

# Locating and using Advocacy Resources:

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**WORLD FEDERATION OF NEUROLOGY**  
A non-governmental organization in association with the World Health Organization



# Disclosure

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- There are no commercial disclosures.
- The author is a member of the UEMS/EBN ([www.uems.net](http://www.uems.net)) and a trustee of the WFN ([www.wfn.org](http://www.wfn.org))

# Learning objectives

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- 1) Project management
- 2) Definition of resources
- 3) Resource finding
- 4) Industry relations and ethical aspects

# Content

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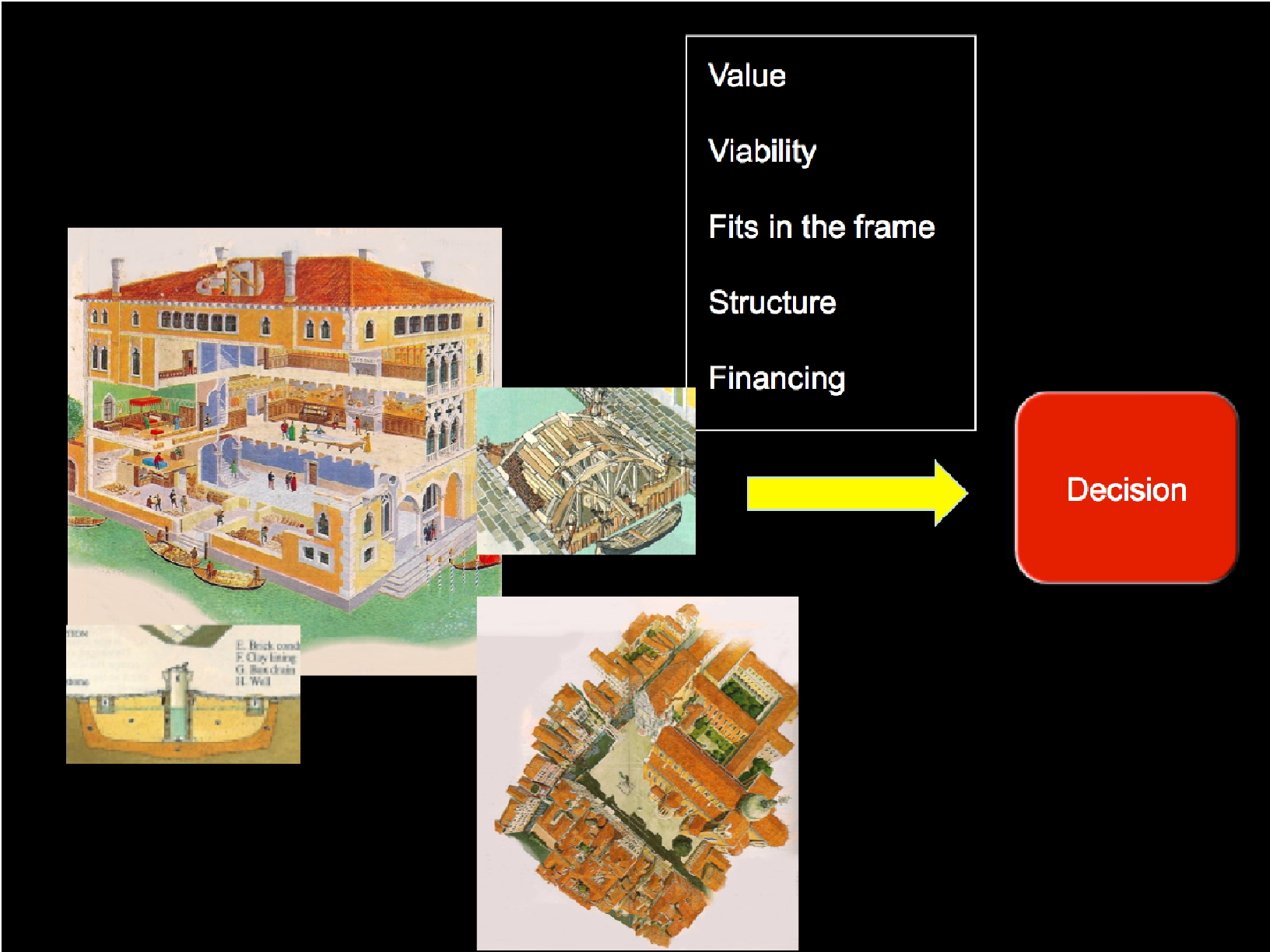
- Projects
- Advocacy resources
  - Human resources, financial, hospital, public, political,
  - media, press, patient, NGO, industry
- Ethical issues
- Contact- whom ?

# Everything is politics....

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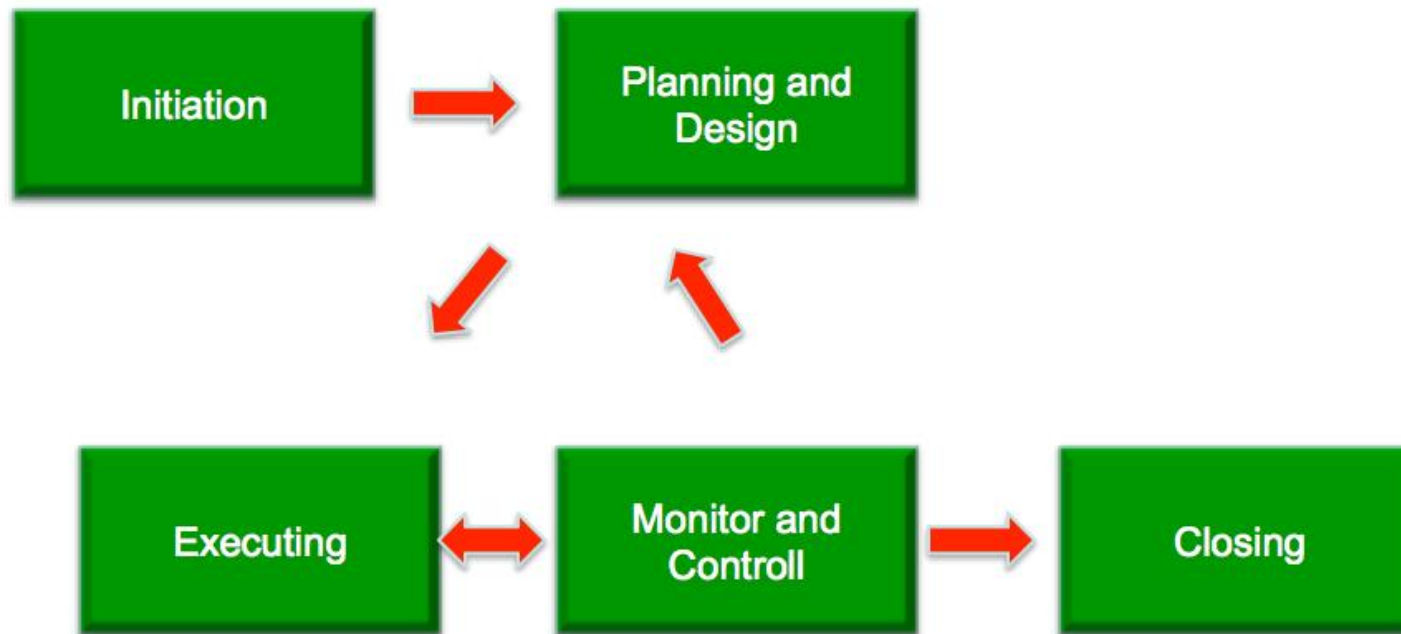
- “Everything is politics” is one of the main sentences which have followed me since my first AAN advocacy meeting in the US.
- Although one is aware of this in daily work and practice, the AAN Palatucci course has made this more transparent to me in daily life.
- The best ideas with the most valuable content can not take off if not properly fuelled with manpower and tools to create an impact.

