



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Professionalisation and representativeness among civil-society representatives

Outcomes of a brief research project

Presented by: Christopher Gadd
Communications Sector

An agency of the European Union

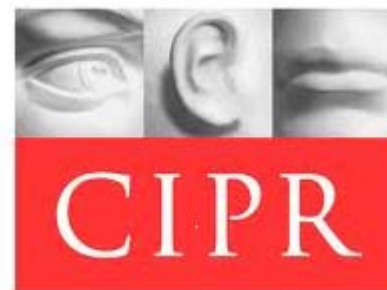




Research project

Requirement for post-graduate diploma in public relations

Professional masters-level qualification awarded by the Chartered Institute of Public Relations (CIPR)



Brief: conduct a self-directed research investigation into an aspect of public relations practice and/or theory



Why public relations?

Public relations is the discipline which looks after reputation, with the aim of earning understanding and support and influencing opinion and behaviour.

It is the planned and sustained effort to establish and maintain goodwill and mutual understanding between an organisation and its publics.

CIPR 2011



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Why public relations?

Public relations is the discipline which looks after reputation, with the aim of earning understanding and support and influencing opinion and behaviour.

It is the planned and sustained effort to establish and maintain goodwill and mutual understanding between an organisation and its **stakeholders**.

CIPR 2011



Partnerships between key stakeholders and public sector

Governmental bodies often form partnerships with non-governmental organisations (NGOs)

Allows governments to *"take their cues from the civil society discourse"* (Taylor 2009)

Brings:

- Representation of citizens' interests in political decision-making
- Raised awareness of government issues in public sphere
- Greater legitimacy to both groups
- Improved communication between governments and civil society

(Edwards 2009, Buth 2011)



Limitations to partnership

Received attention by political theorists, e.g. Connecting Excellence on European Governance (CONNEX) project

NGOs need level of “professionalisation” to work with international governmental bodies:

- NGOs employ staff with professional backgrounds, e.g. public affairs, law, public relations (Saurugger 2006)
- Powerful NGOs receive financial support from those uninterested in active involvement and fail to engage in internal democracy (Maloney 2008)

Assumption = representatives lose touch with grassroots



A “more nuanced” approach

More recent work questioning these assumptions:

- Professionalised representatives can enhance social legitimacy among membership
- Professionalisation improves an NGO's credibility in broader society
- Internal democracy can be replaced by solidarity over issues, e.g. Greenpeace
- New models of communication can maintain contact with grassroots, e.g. social media

Professionalization may indeed improve group representativeness

(Buth 2011)



A “more nuanced” approach

Qualitative empirical research is required to detect whether professionalization takes place at the cost of representativeness or whether groups are actually both professional and representative.

(Buth 2011)



Research objectives

To explore the tactics used by representatives of civil-society organisations to maintain their representativeness during long-term partnership with the Agency

- Is there evidence of professionalisation among the Agency's key stakeholders?
- How do these stakeholders view their representativeness?
- How do they gauge the views of those they represent?
- Is two-way symmetrical communication possible?



Conduct

Qualitative approach

Five in-depth semi-structured interviews

Representatives of patient/consumer and healthcare professional organisations at the Agency

- Patients' and Consumers' Working Party
- Management Board



Professionalisation

All described themselves as coming from professional, European-wide lobbying organisations

All representatives described themselves as professional

- Three had backgrounds related to Agency's work
- Two had backgrounds in different areas



Professionalisation

I'm a former multinational executive. I could join a group like the EMA and not get overpowered by the documentation, the technicality, the numbers.

I'm a lobbyist and lawyer by training. I used to be a partner in a public-affairs consultancy. I can put myself in the shoes of somebody else and represent them where needed.



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- Three had backgrounds related to Agency's work
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Described the need to be professional to work with the Agency



Professionalisation

In the real world, you have to have had some experience in managing things, understand decision-making, understand what boards do, as well as coming with a patient background.

The professional side's to understand the process, the language and to serve as a go-between. Those who have the disease in question, it's out of the question to expect from them that they understand all aspects of the regulatory process.



Representativeness

Complex issue

Ranged from formal representativeness through to claims of no formal representation



Representativeness

I advocate on behalf of [my organisation]. [My organisation] represents 50 million, because that is the total number of individuals being members of the 150 or so [member] organisations.

