WFN-AAN Palatucci- advocacy meeting

Locating and using Advocacy Resources:

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Disclosure

- There is nothing to disclose
- The presentation has not been funded.
- The author is presently an officer of the WFN, and of the UEMS CME governance board
- Previous affiliations were with the EFNS (now EAN), and UEMS EBN (board of neurology)

Learning objectives

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

Preamble: Everything is politics....

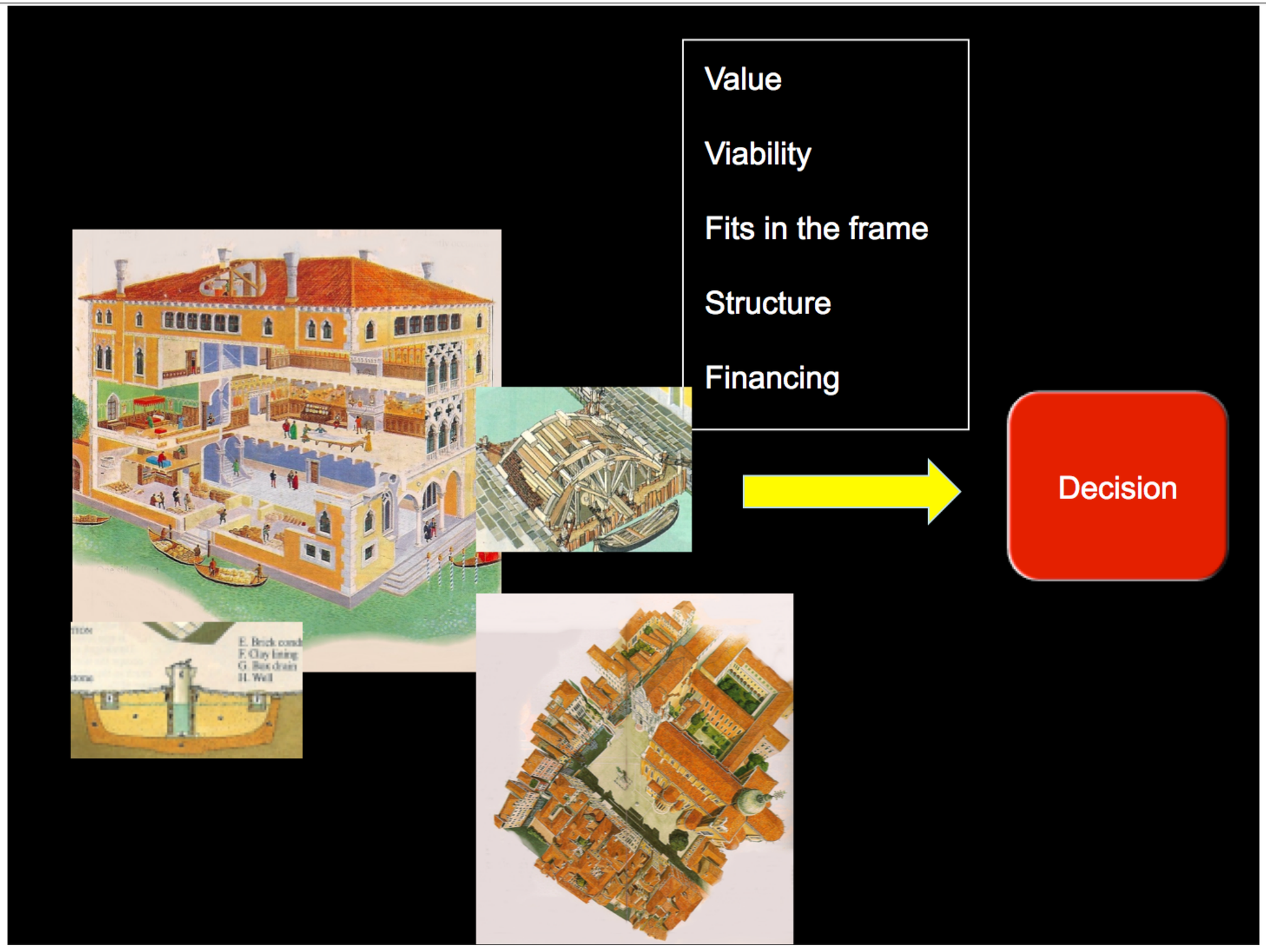
- “Everything is politics” is one of the main sentences which have followed me since my first AAN advocacy meeting in the US.

- 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.