# Funding of a project. Name the project :

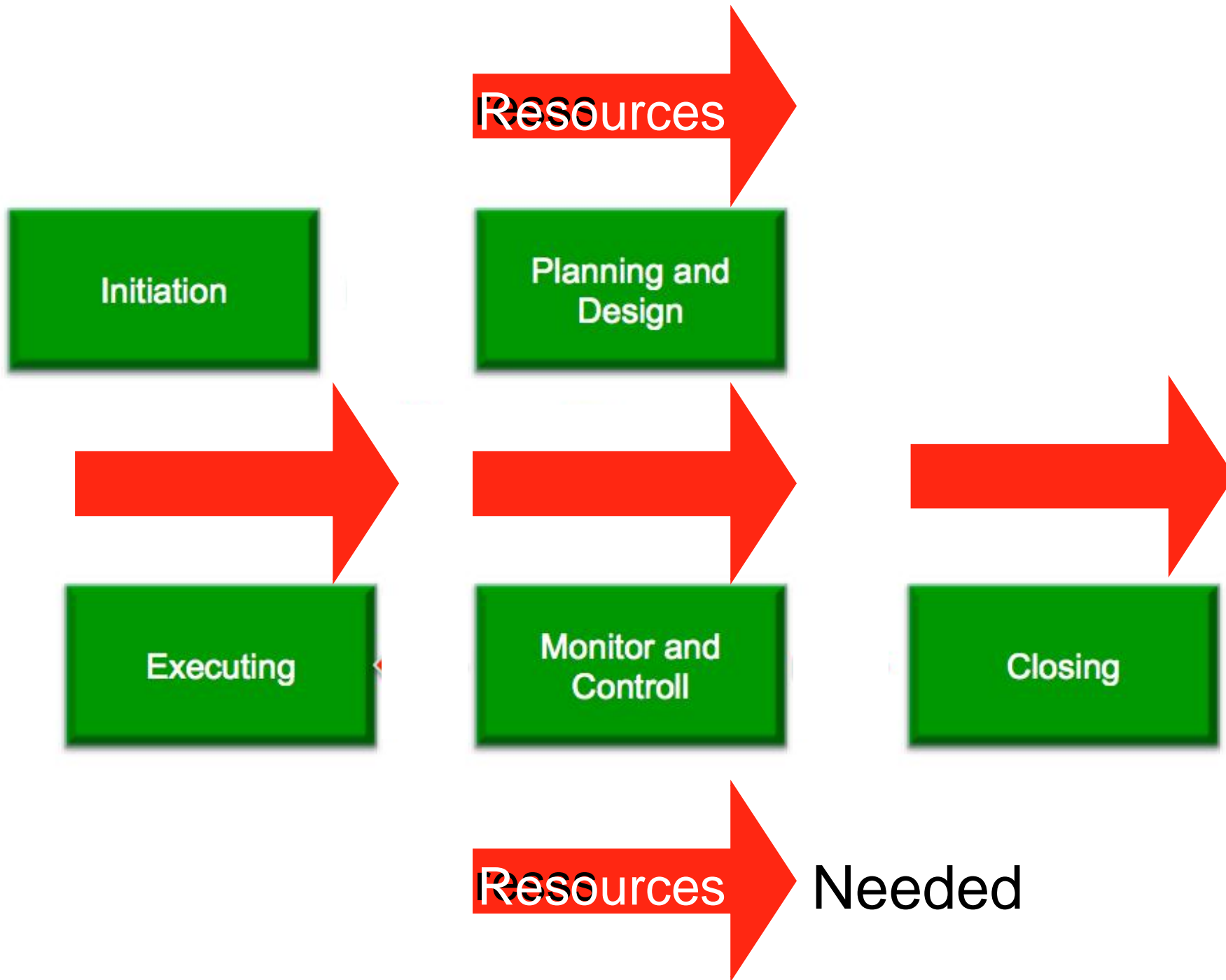


# Project management

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( wikipedia: project management)

