

4.1 Final publishable summary report

4.1.1 Executive summary

The project *bid - brains in dialogue* aimed at fostering a true dialogue among key stakeholders on the scope and limits of new technologies in neuroscience and their impact on society. Focusing on brain imaging, brain devices and predictive medicine in brain science, *bid* provided sound and balanced information and encouraged the discussion on the social, ethical and legal implications, involving neuroscientists, clinicians, lawyers, social scientists, philosophers, policymakers, patients and other citizens.

In particular, *bid* aimed to:

- communicate the state of the art of brain imaging, brain devices and predictive medicine;
- discuss the expectations, benefits and risks of new therapies and technologies;
- build constructive discussions on ethical, legal and social issues;
- foster communication among key stakeholders testing novel dialogue formats.

In order to achieve its scientific and communicative mission, *bid*:

- organized international workshops and public events on the three themes of interests;
- managed a press office active at the European level;
- managed the website neuromedia corner.

All activities were built on a collection of materials and contacts updated throughout the project. A selection of news, views, commentaries and peer-reviewed articles was gathered to achieve an overview of the state of the art of brain imaging, predictive medicine and brain devices and the ethical, legal and social implications. A focus on the European situation was reached by the identification of the main projects on the *bid* themes and the leading European Health Structures and Institutes where research on brain science is realised and translated into clinical applications.

In order to foster the interdisciplinary dialogue and test novel formats, three workshops dedicated to each of the *bid* topics were organized in different European locations: the first – *brains in dialogue on brain imaging* – took place in Cambridge, UK, on March 2009, the second – *brains in dialogue on genetic testing* – was organized in Trieste, Italy, in January 2010, the last one – *brains in dialogue on deep brain stimulation* – was held in Warsaw, Poland, in September 2010. Each event finished with a Café Scientifique or Round Table open to the general public in order to foster public engagement on those issues. Thanks to a six month extension, *bid* also organised, in collaboration with the European Science Communication Network (ESConet), a *Training Workshop on Neuroscience Communication* in Trieste, Italy, in June 2011.

A press office activity was aimed at securing an adequate dissemination of *bid* activities to different targets and carrying out the public relation activity. For each workshop, among other initiatives, the press office circulated a press release, edited a special issue for an open-access scientific journal and recorded several video interviews, now also available on neuromediacorner's channel of YouTube.

The material collected throughout the project was uploaded on the website neuromedia corner (www.neuromediacorner.eu), a portal where experts and citizens could find original news, scientific content, video interviews, research centres, events and useful links. The website contained all outcome material related to *bid* activities and also provided media operators with useful and well-founded news and information. In order to increase the visibility of the project and the website and foster the discussion, a Facebook page was also created under the name neuromediacorner with links to the project website or to interesting news, pictures of the *bid* events, comments.

On 6 July 2011 *bid final conference – dialogue to dialogue* took place in Brussels, Belgium, where three and half years of initiatives, workshops, publications about neuroscience and its impact on society were presented and discussed. A true interdisciplinary dialogue on neuroscience is an achievement as crucial as difficult to put in practice and more experiences like *bid* are needed.

4.1.2 A summary description of project context and objectives

4.1.2.1 The context

Health care and technological innovation are key ingredients of contemporary societies and major motors of welfare and economic growth. However, it is widely recognised that society's relationship with science, technology and health is in a critical phase.

Medical science today is promising great developments, but often common people feel uneasy about the rapid pace of advancement of many medical areas. If on one side there is a real necessity for citizens to understand and appreciate the contributions and the limitations of what science and technology can provide for welfare and human health, on the other side there are many barriers hampering an effective communication between the scientific community and the public, starting from an effective contact between scientists, health operators and service users.