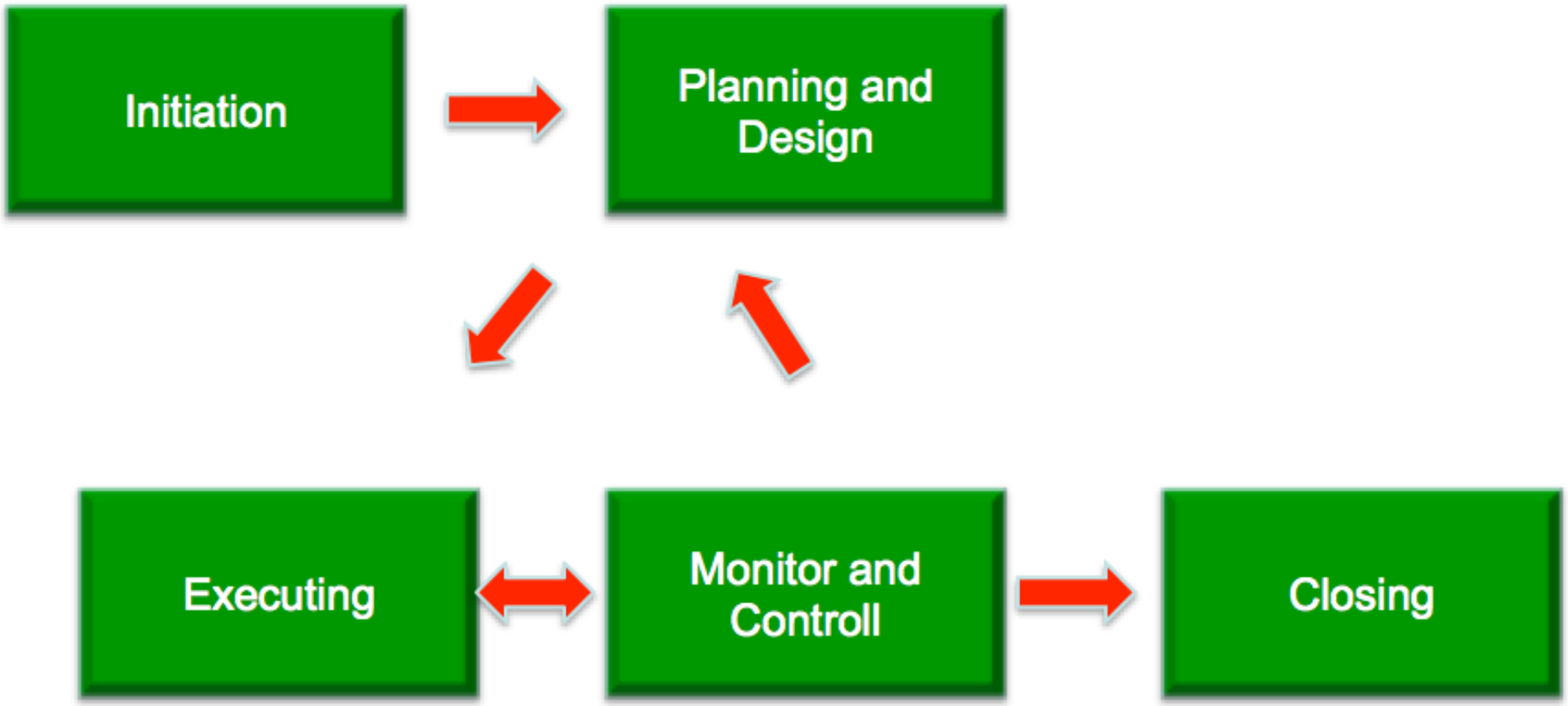
- The best ideas with the most valuable content can not take off if not properly fuelled with manpower other resources to create an impact.

1 Project management

Funding of a project. Name the project :



