Introduction

In its forward strategy for 2014–20, 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. The European Commission has proposed an ‘Innovation Partnership on Active and Healthy Ageing’, linking programmes for health, research and enterprise. Although the European Commission emphasizes collaboration with business as the primary force for economic innovation, the objectives of education and health require broader perspectives of social innovation. We have investigated the perspectives for research of health civil society organisations (CSOs) towards health research in Europe. 3

Civil society organisations, social innovation and health research in Europe

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

Methods: STEPS (Strengthening Engagement in 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 CSOs, which represented collectively local and national organizations.

Results: Research was valued positively by the respondents. Health CSOs did not seek to do research themselves, but recognized 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 CSOs are different, and collaboration requires building trust, a shared language and for the power relations and objectives to match.

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

Key points

- The BMI is used to stratify the risk of metabolic and cardiovascular disease but in adults, BMI cut-offs for similar risks are lower in Asian populations.
- From observations of Guadeloupian adolescents with and without Asian Indian origins, the relationship between body mass index and body composition appeared ethnic-specific.
- We reported in adolescents a shift toward higher iliac thickness on most of the observed corpulence range in India-originating Guadeloupian girls, and on all the corpulence range in India-originating Guadeloupian boys as compared to the controls. This is compatible with the high prevalence of diabetes and complications in adults of this ethnicity.

References

social values in decision making and services. The Open Society Foundation 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 and assessed research priorities of CSOs. However, while links between civil society and research have been investigated in low- and middle-income countries, and gained support through the Global Forum for Health Research, there has been little published on research and health CSOs in Europe.

The European Commission’s Research Directorate, in its Seventh Framework Research Programme for Science in Society (2007–13), developed a theme for the role of civil society, and a seminar on science and CSOs was held in Brussels in 2008. The work reported in this article 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. STEPS was developed in a partnership including EUPHA, and built on previous work with national public health associations analysing research structures and the priorities for research of national public health associations. EUPHA is a member of the European Commission Health and Consumer Directorate’s European Heath Policy Forum, which meets twice yearly for dialogue with CSOs, 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 organizations, representing civil society groups, professional groups, patient organizations and industry. With the support of the European Commission’s officer responsible for the Forum, we identified 16 Forum members complying with the definition of a CSO. We included organizations representing both public health and patient concerns (see Acknowledgements), but not where their concern was primarily individualistic or supported commercial (e.g. pharmaceutical) interests.

The European Commission’s seminar with CSOs 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 CSO’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 organization initially by email to request their participation, sent the questionnaire and then arranged a telephone interview, supported by email, to gain replies. Thirteen organizations replied. Each respondent was a staff member in, and spoke on behalf of, their European CSO (see list in Acknowledgements). The telephone interviews were conducted by one author (D.B.) 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. Although ‘public health’ has a different meaning across languages and countries, 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 organizations 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, and the Commission’s Directorate of Research delivers this responsibility through multianual Framework Research Programmes. The Health Directorate’s Health Programme, which is of direct interest to CSOs, provides for demonstration and dissemination of good practice. However, where CSOs are working with researchers, the separation is not strong, and both terms—research and project—are used.

Results

Description of the organizations

All of the responding organizations had considerable experience working within the health field. The oldest health CSO had been established for 48 years, and the youngest for 7 years. The organizations usually had membership from national networks, varying from 23 to over 400 member organizations, so that the number of individuals represented by these ‘umbrella’ organizations was large, and relatively representative of the EU.

We asked the responding organizations 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 ‘CSOs’. 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 the 13 participants named their organization as an NGO, 3 as a CSO and one said it is not-for-profit organization rather than either of the other titles. Most organizations were not concerned how they are named, but are more used to calling themselves NGOs (table 1). 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 organizations have commissioning and fund raising for the research among their goals and missions. Four organizations have participated in the setting-up research agendas, and two organizations had experience in planning, designing and raising funds for research. Representatives with some organizations have also participated as experts on ethical committees of research projects.

CSOs knew about some funds available for research, projects and programmes 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 organizations suggested that ‘there is more available than we pick up’ regarding their involvement in the research field. Their

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Comparison of features of CSOs and non-governmental organisations (NGOs)</th>
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<tbody>
<tr>
<td>CSOs</td>
<td>NGOs</td>
</tr>
<tr>
<td>Name implies to its constituency and aim</td>
<td>Name defines legal status and aim</td>
</tr>
<tr>
<td>Always not-for-profit</td>
<td>May link to for-profit organizations</td>
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<tr>
<td>May be led by civil citizens, most of the work done by volunteers. Not representing political interests</td>
<td>Work usually led by paid professionals</td>
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<td>Refers to a wide of array of organizations community groups, NGOs, labour unions, charitable organizations, professional associations and foundations</td>
<td>More to do with policy or politics, might be interested in economic issues, frequently have a political point of view. Can have service agreements with the federal government.</td>
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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 organizations 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. The 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.

CSOs involvement in the development of national and European research agendas
Responding organizations considered that there was some involvement of CSOs in developing national and European research agendas, but that it was insufficient or even insignificant. CSOs 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 organizations, 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 does not change the research agenda, and they do not get feedback.

CSO cooperation with researchers
Almost all CSOs responded that their organization’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 organizations, 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 knowledge and networking.

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 CSOs.

‘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 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
Discussion

Public health research draws on medical and social sciences in fields of epidemiology, health promotion and policy, and health services systems and management. At present, there is more research evidence for individual, clinical-level interventions than for population and organizational interventions. 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. 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. 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. 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—to be clear.

The European Commission’s Science in Society Programme includes two further studies of CSO engagement in healthcare research. EPOKS is a sociological investigation across four medical fields of the interaction between patient organizations and medical technologies, and how coalitions come together, organize and disseminate knowledge. HealthGovMatters is exploring perceptions and decision-making interactions between patients, caregivers, health professionals, citizens, patient and professional organizations 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.

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 standardization of national data collection is needed, so that national policies can be reliably compared.
Our survey was part of a wider study of public health research in Europe. Telephone interviews proved to be an appropriate method for gaining responses, with a good final response rate from the selected organizations. 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 CSOs and has also engaged the 12 EU New Member States with less tradition both for social research and for CSOs.

In Europe now, both agricultural and manufacturing industry are declining relatively, while service industries continue to grow. 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, CSOs need to fulfil roles both of developing innovations and organizing for needs that cannot satisfactorily be met by commerce. European CSOs can meet this challenge, and promote social innovation through research to serve European citizens and strengthen the European Innovation Union.

Acknowledgements
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Conflicts of interest: None declared.

Key points
- CSOs form an important constituency, beyond the public sector and business, to promote European policy for economic and social development.
- CSOs 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 CSOs are different, and collaboration requires building trust, a shared language, and for the power relations and objectives to match.
- CSO 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.

References