Main goal of the *bid - brains in dialogue* project was to build an effective dialogue among key-stakeholders and public engagement in a crucial area of health advancement: brain science, and in particular brain imaging, predictive medicine and brain devices. Advancements in these fields continuously provide new and very valuable information all aimed at understanding how the most vital organ works and how neurological diseases can be treated. However, the public and even scientists are still uncertain about the potential applications of this new knowledge and, as we begin to identify them, we see that they raise significant ethical, social and legal issues.

The latest brain imaging techniques such as functional Magnetic Resonance Imaging (fMRI) and Positron Emission Tomography (PET) are providing new links between metabolic processes occurring in the brain and brain functions. These new technologies are already being tested for early diagnosis of several psychiatric and neurodegenerative diseases and are finding potential applications also outside the laboratories for purposes like lie detection, criminal profiling or marketing.

Brain devices offer a new approach to restore or modulate neural functions that are lost or compromised because of a nervous system disorder, injury or stroke. More than eighty thousand patients worldwide have already received deep brain stimulation in order to alleviate symptoms of treatment-resistant disorders such as Parkinson's disease, essential tremor, chronic pain, epilepsy, obsessive compulsive disorder, major depression and Tourette syndrome. Moreover, brain devices that detect neural activity, commonly known as brain-machine interfaces, promise to allow completely or severely paralyzed individuals to control movements of a variety of prostheses, such as robotic arms, legs and wheelchairs providing an undisputable increase in their quality of life.

The recent availability of high-density genotyping devices allows the identification of the genetic basis of common diseases and is crucial in understanding the interplay between genetic and environmental risk factors in neurodegenerative diseases such Parkinson's or Alzheimer's disease. This approach, based on the screening and analysis of individual genomes, might permit the identification of personalized drugs providing the most appropriate treatment for individual patients and has already lead to the development of many genetic tests for diagnostic or predictive purposes.

The use of these techniques clearly has social, legal and ethical implications. Can brain imaging technologies allow us to read minds, and if so, how should we regulate their use? Can brain devices influence our free will? How should we deal with the privacy issues raised by genetic tests? Such questions cannot be answered by scientists alone as involve people from all walks of life: neuroscientists, clinicians, health operators, service users, philosophers, lawyers, sociologists, policy makers, journalists and other citizens.

4.1.2.2 Detailed objectives

Main goal of the *bid - brains in dialogue* project was to foster a true dialogue among key-stakeholders in neuroscience, including scientists, clinicians, delegates of patients associations, experts of ethical, legal and social issues, science communicators and other citizens. Focusing in particular on brain imaging, predictive medicine and brain devices, *bid* aimed at:

- building qualified groups of scientists willing to discuss on proper scientific bases all the sensitive issues;
- involving the right audience: from brain scientists to clinicians, from health operators to targeted patients' associations and experts in ethical and social issues;
- giving a careful and balanced perspective of possible expectations on the new therapies;
- providing an open and critical evaluation of all risks associated to these new technologies;
- finding the most effective way to communicate this information to the European public;
- building a press office working at the European level;
- providing an accessible web portal where information on predictive medicine in brain science, brain imaging techniques and brain devices can be retrieved.

To reflect its scientific and communicative mission, the project was structured in two overlapping steps.

The objective of the first step was to achieve the first four aims of the above list via:

- data collection of relevant information on predictive medicine in brain science, brain imaging and brain devices;
- organisation of workshops and open forums on predictive medicine in brain science, brain imaging and brain devices.

The data collection was aimed at providing an overview on the state of the art of brain imaging, brain devices and predictive medicine and their impact on society in Europe and identifying contacts among some of the key stakeholders.

The closed workshops and public events were aimed at starting a direct dialogue among key stakeholders to discuss the state of the art, risks and benefits of these technologies. The idea was to guarantee a balance of expertise and cultures in order to take into account the specificity of the different European countries. The public events were the opportunities to open the discussion to lay citizens and foster public engagement.

The objective of the second step was to provide the most effective way to spread the results and the information gathered during the first step through the implementation of the last three objectives of the above list via:

- creation of a press office active at the European level;
- development and management of a website.