1 Project management

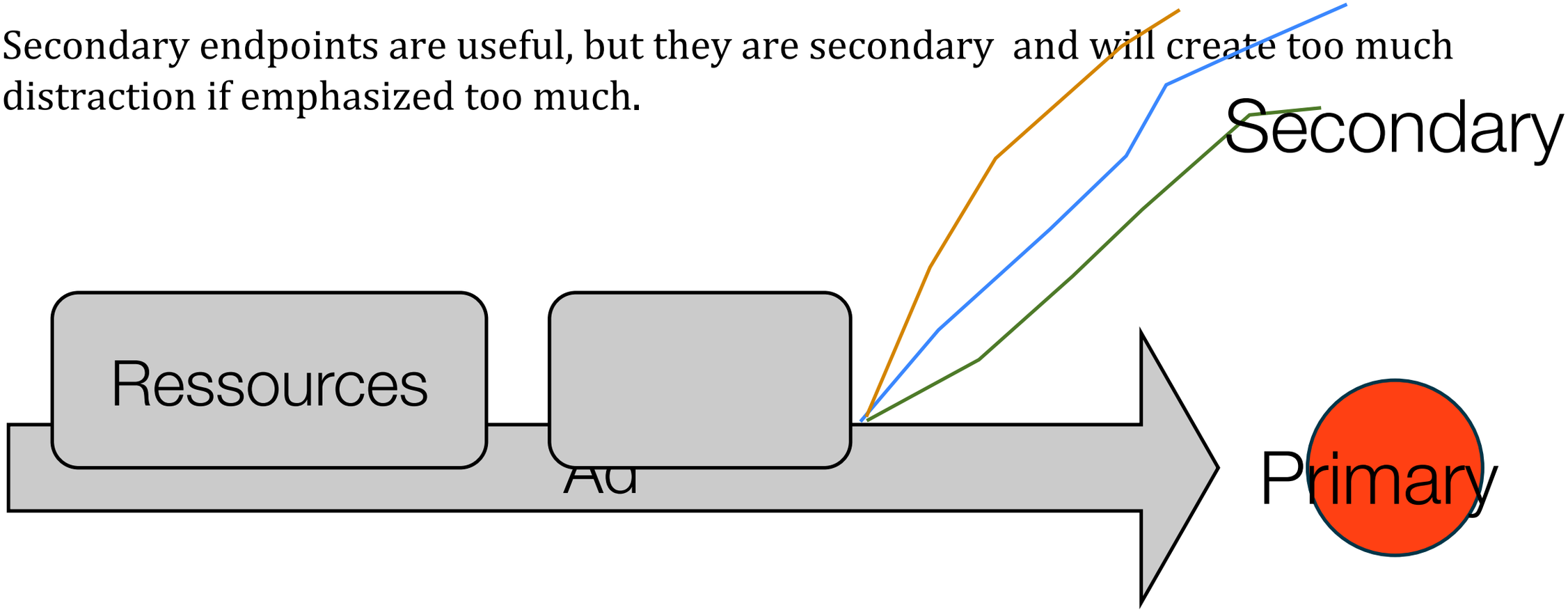


(wikipedia: project management)

Define an End point:

- Like in clinical studies, you need am “endpoint”, one main point, not several. The result , and content needs to be easily understood and “sticks”.

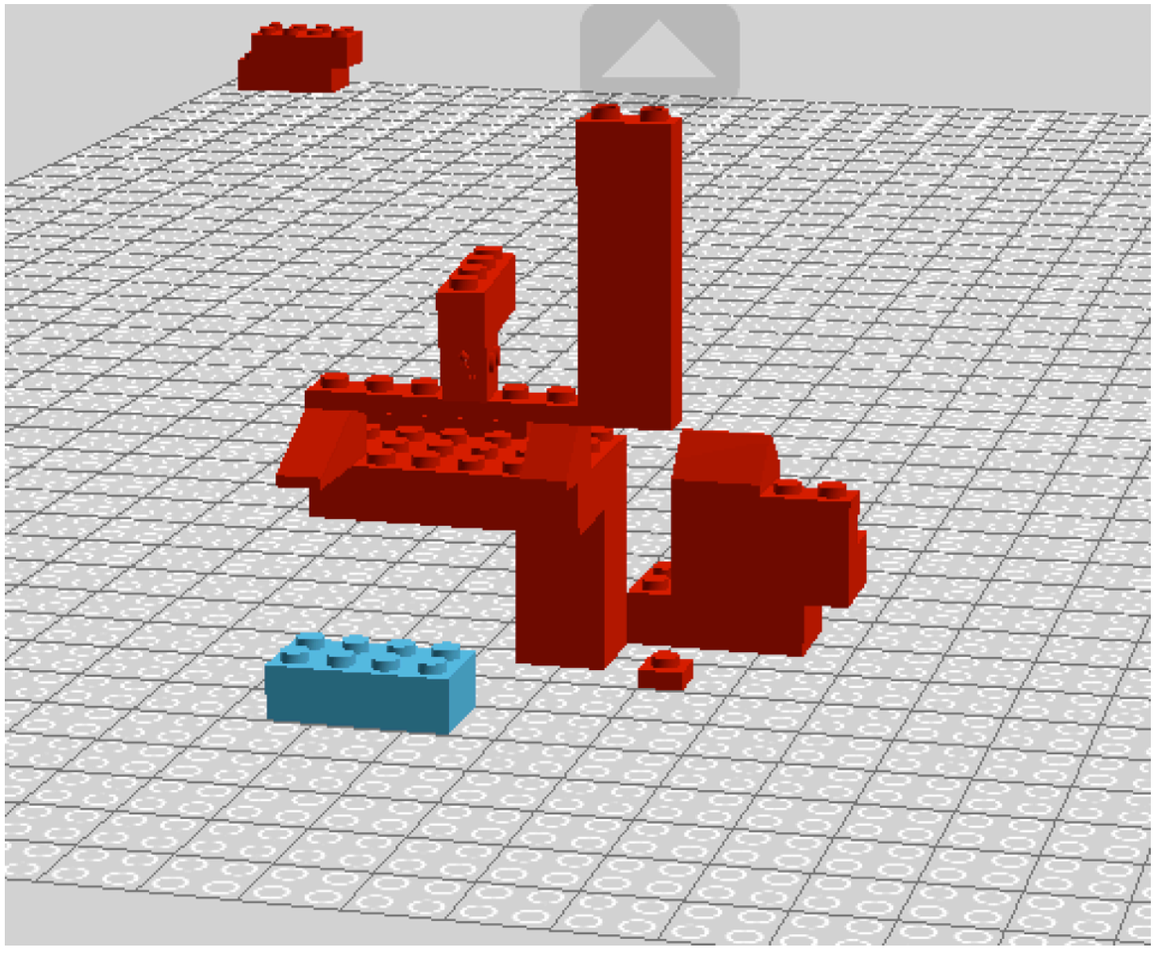
- Secondary endpoints are useful, but they are secondary and will create too much distraction if emphasized too much.