We are not an elected body, so I don't feel comfortable in saying that we represent people. No-one elected us and gave us a specific mandate. We defend [citizens'] interests, which is slightly different.



Representativeness

Complex issue

Ranged from formal representativeness through to claims of no formal representation

Some interviewees described multiple levels of representativeness



Representativeness

[I represent] the members of the national organisations, because of course you can't formally represent people that are not linked to an organisation...

I'm representing all [citizens]. I mean, there is no way in this type of work regarding the Agency that you would say, "Now I only represent a few or a certain group."

I think at the PCWP, we all tend to represent patients at large. Certainly in other committees and working parties, probably we have more specific hats



Representativeness

Complex issue

Ranged from formal representativeness through to claims of no formal representation

Some interviewees described multiple levels of representativeness

One respondent distanced him/herself from a representative role



Representativeness

My duty as a member of the Board is to make sure that the EMA is well governed and I have to do that from the perspective of a Board member, not necessarily a patient representative.



Gauging the views of the membership

All interviewees described:

- Formal internal democratic processes
 - Executive committees and boards
 - Annual general meetings and general assemblies
- Smaller advisory/working/expert groups and taskforces
- Written reports circulated by email and intranet

Variability in formality of communication channels with membership



Gauging the views of the represented

I represent [my organisation]. My reporting is only with the president and the secretary general.

We have surveys that we regularly launch in our network, which work well. Depending on the level of interest, we decide maybe to propose an initiative and sometimes at the Agency.

Our member from Portugal made a focus group on package leaflet and presented to the Agency.



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Variability in formality of communication channels with membership

Most interviewees acknowledged the risk of losing touch with the grassroots; solutions did not include new media



Gauging the views of the membership

I think it's quite rare, but I think the risk is real and individuals have to make sure it doesn't happen to them.

This is the strength for me, to have our members on our back and because they make sure we don't lose track.

In this profession, transparency is always the key word. Members only accept whichever way the organisation is going if they have the feeling they're fully informed about why.



Two-way symmetrical communication

Interviewees described benefits for:

- Their organisations



Two-way symmetrical communication

[It] is a kind of halo kudos effect, frankly.

The benefit is to learn ... how the EMA works.

There is more knowledge and more willingness from our members to interact and to be involved.



Two-way symmetrical communication

Interviewees described benefits for:

- Their organisations
- The Agency



Two-way symmetrical communication

[The Agency has] become more stakeholder-oriented [and] more mature simply because of the good relationship with the stakeholders.

It increases the trust in the Agency when you have consumer/patient organisations.

We're there to maybe push it a little bit further in the sense of, for example, making sure that there is even more transparency.



Two-way symmetrical communication

Interviewees described benefits for:

- Their organisations
- The Agency

Two described the interaction as a “two-way street”

None mentioned symmetry; two expressed imbalances in the flow of information

Barriers to communication:

- Difficulties within the organisation itself



Two-way symmetrical communication

It is difficult to get all members of a federation to actively participate and make sure that their point of view on every subject is heard.

[Patients] are not necessarily available when we need to discuss with them.

You're very dependent on how [the member organisations] communicate with their membership on how things proceed.



Two-way symmetrical communication

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- Their organisations
- The Agency

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None mentioned symmetry; two expressed imbalances in the flow of information

Barriers to communication:

- Difficulties within the organisation itself
- Problems with the Agency’s policies



Two-way symmetrical communication

We have to always come back to [patients], to discuss with them, which is really difficult because your discussions are confidential.

Ideally [patient representatives] should be the ones who would respond to this consultation by the Agency. Now with the policy [on conflicts of interest] in place there are big question marks.



Conclusions

Clear evidence of professionalisation

Acknowledgement that loss of representativeness is a risk

Range of techniques used to overcome this risk:

- Direct contact with research and training at grassroots level
- Maintaining transparency within the organisation
- Self-awareness
- Close monitoring by member organisations

Representatives change methods according to type of interaction

Two-way communication achieved, but symmetry elusive



Opportunities for future discussion

Should the Agency's civil-society representatives discuss and compare their techniques for maintaining representativeness?

Does the plurality of the representatives' roles cause difficulty?

What impact do the Agency's policies have on the quality of communication with its stakeholders?