The press office was aimed at carrying out the public relation activity at the European level and editing and managing all outcome material related to *bid* activities and initiatives. The project's website was thought of as the main tool of the press office.

4.1.3 A description of the main S&T results/foregrounds

The *bid - brains in dialogue* project employed a range of activities that were implemented in different timeframes, taking into account the scientific and communicative mission of the project.

The main activities were:

- Collection of data and contacts
- Organisation of workshops and public events
- Press office activity
- Development of the project website.

Below is a summary of the results obtained for each activity.

Collection of data and contacts

This activity was functional to the organisation of the following ones. It was aimed at providing an overview on the state of the art of brain imaging, brain devices and predictive medicine and their impact of society in Europe and establishing contacts with some of the key stakeholders.

This was achieved through different approaches:

Literature collection

In order to provide information on the state of the art of brain imaging, predictive medicine and brain devices and foster the discussion on the related ethical, legal and social implications, we have gathered a collection of recent scientific publications, available on neuromedia corner, which was regularly updated.

After a broad literature search, we organized the collection as follows:

- *Key readings* include a choice of sound scientific reviews on the application of brain imaging, predictive medicine in brain science and brain devices. Most reviews have been suggested directly by bid advisory experts, while others, as well as views and research articles, have been identified through a semi-automatic informatics tool and have therefore been selected by the bid team. Chosen reviews focus on topics that are considered particularly new and relevant for society. Offering broader and less technical overviews, reviews were considered interesting for a broader target and have therefore been preferred to original research articles. These references are available on neuromedia corner website within each Scientific Area.
- *Research articles* comprise a selection of peer-reviewed articles that focus on the ethical, social and legal issues related to the latest applications of brain imaging, brain devices and predictive medicine. The references are available in the section Viewpoints of neuromedia corner.
- *Views* contain a selection of commentaries, editorials, opinions and news which foster the reflection on the expectations, benefits and risks of these new technologies on society. The references are available for all stakeholders in the section Viewpoints of neuromedia corner.
- *Guidelines* include a set of guidelines and documents related to brain diseases, brain technologies and brain science published by European and worldwide organizations such as the European Federation of Neurological Societies (EFNS), the European Brain Council, the Council of Europe and UNESCO. The references are available in the section *Community&Links* of neuromedia corner.

European centers for research and clinical applications

A collection of structures and institutes where research on brain imaging, predictive medicine in brain science, and brain devices is realized and translated into clinical applications was realized at the beginning of the project. The data collection was based on a multi-source approach using CORDIS (the Community Research and Development Information Service for Science, Research and Development) as a main resource together with national neuroscience associations and EU leaflets on funded brain research. The list of major research structures and institutes was made available on neuromedia corner under each *Scientific Area*.

Public perception of neuroscience

In order to better plan *bid* activities and initiatives we collected data available on the public perception of neuroscience. Even if some studies on this matter have been carried out at the European level (i.e., Eurobarometers) many gaps still exist. For example, a quite rich literature analyses the persuasive potential of brain imaging, but studies strictly focused on citizens' perception are lacking. In our research, with few outstanding exceptions, we didn't find projects that collected the general public opinion on neuroscience. There are no doubts that interest on brain research is increasing; but if the brain fascination is mounting, a critical look that considers the benefits as well as the risks seems to be absent. Probably because, as some researchers pointed out, the debate on neuroscience applications and their ethical and social consequences is still confined into narrow boundaries, involving scientists, on one side, and communicators, on the other. As we underlined in our report (available on neuromedia corner), the discussion between these two categories is deep and, in some cases, characterized by hard tones. Media communication on brain imaging frequently focuses on basic research (studies on higher order cognition and emotion) leading to a misinterpretation of results and their actual meaning.