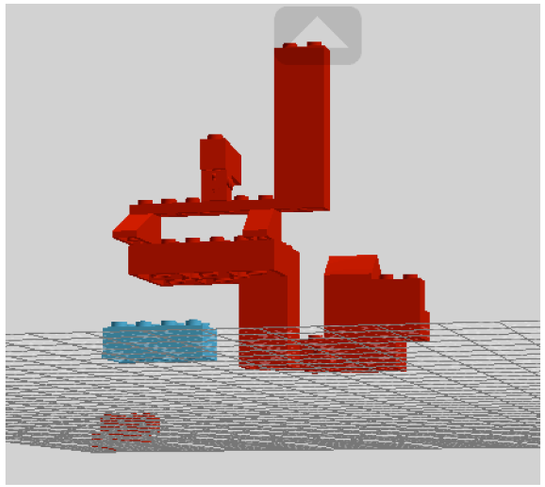


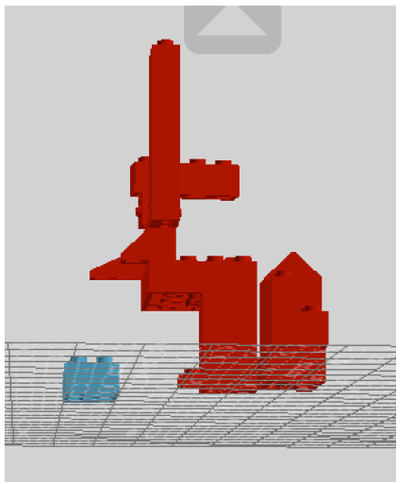
Will this project have an impact ?

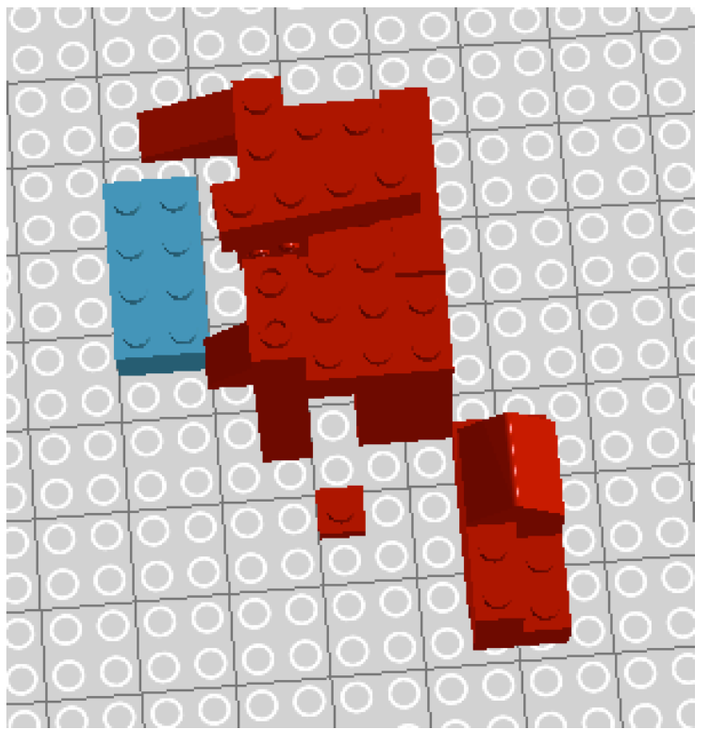
- Will it be valuable ?
- Will it be viable ?
- Can it be sustained after the project is over ?
- Who will be the beneficiary ?
- Feedback ?

