

DisseminACTION: disseminating science in the information age (www.action-euproject.eu: a website for researchers and parents)

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From the womb to the adult

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Abstract

www.action-euproject.eu is a website designed at the University of Cagliari, by the Department of Surgery, Faculty of Medicine, within the project “ACTION – Aggression in Children: unravelling gene-environment interplay to inform Treatment and InterventiON strategies”, a collaborative project which includes twelve international partners, funded under the 7th Framework Programme for Research, technological Development and Demonstration.

Its aim is to properly disseminate official news, events, medical discoveries carried out within the project, with an intent to connect European researchers and citizens with the official source of ACTION’s scientific research.

One of the main problems of the so called “web 2.0” is represented by the growth of viral misinformation, which contributes to create rumours and hoaxes around scientific threads. In order to avoid this kind of problems, www.action-euproject.eu is also designed to directly reach its audience even with social networks integration and with newsletters.

Informatics is the discipline that studies the information processing through automated elaborations. The term appears for the first time in 1957, and since that time Computer Science has grown, reaching an unthinkable evolution, so that the common devices we use in our everyday lives (personal computers,

notebooks, tablets, smartphones) are more powerful than the NASA calculators at the time of moon's landing. This evolution leads to privacy and security matters: our devices process everyday an important number of sensitive data, and are everyday exposed to the risks of computer security.

This website has been designed following usability guidelines, with a logical sitemap, an easy system of options, a clear graphic style, a responsive graphic template and a robust Content Management System, in order to ensure the website security and a rigid privacy policy.

Keywords

Website, scientific dissemination, misinformation, usability, privacy, computer security.

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Introduction: a road to instantaneous communication and digital dissemination

The word “informatics” is inherently related to the term “information”. Informatics, or computer science, is the scientific discipline which deals with the information processing through automated elaborations. The term appears for the first time in 1957, in an article by Karl Steinbuch [1].

Of course, since that time, so many considerable progresses have been made in this field; just to name a few: ARPANET (Advanced Research Projects Agency NETWORK) was created by DARPA (Defense Advanced Research Projects Agency) in 1969 [2] and was the military predecessor of the Internet. Then, the World Wide Web (developed at CERN, European Organization for Nuclear Research, by Tim Berners-Lee), started its evolutions in 1989, until it reached the current *web 2.0* version [3]. And now, the so called “Internet of Things (IoT)”, or “web 3.0”, is preparing a revolution of our everyday life, connecting humans with objects

and objects with other objects, facilitating the human-machine interactions [4]. Not always facilitating, to say the truth, if we consider the last Samsung's blunder: the company warned customers about discussing personal information in front of their smart television set [5].

In this context, scientific research has not lagged behind and scientific divulgation themes have increasingly appeared on the web, without abandoning the canonical ways of information sharing: conferences, workshops and publications. The European Union (EU), in this frame, has not been silently watching. Being one of the main drivers of research, through its Research & Innovation Framework Programmes, the EU is in fact equipped to push for a more diversified science divulgation, that stimulates creativeness and requires a digital presence. Nowadays the dissemination of scientific research projects is in fact strictly governed by contracts between the European Union and the recipients of funding.

This is done to emphasize the importance of an adequate communication and to better connect European citizens to scientific progress [6] and, in the specific case of this article, to the discoveries reached in the medical field.

The power of misinformation

June 2012: the labour court of Rimini, Italy, granted a compensation of 200,000 euro to a family claiming that the MMR vaccine administered to their child eight years before (2004, when the child was 15 months old), caused his autism. The court compensated them on that theory even if this decision partly depended on the testimony of an expert opinion who relied, in turn, on a debunked study (made by Andrew Wakefield) [7-9].

No scientific papers available in that moment demonstrated a link between MMR vaccine and autism, and all scientific papers available from that moment demonstrate the falsehood of this theory, that, despite of the facts, was used by anti-vaccine activists as part of their claims.

On February 13, 2015, a Court of Appeals in Bologna overturned the decision made by the labour court of Rimini two years before. Nonetheless, this misinformation episode demonstrates a clear example of lack of connection between available scientific knowledge and citizens. In fact, the misinformation about vaccines has permeated different layers of citizenship, fuelling rumours and hoaxes on social networks and achieving a high

echo, until coming to permeate even the judges' decisions.

Global warming, chemtrails, stem cells, alkaline diets, are not rare cases where convictions unsupported by scientific theories, work their way through the population that has no access to official scientific information, causing beliefs and chain reactions such as the one presented in the lines above [10, 11].

The website we are going to present in this article is thought to be the direct connection between European citizens and the official source of news, events, medical discoveries carried out within the project ACTION – Aggression in Children: unravelling gene-environment interplay to inform Treatment and InterventiON strategies.