Therefore our research focused on the following topics:

- Neuroscience in the media: we analysed some recent cases in which the debate and disagreement between media and scientists, and between scientists too, emerged.
- Scientific researches on neuroscience media coverage: through a scientific literature research we selected and analysed the main researches performed in the last few years exploring neuroscience media coverage (themes, tones, topics, etc.).
- Researches on brain imaging persuasive power: we considered studies dedicated to investigate the persuasive power of brain images on different publics.
- Projects on brain perception: we took into consideration European studies and projects dedicated to brain research perception in the general public. In this sense, the project "Meeting of minds" results as a virtuous example of non-experts' engagement in the debate about neuroscience.

We considered and analysed more than 80 documents, papers and reports, but only the most significant ones were included. The report aimed at giving an overview on the available material on public perception highlighting at the same time the need for further studies and projects that strongly involve citizens in the discussion about the complex topic of brain science. A related paper by Donato Ramani entitled "The brain seduction: the public perception of neuroscience" was published on the Journal on Science communication (JCOM, <http://jcom.sissa.it>).

National Health Contact Points

The list of National Contact Persons of all European State Members in Health was obtained through the CORDIS website. The interaction with them played a crucial role in involving scientists, health operators and patients from different European countries.

National Patients' Associations in Europe

The list of national patients' associations (available on neuromedia corner) was collected starting from the main European and International charities and looking then at a national level. We choose to refer to diseases that are relevant to the *bid* themes. We found that for the original EU members and western EU countries in general, charities are numerous and well organized. The new EU countries show still a gap in this field, the charities being often the result of individual initiatives, with no website and network.

Organisation of workshops and public events

This activity represented the core of the project as the events organised were the opportunity to discuss at an international and interdisciplinary level the scientific and clinical state of the art in brain science and its impact on society and test novel dialogue formats.

Over the three years different types of events were organised on different topics and for different targets. More information on main *bid* events are available on neuromedia corner in the section *bid past events* or through the section *bid reporting*.

Main bid workshops

The first *bid*-workshop *brains in dialogue on brain imaging* took place on 17-18 March 2009 in Cambridge, UK. Over forty participants including scientists, clinicians, lawyers, philosophers, service-users, delegates of the European Commission and the European Brain Council, science communicators and other experts from nine European countries gathered to find a common language and discuss the state of the art of brain imaging and its broader social, legal and ethical implications. The meeting focused in particular on the current applications of brain imaging in psychiatry, a topic that was selected after informal interviews with several experts in the field.

The workshop comprised five sessions and a public event. The first four sessions provided some background information on key aspects of brain imaging: 1) Scope and limits of brain imaging in psychiatric conditions 2) Brain imaging in your life 3) Brain imaging and the law 4) Social and ethical issues in brain imaging. The fifth session included a group activity during which participants had the opportunity to play out the bringing together of all the different types of expertise in informed and deliberative group discussions. Participants were organized in small heterogeneous groups where they could address specific issues in further details, trying to establish a common ground and bring forward concerns and recommendations.

The meeting finished with the Café Scientifique *Can we read minds?* aimed at fostering public engagement on some of the latest applications of brain imaging technologies. In order to attract a good audience, the event was organised at the Michaelhouse Café as part of the [Cambridge Science Festival](#) and the [Brain Awareness Week](#). After brief presentations from the speakers, an active debate with the public started, focusing on the scope and limits of brain imaging technologies for mind reading and their potential use for non-clinical applications like lie-detection.

The second *bid*-workshop *brains in dialogue on genetic testing* was organized in collaboration with Paolo Gasparini of IRCCS-Burlo and University of Trieste and took place at the Adriatico Guesthouse in Trieste, Italy, on 27-28 January 2010. Almost sixty selected participants including scientists, clinicians, patients, sociologists, lawyers, philosophers, science communicators and other experts from fifteen European countries, Unites States and Canada took part in the two-day. The meeting focused on the state of the art of predictive genetic testing and its broader social, legal and ethical implications. Particular attention was dedicated to the current applications for main

neurodegenerative disorders, like Alzheimer's, Parkinson's and Huntington's diseases, which were used as models in the discussion.