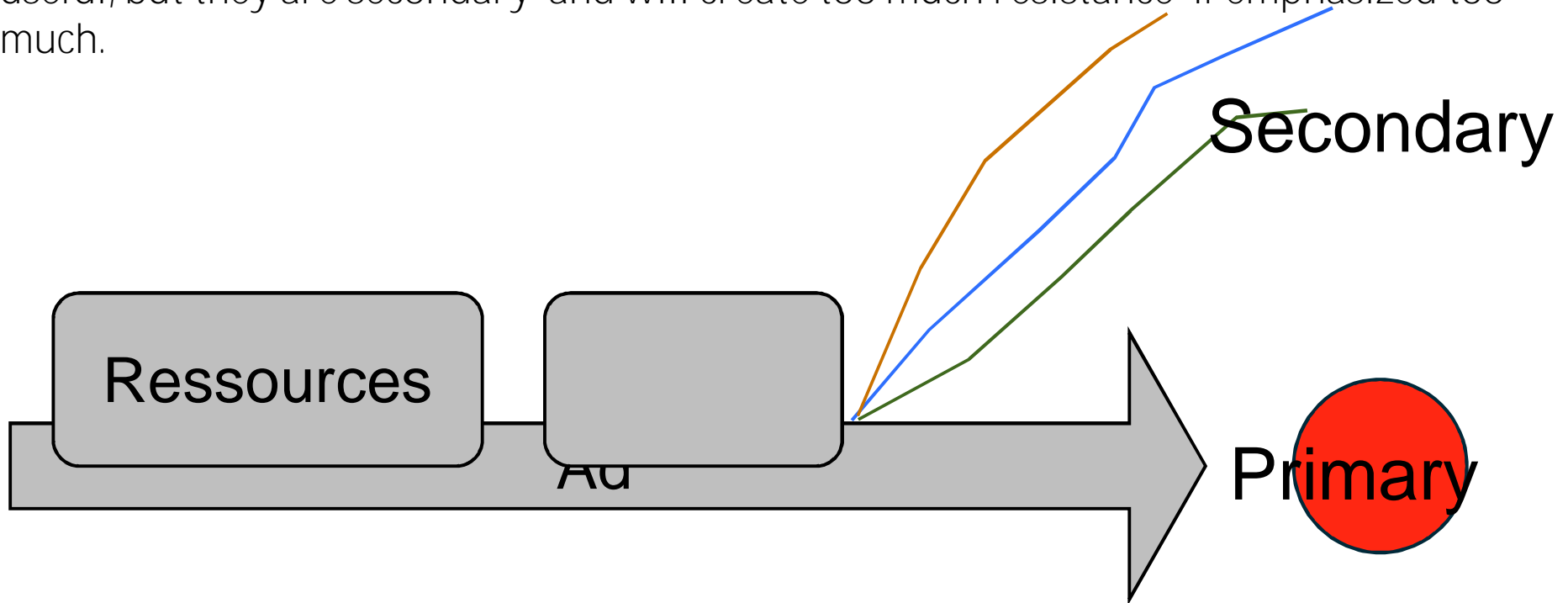




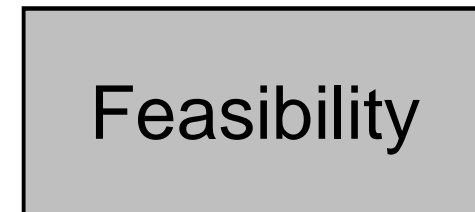
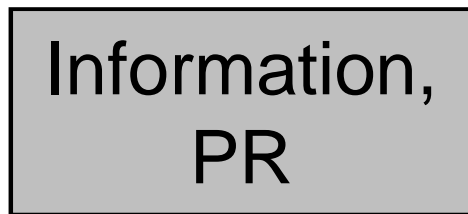
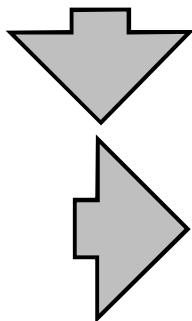
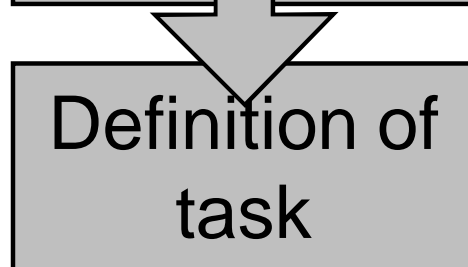
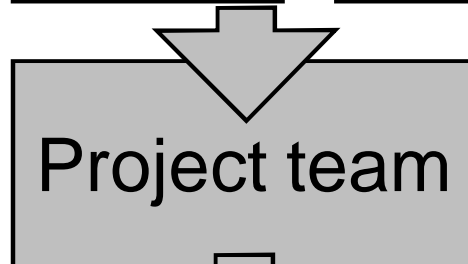
# Define and : End point

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- Like in clinical studies, you need is a “clinical endpoint”, one main point, not several, and a content that can be easily understood , is clear and “sticks”. Secondary endpoints are useful, but they are secondary and will create too much resistance if emphasized too much.



# Project: WCN - patient day



# Will this project have an impact ?

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- Will it be valuable ?
- Will it be viable ?
- Can it be sustained after the project is over ?
- Who will be the beneficiary ?
- Feedback ?

# Resources



Human

Financial

Indirect

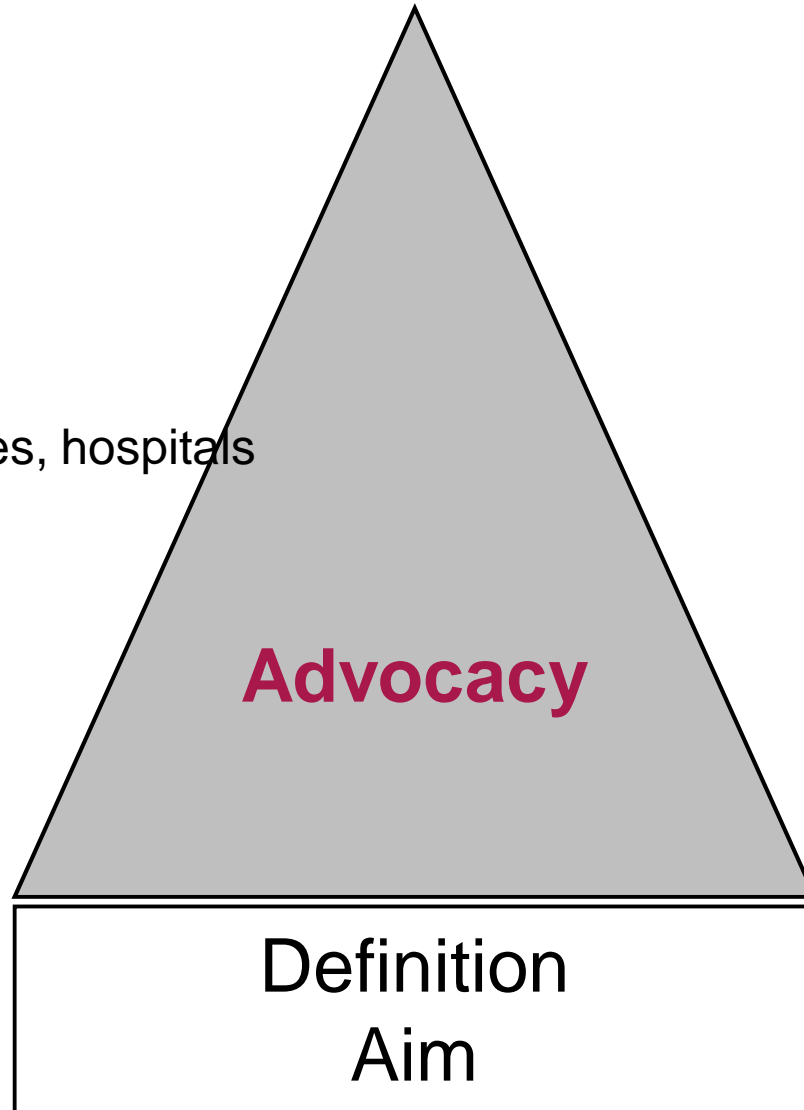
Politics, Public sources, hospitals

Media and Press

Patient/Relatives,  
NGOs

Scientific societies

Industry



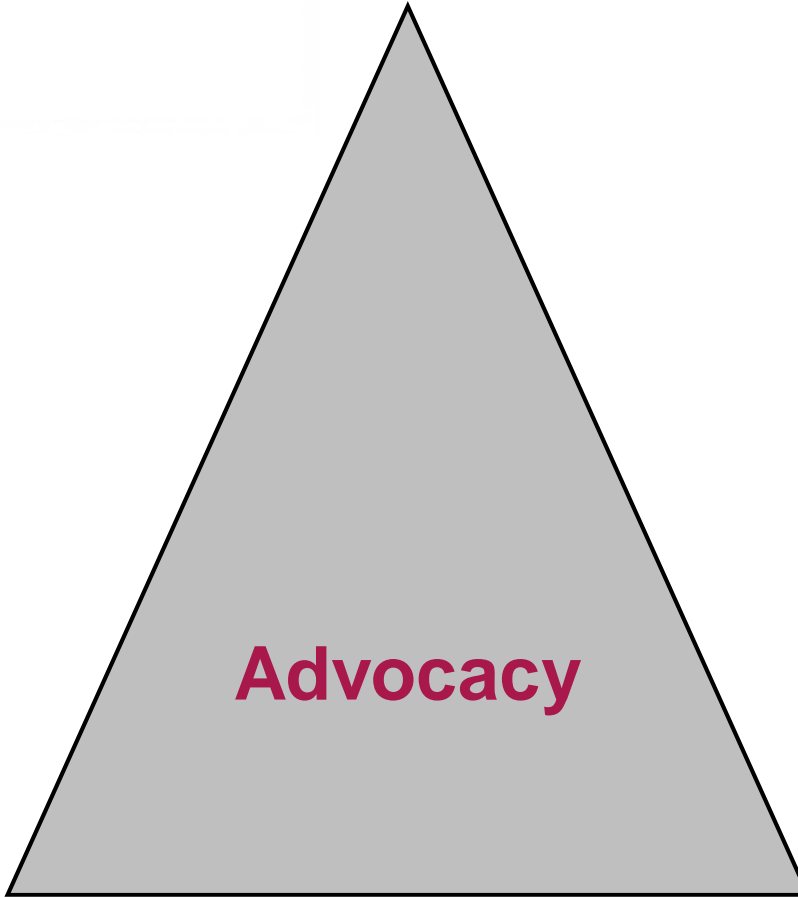
Alliances ?