A website for researchers and parents

www.action-euproject.eu is a website developed at the University of Cagliari, by the Department of Surgery, Faculty of Medicine. ACTION is a collaborative project which involve twelve international partners, it has been selected by the European Commission as one of the projects funded under the 7th Framework Programme for Research, technological Development and Demonstration.

The project is financed under the sub-programme HEALTH.2013.2.2.1-3: “Paediatric conduct dis-

orders characterised by aggressive traits and/or social impairment: from preclinical research to treatment”, and aims to improve the understanding of the causes of individual differences in aggression among children [12].

The website is scientifically oriented, so it is thought to be useful to researchers, but as the website's goal is mainly intended to raise awareness about the project activities, the website's target is non-specialists people. Hence, the language used is non-technical. In a members' restricted area, instead, technical material and topics are uploaded and professional terms are used.

Aggression inflicts a personal, psychological and financial burden on affected individuals, their relatives, and society at large, so that the website will host, during the next years, a new section, useful for parents and relatives.

The site also includes some *prosthesis* in order to reach its end-users even when end-users don't access to it (if the mountain won't come to Muhammad then Muhammad must go to the mountain [13]). In fact, to properly disseminate its contents, the website is designed with a *social soul*, and it is integrated with some social network official profiles and with an aperiodic newsletter, containing news, galleries, call for papers and other relevant material related to the project, to which everyone can subscribe (**Fig. 1**).

The screenshot shows a web browser window with the URL www.action-euproject.eu/content/action-newsletters. The page has a blue header with the ACTION logo (a yin-yang symbol with stars) and the text "Aggression in Children: unravelling gene-environment interplay to inform Treatment and InterventiON strategies". To the right is the European Union flag. Below the header, the page is titled "Action Newsletters" and includes the instruction: "Please submit your e-mail in the module form on the right to subscribe to ACTION Newsletter." On the right side, there is a "Newsletter Subscription" form with the following fields: "Email Address" (with a red asterisk), "First Name", "Last Name", "Organization/Partner", and "City". Each field has a corresponding text input box.

Figure 1. The webpage with the ACTION Newsletter subscription form (<http://www.action-euproject.eu/content/action-newsletters>).

A short overview on ACTION's website technical development

The website, developed with an open source Content Management System, a platform called Drupal 7 [14], is divided into five main areas (Project, Partners, Events, Publications, Media), and some other sections dedicated to news, contacts, and a private area accessible to the project's staff, as mentioned before.

Each area is divided into several sub areas, in particular the media and events sections contain pages dedicated to galleries, video-galleries, project's media coverage, press releases, conferences and workshops, seminars and courses, meetings.

The layout of the website is composed of:

- a header, which displays the project title, its logo, the European flag and contains a centered main navigation bar, displaying the navigation menu;
- the main body, displaying the main content's page (different in every page);
- a right column, which in every page shows different contents or a secondary menu with several navigation options.

Furthermore, a footer area displays contacts, credits, social network buttons, and the access to the newsletter subscription and to the members area.

Fig. 2 and **Fig. 3** explain the website structure.

The partners' page shows the complete details, in a transparent way, of all staff members, since the project relies on a large body of competences, comprising 12 partners, from 8 different countries: VU University Amsterdam, Leiden University Medical Center, Leiden University, Erasmus University Medical Centre and Good Biomarker Sciences (the Netherlands); Queensland Institute of Medical Research (Australia); Karolinska Institutet (Sweden); University of Helsinki (Finland); King's College London (UK); University of Notre Dame du Lac (US); University of Cagliari (Italy); Diagenode SA (Belgium). **Fig. 4** shows some details of this page.

An affordance matter...

Despite the last lines, this article is not meant to be a technical description of the website, nor a step by step guide of the user experience, due to the fact that a website designer works with the belief that if its job is well done, users learn how to browse a site by themselves (the so called *learning by doing* process) [15].

