

Civil society organisations and health research in Europe

Original Article

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

Abstract

Background. European Union strategies and programmes identify research and innovation as a critical dimension for future economic and social development. While European research policy emphasises support for industry, the health field includes not-for-profit civil society organisations providing social innovation. Yet the perspectives of civil society organisations towards health research in Europe are not well understood.

Methods. STEPS (Strengthening Engagement with Public Health Research) was funded by the European Commission's Science in Society research programme. Within the study, we interviewed by telephone respondents of 13 European health civil society organisations which represented collectively local and national organisations

Results. Research was valued positively by the respondents. Health civil society organisations did not seek to do research themselves, but recognised the opportunity of funds in this field and welcomed the possibility of collaborating in research, of using the results from research and of providing input to research agendas. Links between research and users provides knowledge for the public and improves impacts on policy. Research and evaluation can help in demonstrating the benefit of innovative activities, and give support and legitimacy. However, the cultures of, and incentives for, researchers and health civil society organisations are different, and collaboration requires building trust, a shared language, and for the power relations and objectives to match.

Conclusions. Health civil society organisations contribute social innovation in organising services and activities such as advocacy that cannot be satisfactorily met by industry. Engaging civil society organisations in research and innovation will strengthen the European Research Area.

Key words

Research/organization and administration [Mesh]

Europe [Mesh]

Data Collection [Mesh]

Social Conditions [Mesh]

Introduction

In its forward strategy for 2014-2020, the European Union identifies research and innovation as critical for economic and social development, and has stated that, along with industry and the public sector, civil society should contribute [1]. The European Commission has proposed an ‘Innovation Partnership on Active and Healthy Ageing’, linking programmes for health, research and enterprise [2]. Although the European Commission emphasises collaboration with business as the primary force for economic innovation, the objectives of education and health require broader perspectives of social innovation [3]. We have investigated the perspectives for research of health civil society organisations.

Civil society organisations (CSOs) in the definition of the European Commission are ‘non-governmental, non-profit organisations that do not represent commercial interests, and pursue a common purpose in the public interest’ [4]. Complementing the major contributions of the public sector and business to research, CSOs form an important ‘third way’ in contributing social values in decision-making and services [5]. The Open Society Foundation [6] has supported CSOs in public health in central European countries, and the European Public Health Association (EUPHA) has built alliances in Eastern Europe and Central Asia [7] and assessed research priorities of CSOs [8]. However, while links between civil society and research have been investigated in low and middle-income countries [9], and gained support through the Global Forum for Health Research [10], there has been little published on research and health civil society organisations in Europe.

The European Commission's Research Directorate, in its Seventh Framework Research Programme for Science in Society (2007-2013), developed a theme for the role of civil society [11], and a seminar on science and civil society organisations was held in Brussels in 2008 [4]. The work reported in this paper was undertaken within STEPS (Strengthening Engagement in Public Health Research, an EU Research Support Action proposed and funded through a competitive call from the Science in Society programme), and was informed by the seminar [12]. STEPS was developed in a partnership including the European Public Health Association (EUPHA), and built on previous work with national public health associations analysing research structures [13] and the priorities for research of national public health associations [14]. EUPHA is a member of the European Commission Health and Consumer Directorate's European Health Policy Forum, which meets twice yearly for dialogue with civil society organisations [15], and through which our study was able to identify health CSO links to public health research.

Methods.

The European Health Policy Forum has around 40 invited member organisations [15], representing civil society groups, professional groups, patient organisations and industry. With the support of the European Commission's officer responsible for the Forum, we identified sixteen Forum members complying with the definition of a civil society organisation. We included organisations representing both public health and patient concerns (see Acknowledgements), but

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not where their concern was primarily individualistic or supported commercial (e.g. pharmaceutical) interests.

The European Commission's seminar with civil society organisations [4] brought together around 60 researchers and European science administrators across social fields to discuss issues for the Science in Society programme. From this, and project discussions, we determined issues for an open-ended questionnaire to investigate each civil society organisation's experience of involvement in research, their involvement in the development of national and European research agendas, issues in collaboration between researchers and health CSOs, and the needs and opportunities for public health research. We approached each organisation initially by email to request their participation, sent the questionnaire, and then arranged a telephone interview, supported by email, to gain replies. Thirteen organisations replied. Each respondent was a staff member in, and spoke on behalf of, their European civil society organisation (see list in Acknowledgements). The telephone interviews were conducted by one author [DB] and recorded on interview sheets. Our report follows the order of the questions.