Resource program

Financial Frame

Financial structure

Book keeping



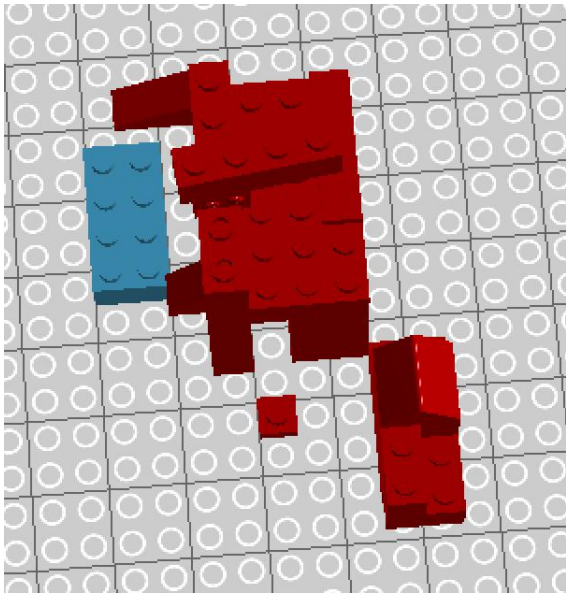
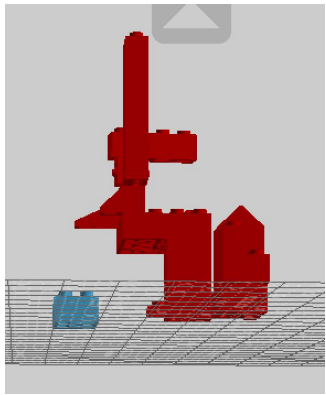
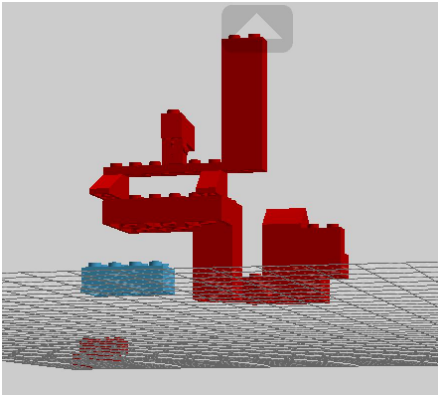
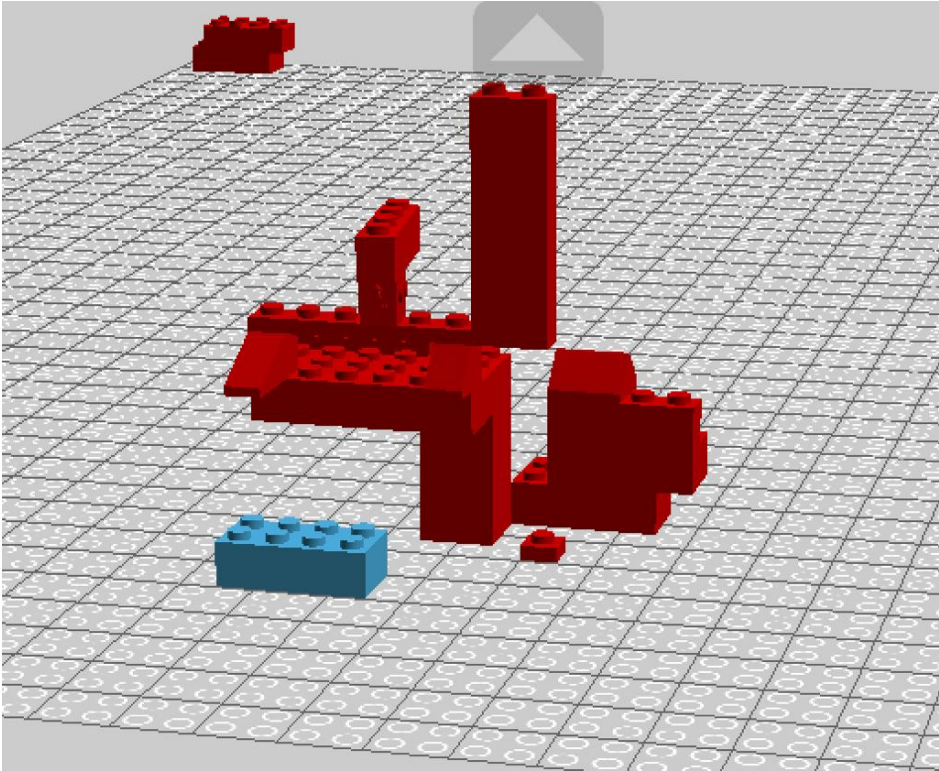
- General versus individual interests

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- Advocacy is a strong and powerful tool.
- Before each project make sure the aims and purposes are clearly defined.
- Individual or personal interests are often the driving force of advocacy, but must be in accordance with medical availabilities, resources and also ethical aspects.

# Point of view

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# Human resources

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- Human resources are the fuel of any advocacy activity. This resource is also the most valuable .
- Make sure to include multidisciplinary or multi-professional participants if needed. For a long time „patient`s „ and „carer“`s opinions were ignored.
- Advocacy needs some bureaucratic background for organization, contacts, and recording.
- Mould your human resources into a workable structure.



# Human resources

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- Human resources
- Physicians, students
- Staff - organisation
- Patients, carers, NGO