The workshop comprised three themed sessions in which background information, research advancements and critical issues related to predictive genetic testing were presented through non-technical talks. More in details the themes of the sessions were: 1) Genetic test and brain diseases 2) Social and ethical challenges 3) Public opinions and personal perspectives.

A facilitated general discussion ended the workshop and preceded the public round table *Health and DNA: my life, my genes*, held at the Scuola Superiore di Lingue Moderne per Interpreti e Traduttori. Focus of the public discussion was the impact of genetic tests on our identity and our health.

The last *bid*-workshop *brains in dialogue on deep brain stimulation* was held at the Polonia Palace Hotel in Warsaw, Poland, on 20-21 September 2010. The meeting, open to about seventy selected participants coming from 25 European and extra-European countries, focused on the potentials and limitations of deep brain stimulation (DBS). As in the previous meetings, great attention was given to the ethical, social, legal implications and to the role of the media. Particular consideration was also devoted to the personal perspectives: the workshop opened with the voices of two DBS patients who gave an account of their personal experiences. Then the meeting comprised two main themed sessions: 1) Potentials and limitations of DBS 2) Social and ethical challenges.

A final session was dedicated to a discussion game, built on the model of the "discussion continuum" (www.at-bristol.co.uk/cz/teachers/Default.htm), involving speakers and audience. Divided in groups of 8-9 people, the participants were invited to debate about a list of statements covering some critical aspects of deep brain stimulation. In a half an hour every group had to order the statements in a range comprised between "I agree" and "I disagree". The groups' rankings were then discussed in a plenary session in order to analyse the differences and similarities. Despite the initial scepticism, most of the participants enjoyed this format of discussion which was a great opportunity for all to express their thoughts and points of view.

The discussion was opened to the public with the Café Scientifique *Brain, machine and something in between* which took place at the Café Skwer as part of the Warsaw Science Festival. The animated debate focused on the state of the art and the ethical implications of deep brain stimulation and brain machine interfaces.

A report of each workshop is available on neuromedia corner together with articles, presentations and video interviews. An evaluation form was collected and analysed after each major event to collect suggestions and better tune following events.

Training workshop

Thanks to the six month extension, the *bid* team also had the opportunity to organise, in collaboration with ESConet, the European Science Communication Network, a *Training Workshop on Neuroscience Communication* which was held in SISSA (Trieste, Italy) on 20-22 June 2011.

The course gave the opportunity to young neuroscientists and researchers interested in the social, ethical and legal implications of neuroscience to improve their communication skills and understand the media logic. Led by three trainers, the course included five modules which made use of examples from neuroscience. Seventeen trainees from twelve European and non-European countries attended the workshop. An evaluation form was collected after the meeting and some of the trainees' comments are available on neuromedia corner.

Public events

In order to further foster public engagement in neuroscience, *bid* also organized public events which were not directly connected to the workshop activity:

- On 20 April 2008, the round table *A market for genetic tests?* which was part of the Second edition of the International Science Media Fair (FEST) in Trieste. The event addressed the risks and benefits of genetic tests and the ethical, social and legal implications of commercialized tests.
- On 24 March 2009, the round table *Imagine the mind*, which was also part of the Brain Awareness week in Trieste. Scientists, delegates of patients' associations and citizens discussed the promises of neuroimaging for earlier detection of Alzheimer's disease and their practical and ethical implications.
- On 8 April 2009, the round table *Biology of Freedom: Neural Plasticity, Experience, and the Unconscious* in Trieste where neuroscientist Pierre Magistretti and psychoanalyst François Ansermet discussed the possibility of a fruitful dialogue between neuroscience and psychoanalysis.
- On 3 July 2010 in Turin, Italy, the panel discussion *When the final hour comes: End of life care, ethics, costs, and the role of the media* as part of the Scientific Programme of Euroscience Open Forum (ESOF) 2010. The event addressed the critical issues related to life-prolonging treatments involving scientists, clinicians, philosophers and journalists and fostering a public debate on the ethical, legal and practical questions.
- On 27 June 2011, in Trieste, the public conference *Genes and environmental cues in brain construction* with neurobiologist Yehezkel Ben-Ari of the Institut de Neurobiologie de la Méditerranée, Marseille, France.

