however, is not directed towards Europe, where there is little previous evidence on CSO involvement in health research in Europe. A survey for *SPHERE* among 80 CSOs from European, national and local organisations, identified a relatively good capacity, including international experience, although more often with public health action than research itself [9]. The main research priorities reported included environmental health, diabetes, obesity, nutrition and tobacco control: interestingly, these were not necessarily the same as the CSOs' own work field. In the STEPS workshops issues for involvement of CSOs in research were both technical and attitudinal – that is, their capacities and interests.

Several of the STEPS Workshops called for further national discussion on public health research, and some for establishing a national platform for public health research to which CSOs could contribute. At present, however, national structures and agendas for public health research are poorly defined [21] and a platform would provide continuity for dialogue and development although issues described in the Workshops, of competition, research paradigms and power, would continue to be evident. These could benefit from national public health association leadership, as ministries of health do not at present give priority to research.

The workshops confirmed earlier findings that, while ministries of research tend to regard health research as the responsibility of ministries of health [22], the ministries of health themselves have taken less interest in research [21]. Achieving benefits to health through research across other non-health sectors is equally challenging. The European Union research paradigm considers innovation as the crucible for competition and economic development, and for health the arguments for not-for-profit research towards social benefit are less well heard [23]. Civil society organisations can be the 'third sector' needed for research for social benefit, just as commercial partners are needed partner for applied research in the for-profit economy. Public health research and civil society organisations should be powerful allies in the future in Europe.

Acknowledgements

We are grateful to Dace Beinare, who contributed to the framework analysis; to the 12 Workshop organisers Gerli Paat, Anita Villerusa, Jurgita Poškevičiūtė, Krzysztof Krajewski-Siuda, Zuzana Katreniak, Jitka Bouskova, Katalin Szőke, Matej Košir, Florentina Furtunescu, Petko Salchev, Nicola Critien and Christina Loizou, whose reports provide the foundation for this report; and to Sylvia de Haan, Council for Health Research and Development, for her advice.

Funding

The research leading to these results has received funding from the European Union's Seventh Framework Programme (Science in Society) under grant agreement 217605.

Statement

The authors declare that they have no conflict of interest.

References

1. European Commission and Civil Society (2010). http://ec.europa.eu/civil_society/apgen_en.htm (accessed 7 April 2011)
2. Fazi E, Smith J. Civil society: making it work better. Brussels, Civil Society Contact Group, 2006.
3. Felt U (rapporteur). Taking European knowledge society seriously. Report of the Expert Group on Science and Governance. European Commission, Directorate General for Research, Science Economy and Society, 2007. EU 22700.
4. Stirling A (rapporteur). Towards a framework for 'co-operative research'. Report of a European Commission Workshop Governance and Scientific Advice Unit of DG RTD, Directorate C2 Directorate General Research and Technology Development, Brussels. SPRU – Science and technology policy research, University of Sussex, UK, 2006.
5. European Commission, Directorate General for Research, Science Economy and Society. Goverscience civil society organisations seminar, Brussels, 9-10 October 2008. Luxembourg, Office for Official Publications of the European Communities, 2009. EUR 23912 EN, DOI 10.2777/64742
6. Sanders D, Labonte R, Baum F, Chopra M. Making research matter: A civil society perspective on health research. Bull World Health Organ. 2004;82:757–763.
7. Council on Health Research for Development. Civil society engagement in research for health. <http://www.cohred.org/supporting-countries-to-build-systems-that-focus-health-research-on-achieving-equity-and-national-development/civil-society-engagement-in-research-for-health> (accessed 16 March 2012).
8. World Health Organisation. Global Ministerial Forum on Research for Health. http://www.who.int/mediacentre/events/meetings/forum_rh/en (accessed 16 March 2012).
9. Gulis G, Garrido-Herrero L, Katreniakova Z, Harvey G, McCarthy M. Public health research priorities in Europe seen by non-governmental organizations. Cent Eur J Public Health,

2008;16(4):209-12.

10. McCarthy M, Harvey G, Conceição C, la Torre G, Gulis G. Comparing public-health research priorities in Europe. *Health Res Policy Syst.* 2009 Jul 14;7:17.

11. McCarthy M, Clarke A. European public health research literatures—measuring progress *European Journal of Public Health* 2007; 17(suppl 1): 2-5.

12. Misigova I (rapporteur). EPHA Conference on Health in the Enlarged EU, held 16-17 April 2007, Bratislava (Slovakia). Conference Report. Brussels, European Public Health Alliance, 2007.

13. European Commission (2010). Research for the benefit of specific groups – civil society organisations. <http://ec.europa.eu/research/science-society/csofp7-funding.htm>

14. US National Library of Medicine (2003). National Institutes of Health. <http://www.nlm.nih.gov/tsd/acquisitions/cdm/subjects89.html> (accessed 7 April 2011)

15. Wiener A, Diez T. *European Integration Theory*. Oxford, Oxford University Press, 2009.

16. Rayner G. *Creating national public health alliances in the new member countries of the European Union. A Handbook for Organisation Building*. Brussels, European Public Health Alliance, 2004.

17. Evers A, Laville J-L (eds). *The third sector in Europe*. 2nd Edition. Cheltenham, UK: Edward Elgar, 2009.

18. Kuruvilla S. *CSO Participation in Health, Research and Policy: A review of models, mechanisms and measures*. London, Overseas Development Institute, 2005 (Working paper 251)

19. Delisle H, Roberts JH, Munro M, Jones L and Gyorkos TW. The role of NGOs in global health research. *Health Research Policy and Systems*, 2005;3:3.

20. Conceição C, Leandro A, McCarthy M. National support to public health research: a survey of European ministries. *BMC Public Health*. 2009 Jun 25;9:203.

21. Stein H. Supporting and using policy-oriented public health research at the European level. *Eurohealth*; 2010; 14(1);18-22.

22. McCarthy M. Who supports health research in Europe? *European Journal of Public Health*, 2010; 20(1): 3-5.