# Financial

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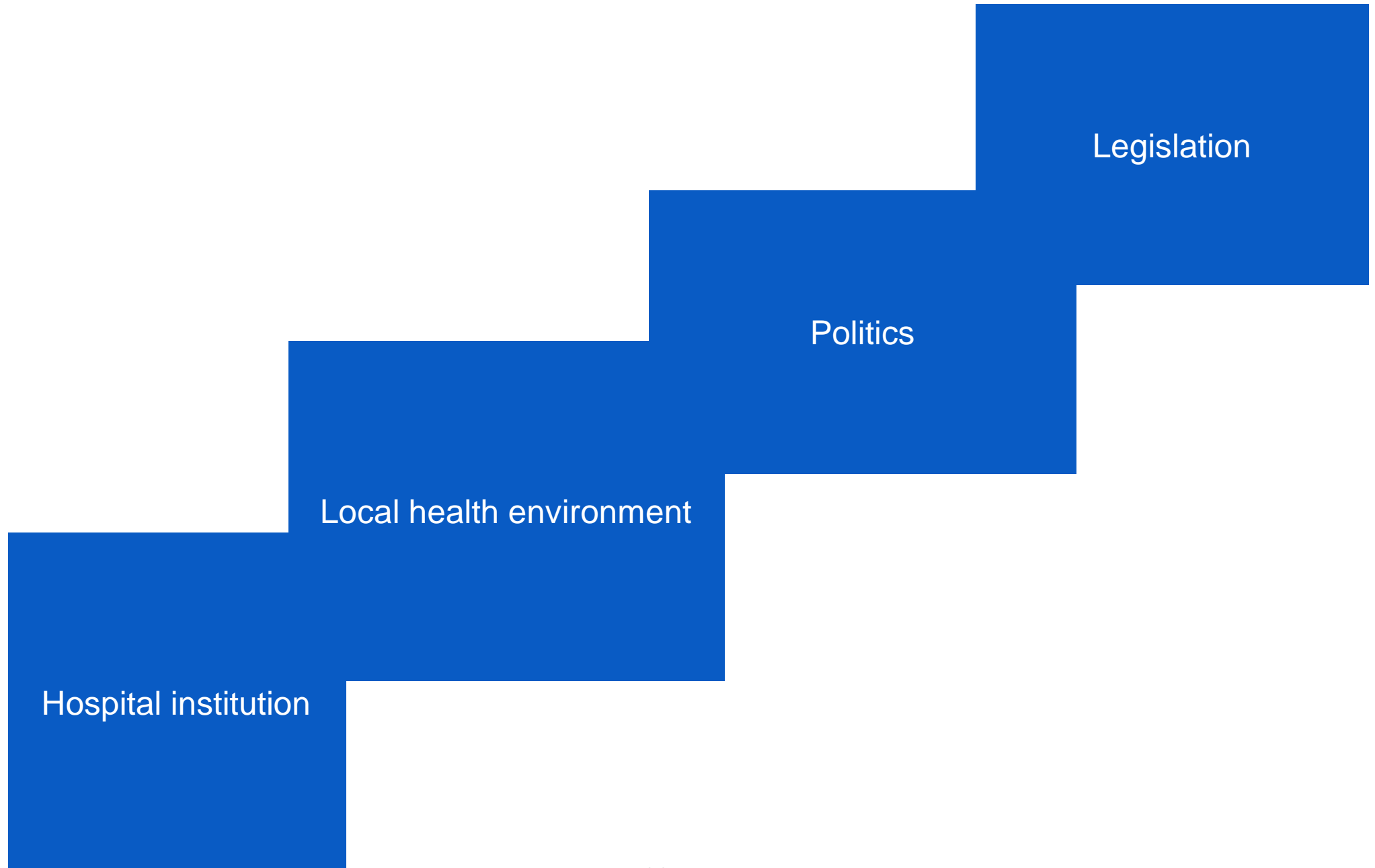
- Despite the fact that advocacy is usually done by volunteer work, you still might consider to draw a budget. This should include direct and indirect costs, and also an estimation of the human resources you will need.
- Funding is differently done in all parts of the world. Ideally funding from an „official“, a government, or a NGO site can be obtained. All funds create interaction between the donor and the recipient. Also a dependency might result

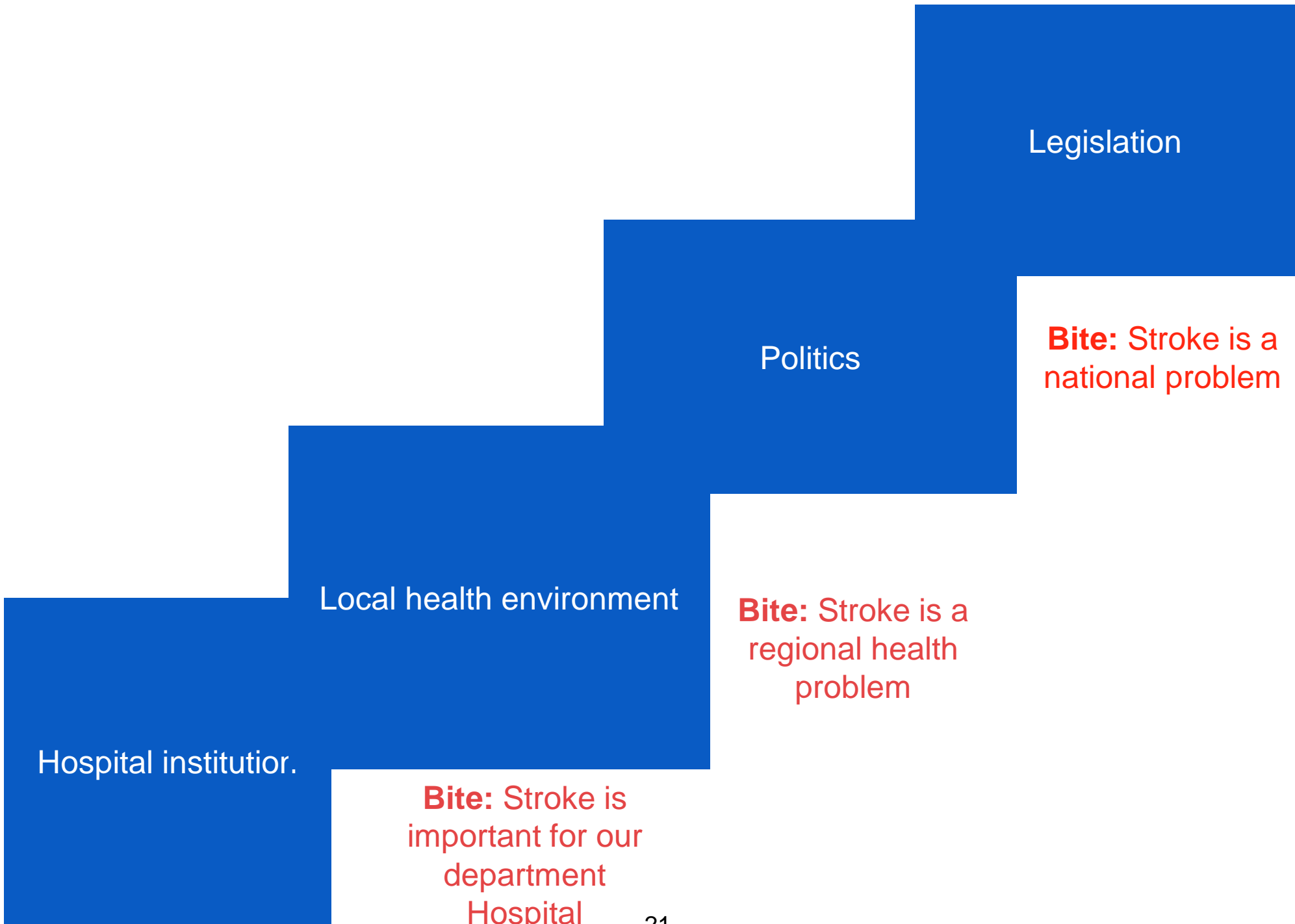
# Indirect costs

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- Indirect costs are costs which occur frequently, and usually go unnoted. It is important for any project. Examples are:
- Rooms
- Telephone and communication
- Faxing, printing.
- Office and secretarial work