The same object: different point of view.









2) Definition of resources

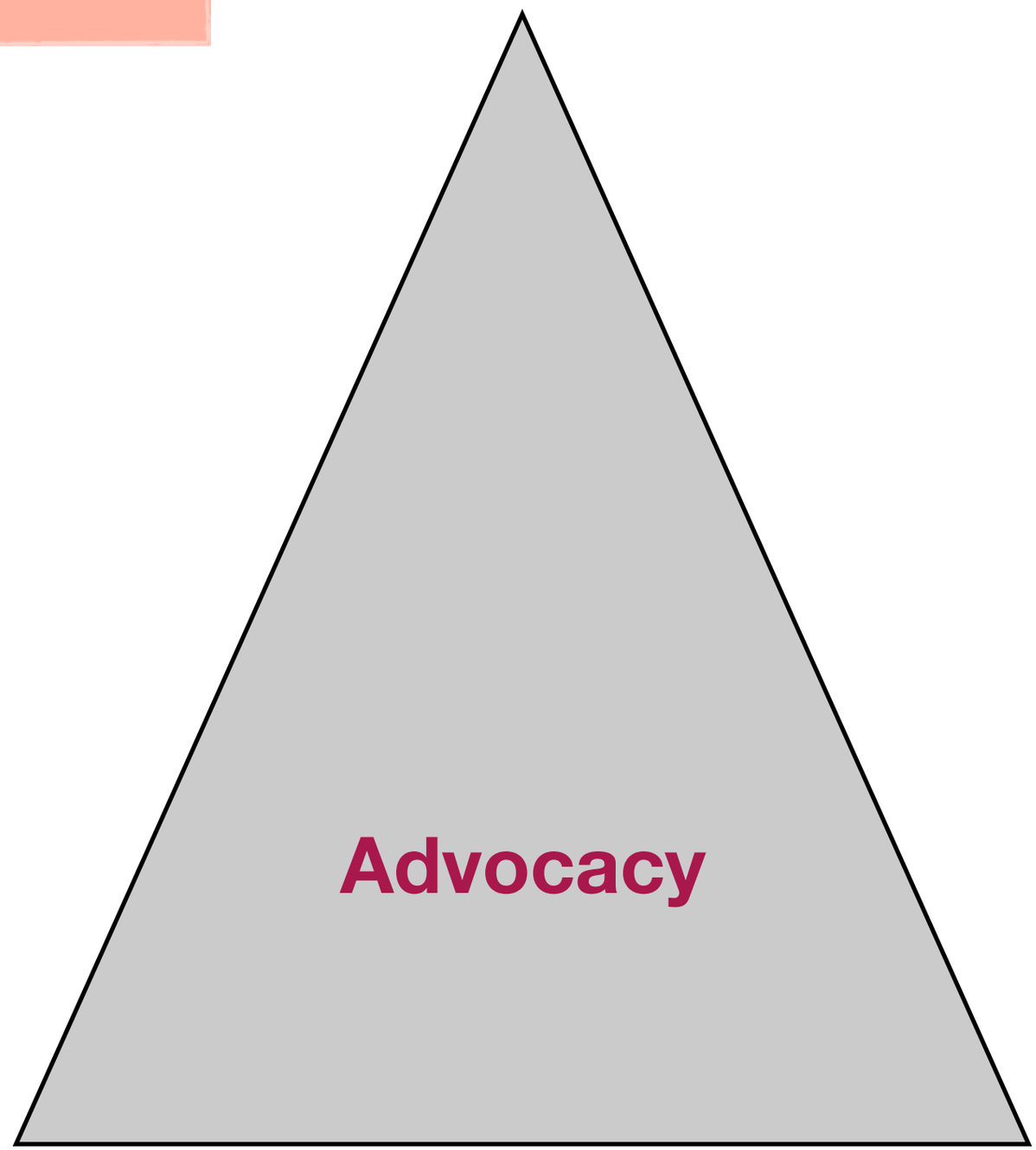
Human Ressources

Financial

Indirect

Sponsoring

Patient/relatives, NGOs



Human resources

- 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. Implement and ask for „patient`s „ and „carer“`s opinions.

