

Patient Self-help in Europe: An ELPA Survey

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Europe-wide input



Outline

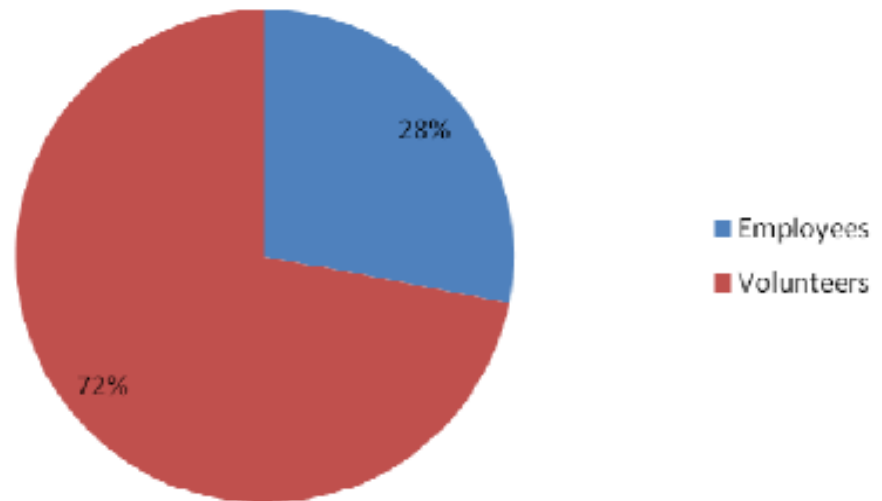


- Dependence on volunteers
- The unique role of liver patient groups:
 - Counseling
 - Awareness raising
 - Stakeholder engagement
- Remaining challenges and our proposals for the future

A dependence on volunteers



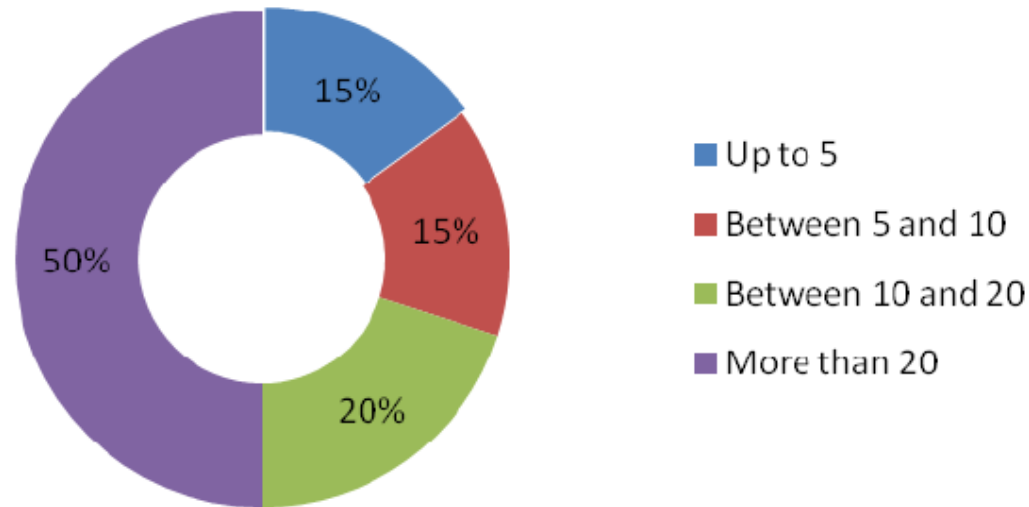
- 72% on average are volunteers
- Volunteer contribution vital, these include patients, specialists and doctors



Unique counseling function



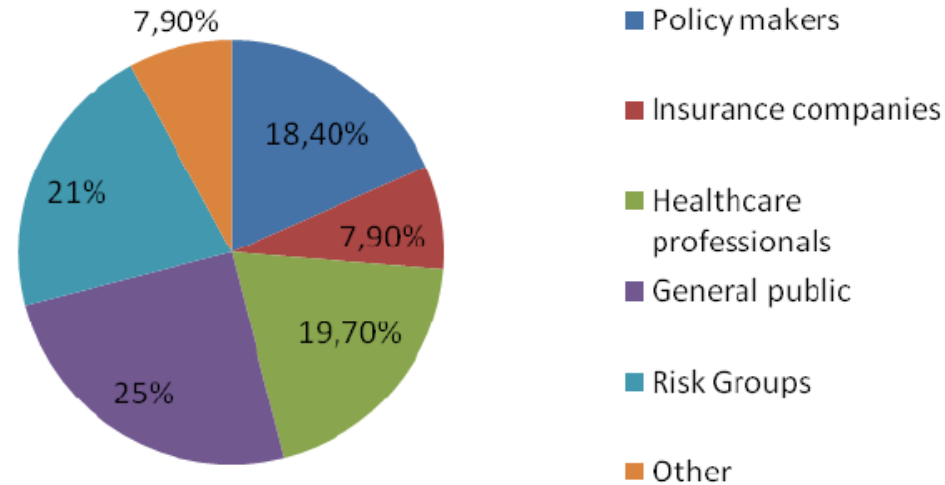
- First core activity of patient groups
- Relieves the psychological burden
- Provide a contact point for sufferers of a much-stigmatised disease



Awareness-raising



- Up to 90% of infected people not aware of their condition
- Target general public, specific risk groups and healthcare professionals



Engaging stakeholders



- Contact with policy-makers to drive sustainable improvement
- Problems attracting celebrities because of perceived stigma
- Support from specialists but problem remains of attracting attention of general practitioners

Evaluation



- Counseling function has been a success and could be expanded if there were greater resources
- Awareness-raising success difficult to measure
- Availability of treatment not an issue in most MS
- Waiting times for treatment also greatly reduced
- But problems remain in certain Member States, as regards the provision of primary treatment

Evaluation



- **Screening** is the biggest concern of patient groups – no government has made sustainable efforts to improve this, except France and Scotland
- But Croatia and UK have adopted or nearly adopted liver strategies

Challenges



1. Stigmatization of the disease
2. Health professionals are not interested and have no incentives to do so

Conclusions



- Patient groups doing fantastic job in difficult circumstances – e.g. funding problems and lack of interest from media and health professionals
- Patient groups only body to provide fellow patients with psychological support
- Need a comprehensive strategy which is supported by governments and public health authorities – EU is a natural ally

Thank you!

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