The Treaty of the European Union Article 168 gives 'improving public health' as a primary goal [16]. Although 'public health' has a different meaning across languages and countries [17], our broad approach includes population and system level policy and practice (including health systems, health determinants and health promotion). We found generally, in the responses to the questionnaire, that the word 'health' reflected this approach, in contrast to 'medicine' which implied treatment and a more bio-medical model, although some of our responding organisations represented patient (sickness) rather than citizen (health) perspectives. The Treaty Article 179

also requires the EU to undertake ‘research’ on behalf of all its policy areas [16], and the Commission’s Directorate of Research delivers this responsibility through multiannual Framework Research Programmes. The Health Directorate’s Health Programme [18], which is of direct interest to civil society organisations, provides for demonstration and dissemination of good practice. However, where civil society organisations are working with researchers, the separation is not strong, and both terms – research and project – are used.

Results

1. Description of the organisations

All of the responding organisations had considerable experience working within the health field. The oldest health civil society organisation had been established for 48 years, and the youngest for seven years. The organisations usually had membership from national networks, varying from 23 to over 400 member organisations, so that the number of individuals represented by these ‘umbrella’ organisations was large, and relatively representative of the EU.

We asked the responding organisations how they described their legal status – as NGO (non-governmental organization) or CSO (civil society organization) – and their opinion on the Science-in-Society programme definition of “civil society organisations”. Did it sound more positive than “non-governmental”, which includes negative wording? Was it better or not to refer directly to government or to society? Nine out of 13 participants named their organisation as an

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NGO, three as a CSO and one said it is not-for-profit organisation rather than either of the other titles. Most organisations were not concerned how they are named, but are more used to calling themselves NGOs (Table). All said that they are not-for-profit.

Current involvement of CSOs in the research area

The mission of most health CSOs is the day-to-day support of their members, and dissemination of information including research results to members and in their work on EU health policy.

They do not have much knowledge about how to do research and science themselves, but the majority said they have experience in cooperating with researchers as partners in projects. Larger representative organisations have commissioning and fund-raising for the research among their goals and missions. Four organisations have participated in the setting-up research agendas, and two organisations had experience in planning, designing and raising funds for research.

Representatives with some organisations have also participated as experts on ethical committees of research projects.

CSOs knew about some funds available for research, projects and programs from the .

European Commission, including the Seventh Framework Research Programme, the Health Programme, the Innovative Medicines Initiative, the Leonardo da Vinci programme (for mobility), and the European Partnership Action Against Cancer (established by the European Commission Directorate for Health and Consumers, and including industry and patient

associations). Responding organisations suggested that "there is more available than we pick up"

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regarding their involvement in the research field. Their reasons for not being more involved in these projects included lack of capacity and knowledge to write applications.

Possibilities for CSOs in new and old EU member states

Respondent organisations differed in their view whether CSOs from new EU member states are equally involved in the EU research projects compared with the old EU member states. Half were sure that the chances were the same, or potentially even better, because the European Commission promotes research and projects in new member states. Other respondents were more cautious: “In principle yes, but as a matter of fact – maybe not.” Even if the need for involvement is recognized and supported by the Commission, the old member states have more connections, they know better how to write project proposals and which people to involve. Some researchers have their networks and they are very good in writing projects. However, in the new member states, some researchers lack knowledge about procedures and contacts, lack long term experience in coordinating, lack information about opportunities, have poorer financial possibilities, and face difficulties in the heavy bureaucracy of EU projects. They can be involved as partners, but their capacity to take a leading role may be limited.

2. CSOs involvement in the development of national and European research agendas

Responding organisations considered that there was some involvement of CSOs in developing national and European research agendas, but that it was insufficient or even insignificant. Civil

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Society organisations recognize good intentions of the European Commission's Directorates for Research and for Health in improving cooperation with them. "It would be fair to say that if we are being heard, if we are well prepared and have good arguments in the right time, and if we meet the right people, then there are good chances." For other organisations, involvement had happened by chance, without a process. In some countries, national networks have very good collaboration with their governmental bodies, which may involve them in setting research agendas - although these are mostly driven by governments or universities. Otherwise, there may be a wish to get an opinion from a CSO, but that doesn't change the research agenda, and they don't get feedback.