- Advocacy needs some bureaucratic background for organization, contacts, and recording.

- Mould your human resources into a workable structure.

Financial aspects

- Despite the fact that advocacy is usually done by volunteer work, you still need to draw a budget. This should include direct and indirect costs, and also an estimation costs 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. Funding can also be via donations, prizes, and often industry.

- All funds create interaction between the donor and the recipient. Also a dependency might result.

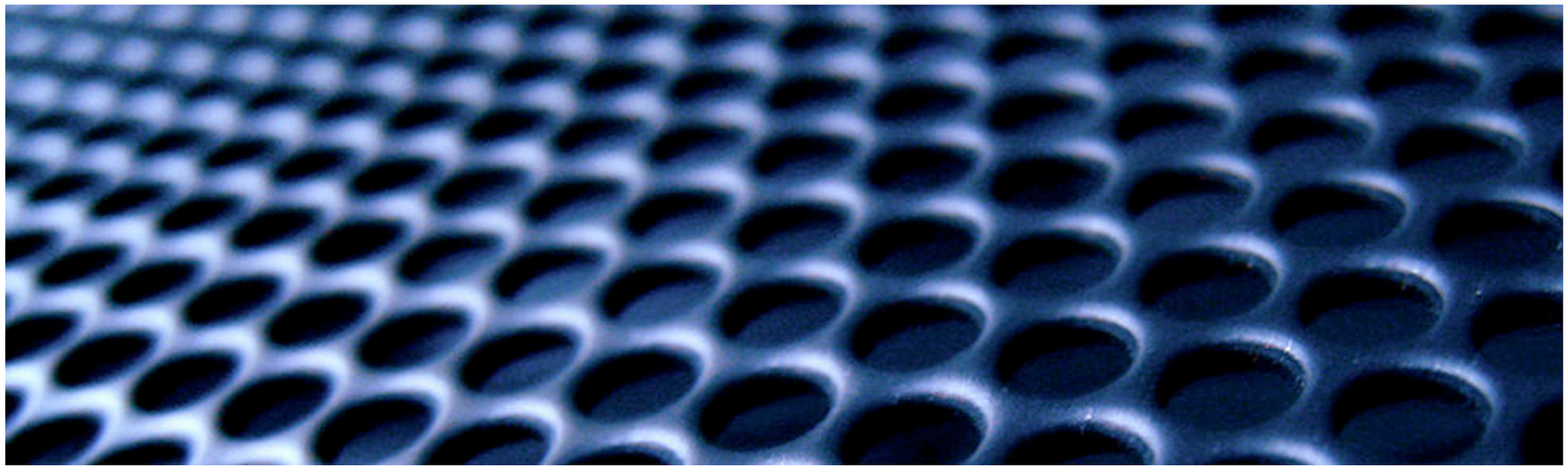
- Consider “indirect” costs.

3) Finding of resources

- Hospital
- Health system
- Scientific societies
- Grants/prices
- Fund raising
- Patient organisations, caregivers
- NGOs
- Industry