Final conference

bid final conference – dialogue to dialogue was organised at the Stanhope Hotel in Brussels, Belgium, on 6 July 2011.

It was an opportunity to present three and half years of initiatives, workshops, publications about neuroscience and its impact on society and discuss the main outcomes through the voices of previous *bid* events' participants. Key challenges and potential approaches were also analysed together with keynote speakers from the European Commission, the European Dana Alliance for the Brain (EDAB) and overseas.

The conference, open to the public, comprised two main sessions: 1) The *brains in dialogue* project – *bid* 2) Neuroscience: challenges and strategies in Europe and beyond.

About forty participants attended the conference and contributed to a lively debate on the key role of different stakeholders in neuroscience and the crucial importance of developing a true dialogue among them. Participants included some of previous *bid* workshops' attendees, members of the European Commission and other organisations from Brussels.

The public conference was preceded by an afternoon of closed discussion involving twelve previous *bid* workshops' participants, two delegates of the European Commission, a delegate of the European Dana Alliance for the Brain and a bioethicist from the University of Calgary. The participants were asked to share their thoughts about the importance of dialogue and the way to proceed forward. This discussion was preparatory to a group activity aimed at suggesting potential topics and approaches to improve the dialogue between neuroscience and society.

Press office activity

The press office played a crucial role for the communicative mission of the project. It was responsible for carrying on the public relation activity, promoting *bid* activities, editing and disseminating the outcome material, handling the scientific and lay material collected. Main tool of the press office was the project's website neuromedia corner (www.neuromedia.eu).

Promotional activity

Because of the interdisciplinary nature of the project, the *bid* team established contacts with different key stakeholders in the field of neuroscience, including researchers, clinicians, delegates of patients' associations, science journalists. The public relation activity started at a local and national level to broaden throughout the project to a European level. In particular, crucial contacts were established with several European patients' associations, the European Union of Science Journalists' Associations (EUSJA) and the European National Contact Points for Health.

bid press office built themed mailing lists after each workshop and a mailing list of science journalists working for some of the most important media in Europe. These were used to disseminate press releases and promote *bid* activities. The different events and initiatives were covered by press articles, radio and even TV programmes at the national and international level. A section named *Press Room* was also created on the project's website to provide informative material for the Media. Moreover the team attended several international conferences to present the project and meet relevant stakeholders. In occasion of ESOF2010 it also prepared a bookmark with information on the project and website to distribute during the activities.

Management of scientific and lay literature

The team developed and used an informatics tool to collect, select or reject for publication (on the website) scientific and press articles on predictive medicine, brain imaging and brain devices, published by selected European and non-European scientific publishing groups and the press. The tool was based on RSS (Real Simple Syndication) protocols and required the indication of some keywords which were then used to retrieve the news.

On average the tool allowed collecting 20/day press stories for each of the *bid* themes from online newspapers and portals (e.g., BBC, New York Times, Physorg.com, Wired News). This were filtered to a number of 0-5 news/day on the basis of their scientific relevance, the grade of innovation of the research described, their impact on health and on society, and, in some cases, their originality.

Among the scientific papers collected, reviews were mainly selected for publication, if considered interesting for a broad target and approved by the advisory experts.

Outcome material

In order to continue the dialogue started during the workshops' activity, the press office edited written and audio-video material which was then made available on the project's website. A reporting section was created within each *Scientific Area* containing material produced by the *bid* team as well as by some of the workshops' participants.