CSO cooperation with researchers.

Almost all CSOs responded that their organisation's partnership with the researchers was good or fairly good. Cooperation in most of cases was seen as very complementary: academics provide their knowledge, CSOs contribute their expertise, their partners and links with broader society. But for some, the difference between the research world and that of CSOs is expressed as a challenge: "As we are so different? - it is difficult to find harmony."

Finding mutual goals is of crucial importance: "That is the challenge, that is the key role".

While CSOs usually have a clear mission, that is less the case for research activities, which sometimes based more on individual or personal interests and ambitions. There are also challenges in cooperation between CSOs and medical staff – these two cultures are very

different. CSOs and researchers also belong to cultures that interpret public health differently, although the challenges are less in the cooperation between social scientists and CSOs.

Building trust. Respondents observed that CSOs do not trust all researchers – especially those which are supported by industry. “It is much easier to trust research that is supported by a public body.” CSOs are also concerned when research does not respect the real needs of intended users, but is driven by the ambition of researchers, or industry pushing for certain technology and treatments for market reasons. Sometimes researchers lack confidence in CSOs’ expertise – and vice versa. “Sometimes CSO participation *looks* good, but researchers frequently do not understand or undervalue the expertise from CSOs.”

Language is a challenge, in two ways: linguistic and understanding. English language is widely used in the world of research, and most research is published in English; but this can cause problems for those for whom it is not a native language. Many European CSOs’ individual members do not speak enough English to cope with scientific articles in English, especially in very technical areas. These differences are more easily resolved between social scientists and CSOs than between medical setting and CSOs.

Finding resources. Financial and time resources were an important challenge for CSOs to be involved in the research. The need for resources for meaningful participation should not be underestimated: often CSOs are expected to be involved in research without sufficient resources. CSOs are usually volunteer organisations, and researchers have to reserve funding for

them. In addition, the co-funding rules of the European Commission, do not allow volunteers' unpaid time to be regarded as financial contributions to projects.

How partners are found

The most common start for links is by the researchers contacting the CSOs, because their involvement would be “good for the project”. These informal ways seem to be very practical and used much: “mouth to mouth” recommendations and networking of contacts. CSOs that commission research also find the researchers in the same way: many of the contacts are established through previous experience in the research field, with partnerships are made over years. Also partners are found at conferences, dissemination events of other projects and European Commission open days. Several CSOs have an expert advisory group which includes researchers, which is a useful and succesful pattern for exchanging knowledege and networking.

3. Cooperation between researchers and health CSOs

The questionnaire asked about the benefits of cooperation between researchers and CSOs through propositions and conclusions from the European Commission's Science-in-Society seminar (6) bringing together researchers and representatives of civil society organisations.

“CSOs help to develop a user-led agenda for the research” was agreed by majority of participants, although for some, it was expressed in the form of desire: “Broadly it should be true, but I am not sure if it happens”. The concern is that research is too often not built around

the real needs of people. For example, patients may not be consulted on how they live with their disease, what specific aspects they would like research to address, and how research outcomes can impact their daily life - not just their health status. Setting a research agenda is seen to be a very important issue from CSOs' perspective: programmes and projects need to be based on the most recent information and developments to be as effective as possible. European CSOs wish research and new technology to be user-driven. CSOs have the knowledge of the specific challenges in the field. They can phrase research questions, and provide insights on developments or trends needing answers. By knowing political needs and strategies, they can also contribute to policy making. They see the overview at EU level which sometimes researchers see in a more narrow perspective.

“CSOs can bring results back to civil society” was agreed by all the participants. CSOs have more contacts and that is their aim – to collect and disseminate information. The results from research are often not known to those who are the intended beneficiaries of the research. CSOs can use their channels and networks to inform their constituencies, and communicate the results in a manner that is understandable to lay people. Research findings often stay in scientific journals where people in the scientific community know of it, but few others. Dissemination, however, cannot be done automatically and takes resources.