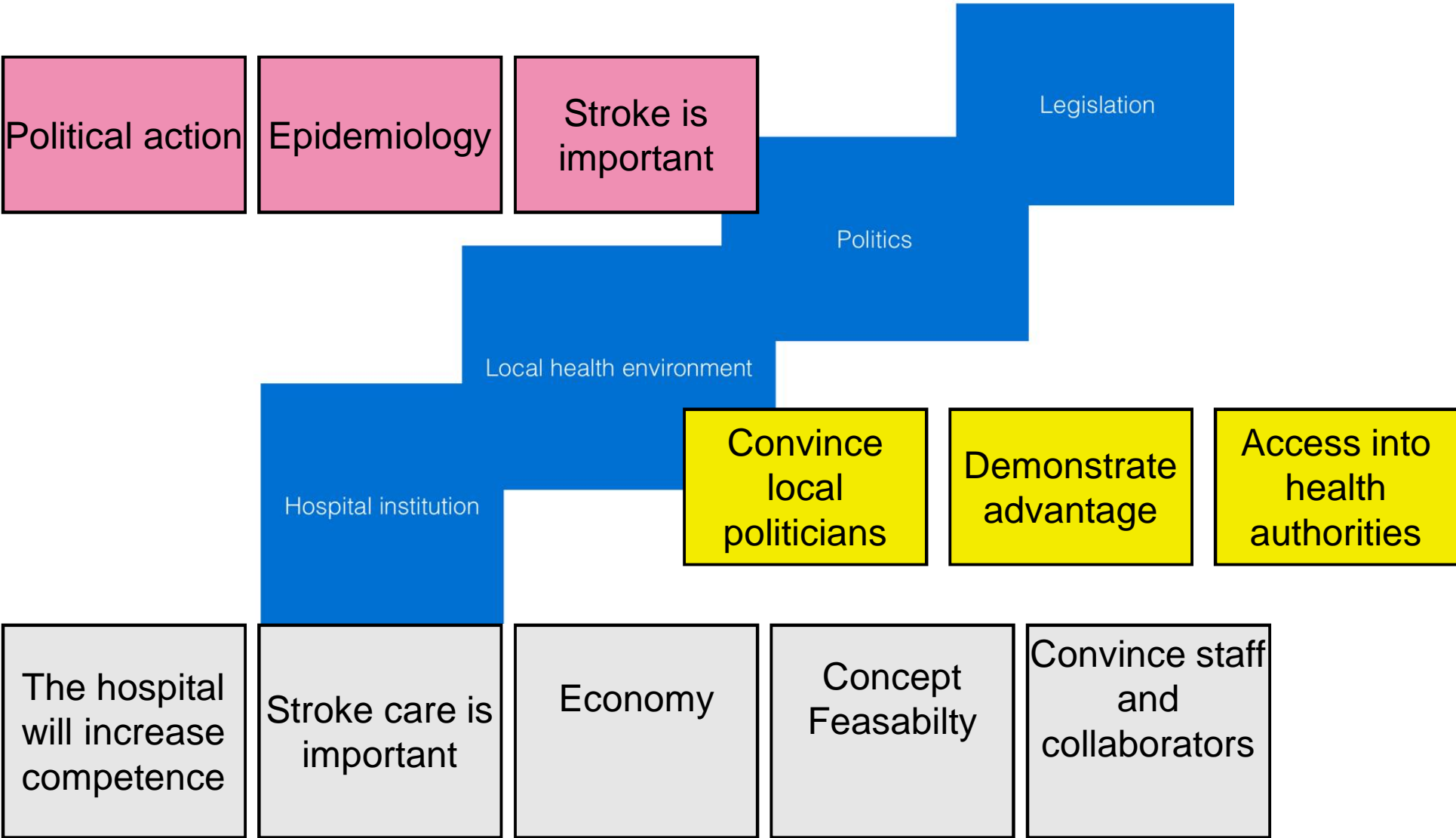
# Hospital- Health-Politics- Legislation





# Project : Stroke unit

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# Media, Press

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- Press training - AAN
- Media Training
- Press conference
- Information
- Radio, television
- local news, national news
- medical press



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# Patient/relatives, NGOs

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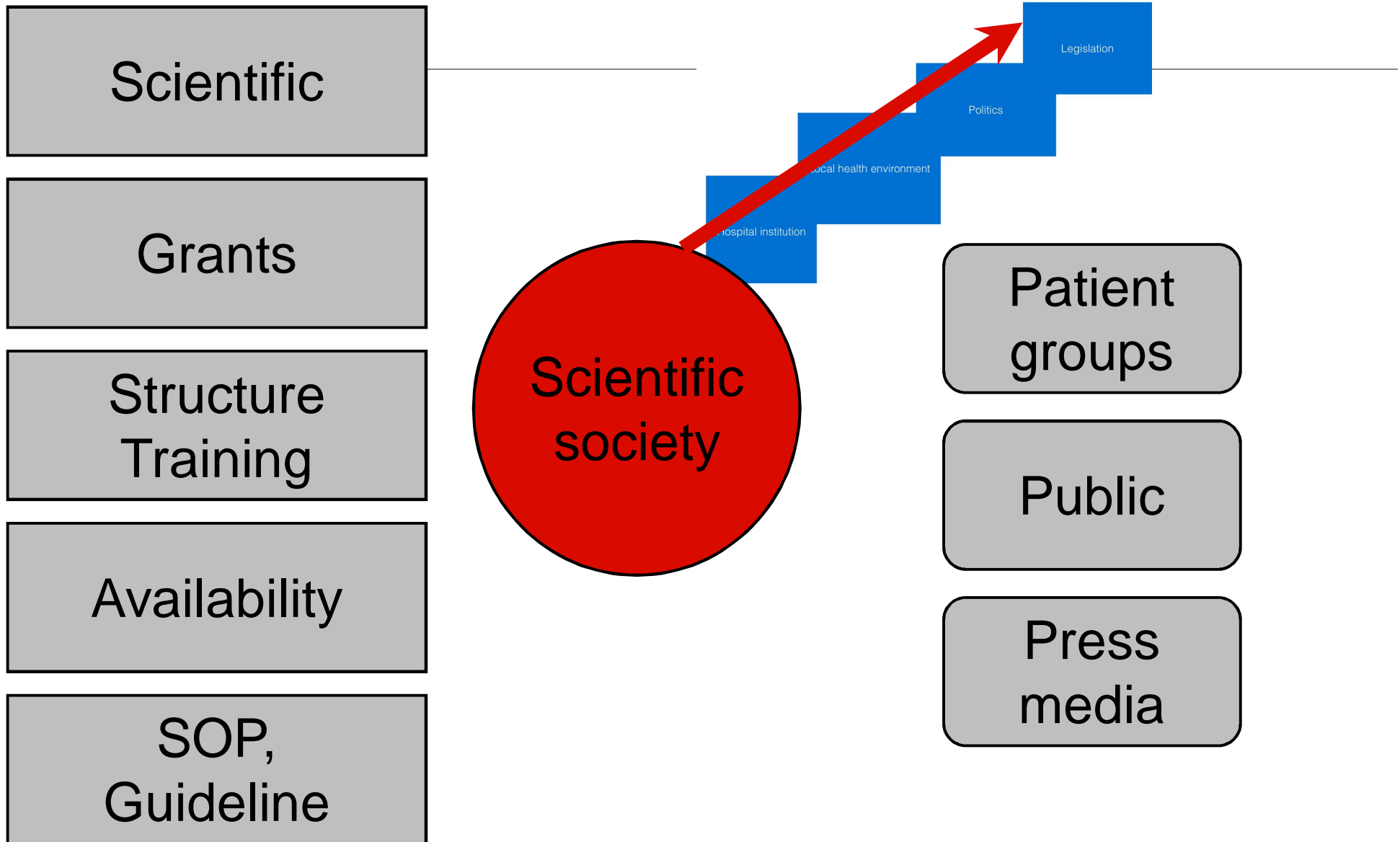
- Patients, relatives and carers are an important resource. This resource can be channeled in many ways as patient service and patient groups, relatives and carer activities and can also consist of several different types as support, activities within the societies, and even fund raising.
- NGOs are often dedicated to individual health groups or diseases. Their purpose is a non profit support for defined issues and topics. In medicine, they are often disease focused.