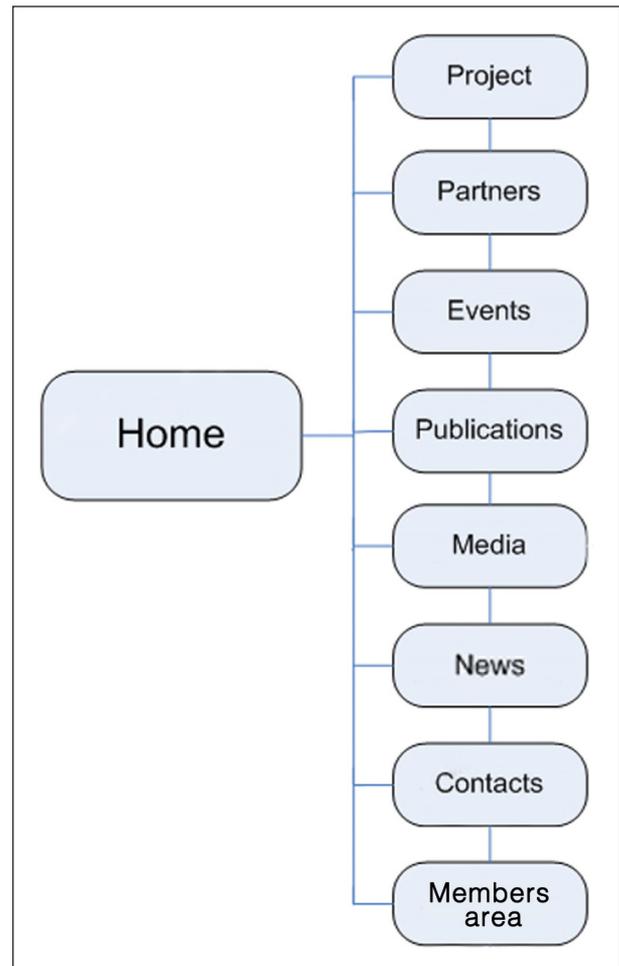


Figure 2. Website's navigation tree.

A good website should be designed following usability guidelines. It is not important how it is useful for the webmaster, but how much time is required to users to reach the content they are searching for [16].

A well designed website should be built like a pair of scissors and not like a *coffeepot for masochists* [17, 18]. Even if we had never seen a pair of scissors, we would know how to handle them. It's a concept called affordance: an object's physical property that naturally suggests to the human appropriate actions to handle, use or manipulate it [19]. Each object has its affordances: a door handle suggest the way we can open that door; spoons, forks, plates seem to communicate not only how to use them properly, but even the consistence of what we are going to eat.

This was the main principle that inspired the website development (with the hope that the website itself invites users to browse through its pages), along with other five conductive wires:

1. a logical sitemap that requires no more than three clicks to reach every available content;

Figure 3. Website's home page. Its main menu reflects the navigation tree shown in the previous figure.

2. an easy system of options, with the double purpose of avoiding digital labyrinths and/or slowdowns in displaying pages;
3. a clear graphic style, simple but clean, without too many needless graphics or decorative animations (e.g. not every device is able to display flash animations);
4. a responsive graphic template (designed to be displayed even on tablets and smartphones);

5. a robust and always updated Content Management System, in order to ensure the website security.

This last point leads us to the last paragraph of this article. It has been stated before that this article doesn't want to describe step by step the website's pages, but spending some words about the private section (members area) is now necessary, because this will allow us to introduce an interesting theme.

Partners map

▼ VU - University Amsterdam - Department of Biological Psychology - Project Coordinator - Partner 1

Department of Biological Psychology

VU University Amsterdam is a leading research university in the Netherlands. Since it was founded in 1880, the VU has been known for its distinctive approach to knowledge. Social relevance is a guiding principle. The VU houses 14 interdisciplinary research institutes, 12 faculties, participates in two national research centres of excellence, one as coordinating institution, and is participant in 40 accredited research schools, 6 as coordinating institution. In total, the VU employs over 1,750 research FTE and yearly more than 6,650 academic articles, monographs and books are published and more than 300 doctorates are honoured. The focus of research at the department of Biological Psychology (around 50 FTE) is the analysis of individual differences in health, cognition, normal and abnormal behaviour, by studying the genetic and biological basis of individual differences in human behaviour, e.g. paediatric, adolescent and adult aggression, using approaches from genetic epidemiology, psychophysiology and molecular genetics. The department maintains the Netherlands Twin Register which was established in 1987 (www.tweelingenregister.org). In the NTR-Biobank project biological material (DNA, RNA, cell lines serum, plasma, and urine) is collected in over 10.000 participants.

Country: Netherlands

Official website

Who we are



Dorret Boomsma
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Official webpage

Relevant expertise: behavioural, molecular, human genetics, statistics, twin studies; analysis of individual differences.



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Relevant expertise: Longitudinal development of child and adolescent psychopathology/ well-being. Behavioural and molecular genetics.

Figure 4. Website's partners' page. Some details of the Partners map and project coordinator.

... And a matter of trust

July 2015: an Italian cybersecurity firm, “The hacking team”, leading company developing

security services to law enforcement and national security organisations, has been targeted, becoming itself the victim of a hack. Since then, it has earned the nickname of “The hacked team” [20, 21]. This

fact teaches that, if a digital content is attackable, sooner or later it will be attacked, with no possibility of escape.