"CSOs help to spread knowledge through new channels". CSOs agreed that they have channels that researchers usually don't have, and vice versa. CSOs can spread knowledge through their members and communicate with policy makers, at both and national levels if

translated into other languages. Many CSO networks have invested in new media (internet and phone texting), making it possible to communicate research results directly to those in most need of them. CSOs can see that information they provide to the public, for example on new research, is often also read by medical professionals – who frequently do not have the time to follow all the medical journals, which are also mostly published in English language.

“CSO cooperation helps achieve a greater impact on research policies”. This was partly agreed by participants. “It would be nice if it were so. But sometimes you do good, and it stays within your organisation. Cooperation doesn't always impact on policy.” Knowledge of real needs and challenges can contribute to shaping research agendas to meet those needs. CSOs can help to make sure research is understood and is supported by the public, including recruiting patients in clinical trials and giving people confidence that they should be involved in the research. “We do not want people to be involved in unethical research, but we can increase the public image of good research, to help to understand why research is beneficial.” CSOs can also help in quality of life measurement, eg in health technology assessment.

“Researchers help CSOs get support and legitimacy for their cause”. CSOs "need to have evidence of what works and what doesn't. We always work with scientific evidence. To be effective, CSO should be evidence-based.” Data from research can strengthen policy positions and statements. Research results provide a basis for lobbying initiatives or public health programmes, especially when a topic or issue is contested.

“Researchers give more scientific data and tools for use” was agreed by all participants.

CSOs provide the means to transfer knowledge to the public. However, some see their use of research on the side of certain positions: “Research is important to support our arguments, to prove that we are right”. They suggest that some research is too abstract or too complex: an important reason for including CSOs in the research is to ensure that the outcomes can be implemented in the settings where they are needed.

“Researcher cooperation helps achieve a greater impact on public policies”. There are examples of coalitions including CSOs which have been created to push a research agenda forward. If the general public say “we need more research”, politicians tend to listen. Public policies are increasingly based on evidence, and research is one important source of evidence – complemented with evidence coming from other sources, for instance the patients’ perspective.

“Researchers can help in evaluation of the effectiveness (or non-effectiveness) of CSOs' innovative activities, e.g. services”. This was agreed mostly by CSOs providing services. It depends on what needs to be evaluated and whether the evaluation requires a scientific construct to be considered valid. Not all evaluation methodologies require a ‘research approach’. CSOs also understand that the reputation of researchers can assist in demonstrating the value of their work. CSO can benefit through experience in communication and working with media.

Researchers can invite CSOs to collaborate on dissemination, while CSOs can use researchers as experts. Joint policy positions can be beneficial to the public and to researchers.

4. Opportunities for researcher–CSO collaborations

Practical aspects

Equal power relationships should be established before starting a specific activity. There should be sufficient resources available for the CSO, and their perspectives should be respected by researchers. Researchers tend to use technical jargon, so collaboration should use language and terminology that is understandable to all. The experience of working together can be reviewed in a common forum of exchange, meeting and discussion, to help progress changes that need to be made.

There should be some incentives for researchers to work with CSOs. Researchers are rewarded from publications, but do not gain credit for involving CSOs. Perhaps research grant-giving agencies could recommend priority in funding for proposals involving CSOs. Budgets could be ear-marked for such collaborations and specified in research strategies and programme calls.

Where there is interest, but researchers are not experienced, there could be modules and guidance developed to help proposers – both for researchers and CSOs.

Support for the public health field – are there more needs?

Most of the respondents considered that public health research does not receive enough support, or indeed, that researchers gain more support than CSOs. Yet also the field is unbalanced – there is more research on some topics than others, even where there is pressing need for effective

policies and interventions. The reasons for weak support for public health research themselves deserve research attention.

When new policies are introduced, there should be evaluations of their impacts and effectiveness. There is a need to invest more in the area of prevention. Most health-research funding goes into medico-clinical research and laboratory research: much less towards social science research on behaviour, health determinants and socio-economic factors. Some participants expressed a “desperate need” for data, and monitoring and evaluation of projects. Data from population monitoring provides CSOs with evidence of need and impact. Sometimes provision of data from national and international agencies is very slow. CSOs would like to work with researchers to gain results more quickly. From a European perspective, some standardisation of national data collection is needed, so that national policies can be reliably compared.