# Scientific societies

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- Often it is advisable to seek and continue permanent contact and interaction with the scientific or professional societies.
- There are several benefits as the societies are often an invaluable source of contacts, scientific support and vice versa projects and patient groups and projects can support the scientific society.
- Use synergies between the scientific societies and your advocacy project

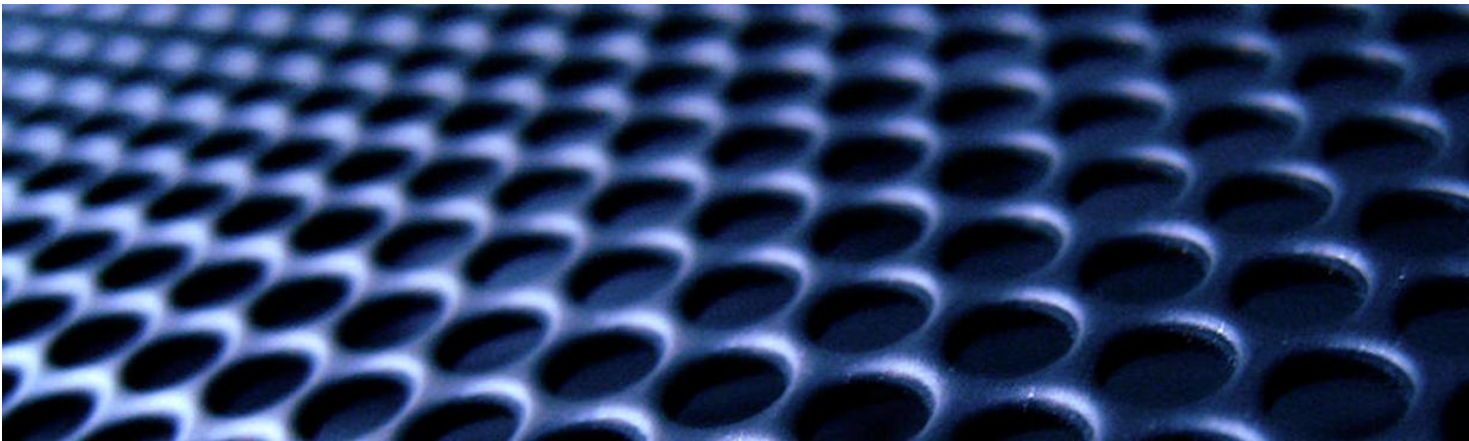
# Project: Implementation of stroke



# Industry

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- Resources provided by industry are invaluable and often very useful.
- However this can be also very ambiguous in many ways.

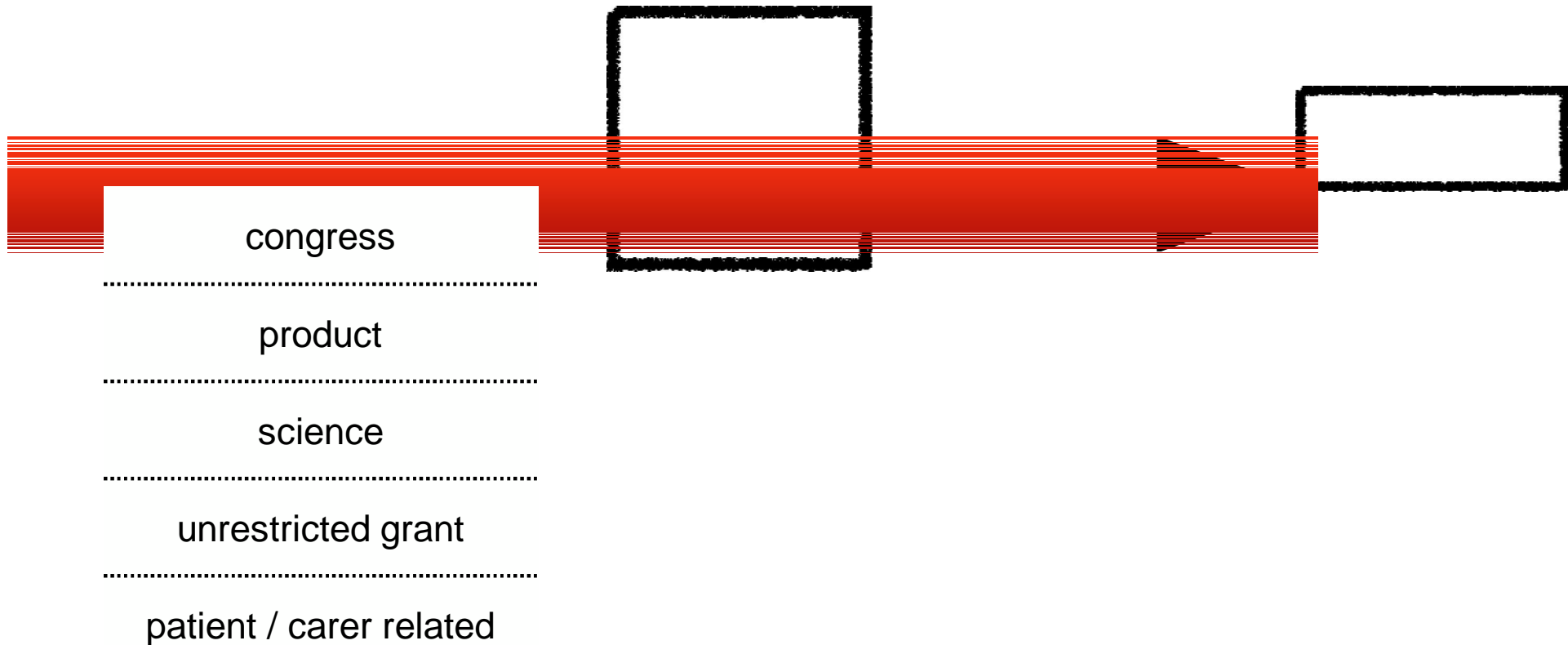


# Industry

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- Not everything that COUNTS, can be COUNTED.

# Pharma industry



# An Industry - story and hazards

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- Advocacy projects can theoretically be sponsored by industry. But be aware that industry support may create problems in many ways, “there is no free lunch”....
- A personal example: A large international pharmaceutical company was in the process of introducing a new drug for an uncureable disease. Several expert meetings were held worldwide, and the company sincerely voiced interest and promised support for the improvement of care in this disease. Local organizations were to be regionally funded and supported, platform for improvement of care in this disease were encouraged to be established. Contact with patient groups and specific NGOs were sought.
- In speciality meetings the product was promoted with effort and large resources of personnel. All in all , perfect paradigm for patient advocacy in a rare disease.

The final study results, however did not meet all criteria to promote the project further, and all interest and support for the project was immediately stopped.