Industry

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



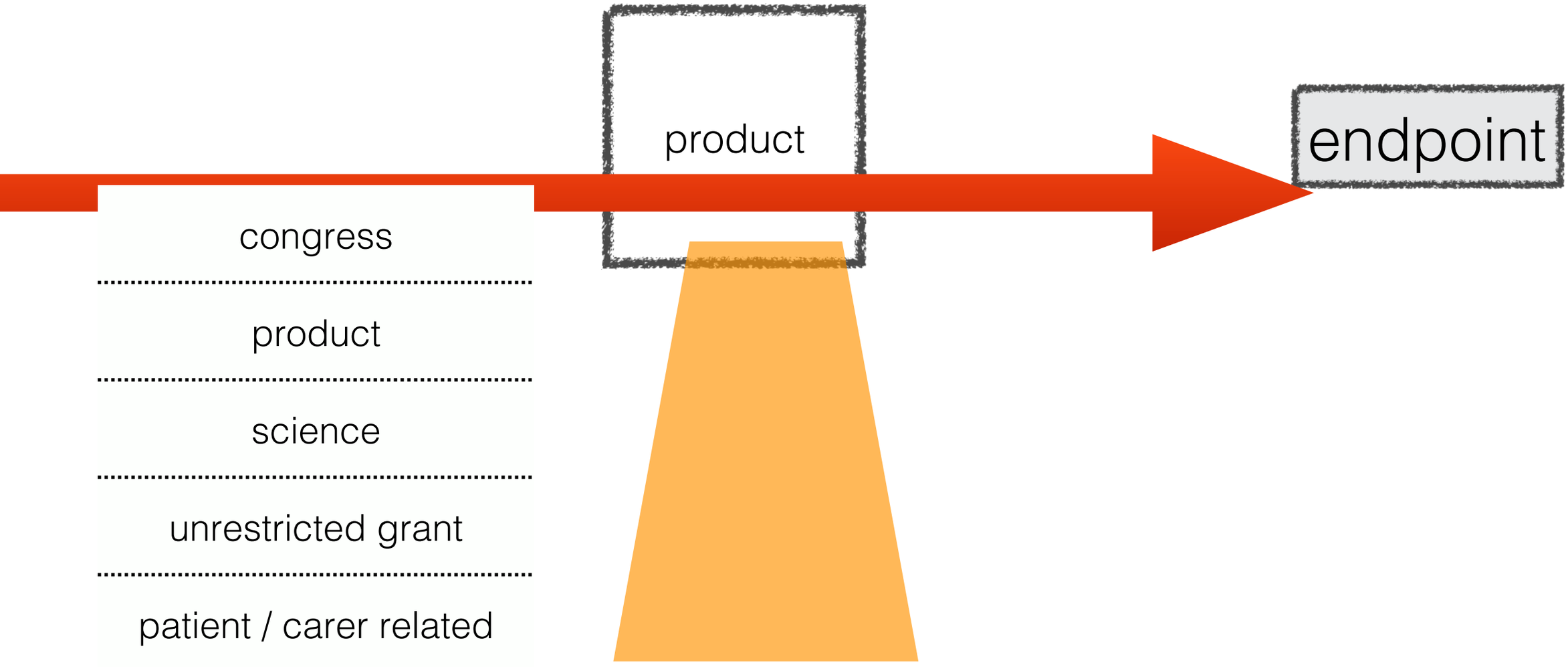
4) Industry relations and ethical aspects

- Sponsoring

- Transparency

- Conflict of interests

Pharma industry



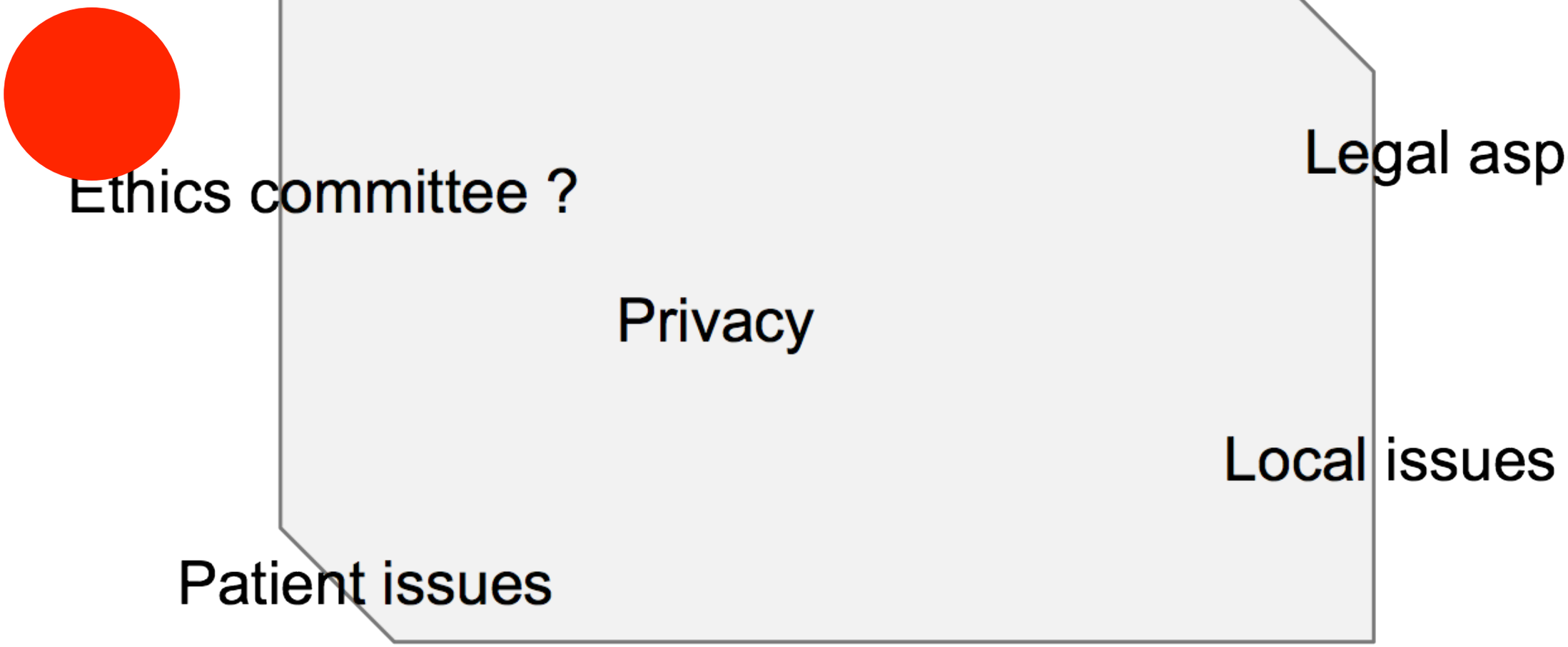
Industry practice to obscure relevant information