Discussion

Public health research draws on medical and social sciences in fields of epidemiology, health promotion and policy, and health services systems and management [19]. At present, there is more research evidence for individual, clinical-level interventions than for population and organisational interventions [20]. Knowledge translation has sought to bring effective interventions to practice through tasks including synthesis and summaries of research, advocacy for its use, evaluating practice, and transforming management issues into research questions [21].

Issues for public health research include the value of research as information input, its relevance and ease of use, and complementarity with other factors in the policymaking process.

Health CSOs work in areas of information, policy, advocacy and service provision. They have interests in use of knowledge that are similar to implementation sciences; but our focus has been on how CSOs perceive the task and opportunities of research, rather than knowledge translation itself. Studies in the USA have found that participation in research helped CSOs to influence change, gain follow-on funding, develop skills and promote partnerships [22]. A survey of 25 AIDS/HIV community-based organizations in Ontario, Canada, found a supporting a culture that rewarded quality improvement and research-based decision-making, but CSOs lacked resources to find research, assess its quality and reliability, and summarize it for users [23]. In our survey, European health CSOs wished to be involved as partners in research development, distributors of information, helping to get participants, and as consultants on ethical issues - but generally not directly as researchers. CSOs could particularly be involved at planning stages when issues of relevance, cooperation and appropriate methods can be discussed and agreed. It is important for the research to be impartial and transparent, and for its objectives and intentions – which for health CSOs may be in the field of social innovation [3] – to be clear

The European Commission's Science in Society Programme includes two further studies of CSO engagement in healthcare research. EPOKS [24] is a sociological investigation across four medical fields of the interaction between patient organisations and medical technologies, and

how coalitions come together, organise and disseminate knowledge. HealthGovMatters [25] is exploring perceptions and decision-making interactions between patients, care-givers, health professionals, citizens, patient and professional organisations in relation to new technologies in imaging, pharmaceuticals and devices in the fields of genetics and neurology. These Science in Society studies address concerns of science as ‘physical’ technologies. Further studies are needed of CSO as service providers in social innovation, assessing the value of information technology in CSO activities, and determining the impact for innovation of participation in research.

Our survey was part of a wider study of public health research in Europe [12]. Telephone interviews proved to be an appropriate method for gaining responses, with a good final response rate from the selected organisations. While EPOKS and HealthGovMatters are collaborations respectively between UK, Ireland, France and Portugal, and Austria, Germany and UK, STEPS investigated perceptions of research by European-level civil society organisations and has also engaged the 12 EU new member states with less tradition both for social research and for civil society organisations [12].

In Europe now, both agricultural and manufacturing industry are declining relatively, while service industries continue to grow [26]. Social innovation is increasingly important in the public sector, where ‘soft’ innovation uses mutual exchange with society (as users and stakeholders) rather than commercial patenting of medical technologies. In the health field especially, civil

society organisations need to fulfil roles both of developing innovations and organising for needs that cannot satisfactorily be met by commerce [27, 28]. European CSOs can meet this challenge, and promote social innovation through research to serve European citizens and strengthen the European Innovation Union.

Conflicts of interest

None declared

Funding

This work was supported by European Commission Directorate General for Research and Innovation Science in Society programme [grant agreement 217605]

Acknowledgements

We thank the participant organisations for their survey responses: European Consumers Organisation; European Cancer Patient Coalition; European Heart Network; EUROPA DONNA; European Network for Smoking and Tobacco Prevention; European Patients' Forum; AGE

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Platform Europe; European Alcohol Policy Alliance; Association of European Cancer Leagues; Swiss AIDS Federation; European Federation of Allergy and Airways Disease Patients; European Public Health Alliance; Mental Health Europe.

Key Points

- Civil society organisations form an important constituency, beyond the public sector and business, to promote European policy for economic and social development.
- Civil society organisations do not do research themselves, but welcome collaborating in research, using the results from research, and providing input to research agendas.
- The cultures of, and incentives for, researchers and health civil society organisations are different, and collaboration requires building trust, a shared language, and for the power relations and objectives to match.
- Civil society organisation should be involved at planning stages to address issues of the study's intentions, relevance, methods and transparency.
- Research should be developed on social innovation and in EU countries with developing traditions for civil society engagement with health.

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