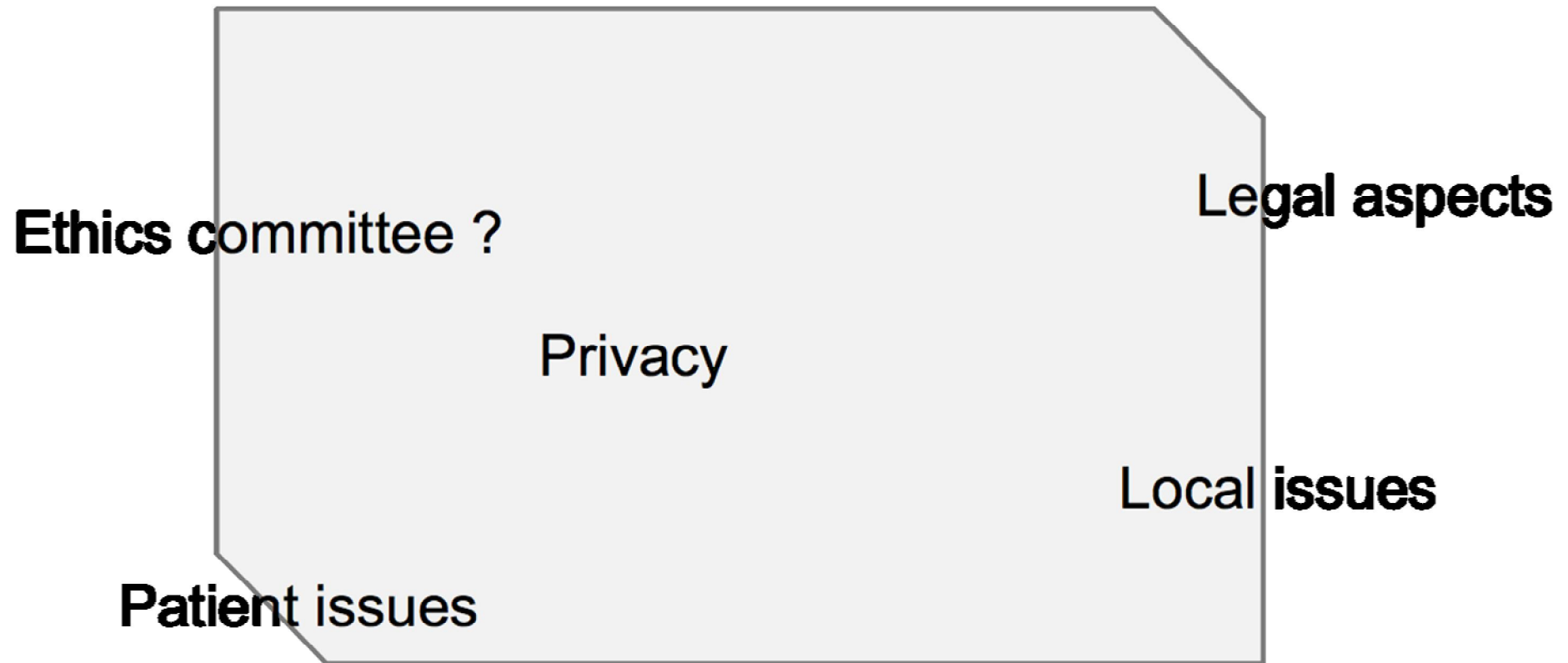
# An Industry - story and hazards

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- What can be learnt ?
- Most industrial supports involve a specific interest.
- The success of the project depends on the success of the product.
- Create projects with industry, but remain independent.
- The moral and ethical attitude of this company needs to be questioned.



# Ethical, legal and "local issues"



# Personal contacts

May be at:

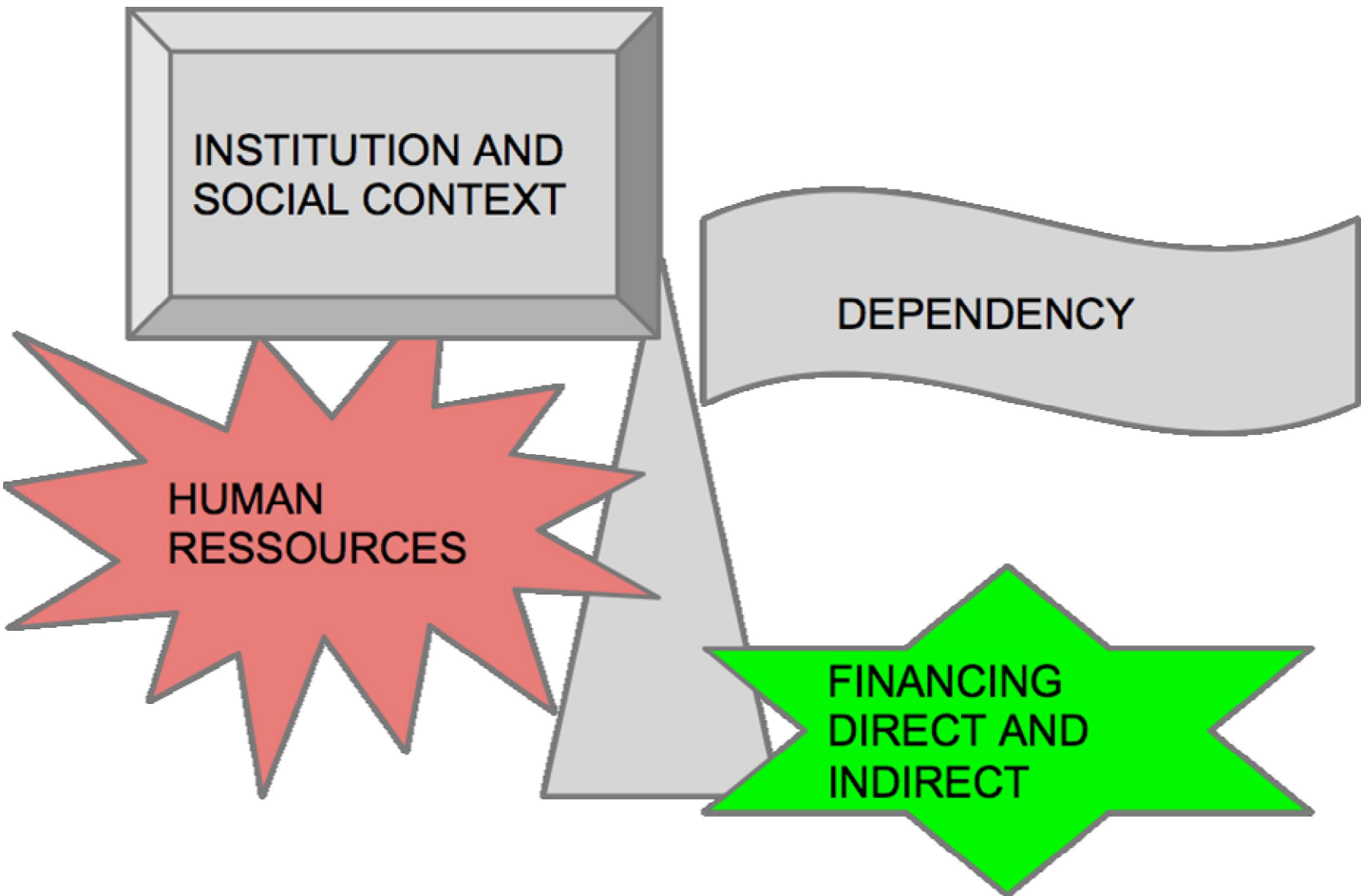


**Patient level** - always consider patient's dependency on you. Do never misuse your position

**Patient relatives/Carers**

**Administration**

**Politician**



**Resources for  
advocacy projects  
need a fine and well  
tuned orchestration**



Text