Everything that is on the Internet is in precarious balance. Today, cybercrime is an industrial automated process: machines that attack and machines that use these machines to attack other machines through which carry out criminal acts [22].

It doesn't matter if a site was born to sell jam: if it has a security fall, it could be contaminated, becoming itself unwittingly victim and attacker at the same time.

ACTION's members area is dedicated to private staff's communication, and contains managerial documents, reports, presentations, schedules.

<http://action-euproject.eu> has been designed with highest information security standards, but it doesn't want to fall into the trap previously described, sinning of pride; the designers know that this website is not unassailable, or rather won't be impenetrable forever. Attackers always run twice faster than defenders can do.

That's why it was decided that patients' data, obtained during the research activities carried out within the ACTION project, won't be hosted in the restricted area of the website. Attackers can even follow the Hansel and Gretel's breadcrumbs but they won't find sensitive data.

Ending this article where it started, it can be said that, since its beginning until today, informatics has grown, reaching an unthinkable evolution, so that the common hardware devices we use in our everyday lives (personal computers, notebooks, tablets, smartphones) are more powerful than the whole arsenal of calculators that NASA had when man was sent to the moon for the first time [23, 24]. Our computers, if not kept in security, are real bombs.

Using a familiar language for the ACTION project, that studies aggression in children, our devices are authentic bombs in the hands of kids (in this case we all are the kids). And what happens if we leave bombs in children's hands?

That's why we have taken steps to defuse the bomb giving back to children a toy: a useful, secure and trusted one, helping from our side, the objectives and aims of the project.

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Declaration of interest

The Author declares that there is no conflict of interest.

References

1. Steinbuch K. Informatik: Automatische Informationsverarbeitung. Berlin: SEG-Nachrichten, 1957.
2. <http://www.darpa.mil>, last access: September 2015.
3. Lyon M, Hafner K. Where Wizards Stay Up Late: The Origins of the Internet. New York: Simon & Schuster, 2006.
4. <http://www.theinternetofthings.eu>, last access: September 2015.
5. <http://www.bbc.com/news/technology-31296188>, last access: September 2015.
6. European Commission. Communicating EU Research & Innovation – A guide for project participants, Luxembourg: Publications Office of the European Union, 2012.
7. <http://www.ageofautism.com/2015/01/recent-italian-court-decisions-on-vaccines-and-autism.html>, last access: September 2015.
8. <http://www.skepticalraptor.com/skepticalraptorblog.php/italian-mmr-autism-decision-overturned>, last access: September 2015.
9. <http://www.forbes.com/sites/emilywillingham/2013/08/09/court-rulings-dont-confirm-autism-vaccine-link>, last access: September 2015.
10. Bessi A, Coletto M, Davidescu GA, Scala A, Caldarelli G, Quattrociochi W. Science vs Conspiracy: Collective Narratives in the Age of Misinformation. PLoS ONE. 2015;10(2):e0118093.
11. Anagnostopoulos A, Bessi A, Caldarelli G, Del Vicario M, Petroni F, Scala A, Zollo F, Quattrociochi W. Viral misinformation: the role of homophily and polarization. arXiv. 2014;2014:1411.2893. [Preprint].
12. <http://www.action-euproject.eu/Project>, last access: September 2015.
13. Bacon F. Essays, Chapter 12. Available at: <http://www.literaturepage.com/read/francis-bacon-essays-24.html>, last access: September 2015.
14. <https://www.drupal.org>, last access: September 2015.
15. Eletti V. Che cos'è l'E-Learning. Rome: Carocci, 2002.
16. <http://www.usability.gov>, last access: September 2015.
17. Norman AD. The Psychology of Everyday Things. New York: Basic Books, 1988.

18. <http://impossibleobjects.com/coffeepot-for-masochists.html>, last access: September 2015.
19. Gibson J. The ecological approach to visual perception. Boston: Houghton Mifflin, 1979.
20. <http://www.computerweekly.com/news/4500249354/Italys-Hacking-Team-gets-hacked>, last access: September 2015.
21. <http://www.theguardian.com/technology/2015/jul/06/hacking-team-hacked-firm-sold-spying-tools-to-repressive-regimes-documents-claim>, last access: September 2015.
22. Clusit. Rapporto Clusit sulla Sicurezza ICT in Italia 2015. Available at: <https://clusit.it/rapportoclusit>, last access: September 2015.
23. Kaku M. The Future of the Mind: The Scientific Quest to Understand, Enhance, and Empower the Mind. New York: Doubleday, 2014.
24. http://www.phonearena.com/news/A-modern-smartphone-or-a-vintage-supercomputer-which-is-more-powerful_id57149, last access: September 2015.