Industry Practices to Obscure Relevant Information, Undermine Clinical Trial Research, and Distort the Medical Literature

Practice	Definition
Seeding trials	Clinical trials of a drug or device among human participants that are conducted for the purpose of promoting the drug or device and encouraging its use directly to physicians under the guise of their participating as an investigator in a clinical trial, without disclosing the marketing objectives to patients, physicians, regulators, or institutional review board members.
Publication planning	Organizational and practical work of shaping pharmaceutical companies' data and turning data into medical journal articles to derive the maximum commercial value from clinical research through carefully constructed and placed articles by targeting high-profile journals for high market impact findings and by publishing numerous strategically related market-focused articles within lower profile journals.
Key messaging	Identification of key messages or themes that are expected to promote drug sales, with subsequent planning of publications around these messages and themes.
Ghostwriting	Failure to designate an individual, in this case an industry employee or an external medical writer, who has made a substantial contribution to the research or writing of an article as an author.
Guest authorship	Designation of an individual, in this case an academic investigator not employed by industry, who does not meet authorship criteria as an author to confer external objectivity.
Selective publication	The delayed publication or nonpublication of clinical trials that have findings that do not support a drug or device or that may decrease the commercial value of the product.
Selective reporting	The partial or incomplete reporting of clinical trial findings that do not support a drug or device or that may decrease the commercial value of the product.
Ambiguous reporting	Reporting clinical trial findings that do not support a drug or device or that may decrease the commercial value of the product in a way that is misleading or less likely to attract public attention.

Consequences of Industry Relationships | Peer Reviewed | Ross et al.
American Journal of Public Health | January 2012

Ethical, legal and "local issues"



Media, Press

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

Project management:

elisabeth.zimmermann@univie.ac.at, E. Z. U. o. V., M. F. P. U. o. V. franz-markus.peschl@univie.ac.at and B. R.-N. U. o. V. brigitte.roemmer-nossek@univie.ac.at (2010). "Constructivist Curriculum Design for the Interdisciplinary Study Programme MEi:CogSci – A Case Study." Constructivist Foundations vol. 5, N°3.

Grant reviewing:

David Gurwitz1, Elena Milanesi1, Thomas Koenig3 "Grant Application Review: The Case of Transparency." PLoS Biol 12(12): e1002010. doi:10.1371/journal.pbio.1002010.

Raising Funds

Bernard Lo and Marilyn J. Field, E. C. o., E. Conflict of Interest in Medical Research, and and P. I. o. Medicine "Conflict of Interest in Medical Research, Education, and Practice." ISBN: 0-309-13189-8, 392 pages, 6 x 9, (2009) This PDF is available from the National Academies Press at: http://www.nap.edu/catalog/12598.html; Institute of Medicine, visit the IOM home page at: www.iom.edu.

Mojtaba Parsa1, K. A., and Bagher Larijani3 (2014). "A comparison between conflict of interest in Western and Islamic literatures in the realm of medicine." J Med Ethics Hist Med, 2014, 7:7.

NICE (2007). "Policy on Conflicts of Interest." Document.

Susan L. Norris1*, H. K. H., Brittany U. Burda2, Lauren A. Ogden1, Rongwei Fu3 "Conflict of Interest Policies for Organizations Producing a Large Number of Clinical Practice Guidelines." PLoS ONE 7(5): e37413. doi:10.1371/journal.pone.0037413

Smith R. (1998). "Beyond conflict of interest." BMJ 317: 291-292.

Transparency :

Joseph S. Ross, M., MHS, Cary P. Gross, MD, and Harlan M. Krumholz, MD, SM (2012). "Promoting Transparency in Pharmaceutical Industry–Sponsored Research." Am J Public Health. 2012:72–80. doi :10.2105/ AJPH.2011.300187).

Mietchen, D. "The Transformative Nature of Transparency in Research Funding." PLoS Biol 12(12): e1002027. doi:10.1371/journal.pbio.1002027.