About 10 video interviews were conducted during each workshop. After editing and approval by the interviewees, these were uploaded every couple of weeks on neuromedia corner and its YouTube channel, in order to establish a *fil rouge* with the visitors and not create confusion with too much information.

A report with pictures, comments and evaluation results was also published after each meeting. Moreover three communicative sets concerning the *bid* themes were prepared using the material collected and were uploaded and made available on the website for patient's associations, research institutes, health operators and key stakeholders.

The *bid* team edited three special issues on open-access scientific journals with mini reviews, perspectives and opinion papers from some of the workshops' participants offering different perspectives. A Research Topic entitled "Emerging issues in brain imaging: a multidisciplinary dialogue", edited by Stefano Cappa (Vita-Salute San Raffaele University, Milan, Italy) and Chiara Saviane (*bid* staff, SISSA, Trieste, Italy), was published on [Frontiers in Human Neuroscience](#) after

the first workshop. A special issue for the [Genomics, Society and Policy Journal](#) related to the second *bid* workshop is currently being finalised. Because of a delay in the papers' harvesting and a long refereed procedure, the special issue has not been published yet but should be within a few months from the end of the project. Finally, after the third workshop, Chiara Saviane (*bid* staff, SISSA, Trieste, Italy) and Thomas Schlaepfer, University Hospital of Bonn, Germany, and the Johns Hopkins University, USA, edited a Special Topic for [Frontiers in Integrative Neuroscience](#) entitled "The development of deep brain stimulation for neurological and psychiatric disorders: clinical, societal and ethical issues".

Few articles for scientific or lay magazine were also published: "You read my mind" by Chiara Saviane on The Parliament Magazine's Research Review (May 2009), "The brain seduction: the public perception of neuroscience" by Donato Ramani on the Journal on Science communication (October 2009), "Genetic tests: between risks and opportunities" by Chiara Saviane and Donato Ramani (*bid* staff) on EMBO reports (December 2010). Moreover an article signed by Donato Ramani and Chiara Saviane entitled "Neuroscience: experience of an interdisciplinary dialogue" was published on December 2010 on the PCST 2010 proceeding.

All major *bid* publications were distributed on USB keys during the final conference after receiving editors' permission.

Website management and development

An essential tool for achieving the communicative mission of the project was the website neuromedia corner (www.neuromedia.eu), a portal dedicated to brain imaging, brain devices, predictive medicine in brain science and their applications. Its main objective was to build a legacy of experience, knowledge and answers accessible by the larger scientific and clinical community, health operators, citizens, patients and everyone else, and to provide media operators with useful and well-founded news and information.

The *Home Page* was structured as a journal-like homepage, containing a selection of four news, each accompanied by a picture. This choice responded to the idea of presenting a lively website, where the reader could find immediately something new to be attracted by.

Different sections were made also available on the first level.

An information area level, called *Scientific Areas* and a multilevel structure for the three different *bid* topics: brain imaging, brain devices and predictive medicine. Each theme level comprised a section called *Key Readings* containing a selection of sound scientific reviews on the theme, and a section called *Centers* with a list, divided by country, of the main European research centers in the field and a link that referred to their homepage. Each *Scientific Area* was completed with a section on the workshop's outcomes (presentations, interviews, reports and a complete communicative set with text and video files): the sections were named *bid on brain imaging*, *bid on dbs* and *bid on genetic testing* respectively.

The *News* level offered a collection of news ranging from original *bid* products (e.g., original articles, written/video interviews) to news retrieved via the informatics tool previously introduced which allowed collecting, press news, press releases and posts from different online sources, bibliographical databases, online newspapers and blogs. Few news were selected for publication on the *Home Page* which was updated at least once a week, while the *News* section was updated more frequently, depending on the news collected.

The section *Viewpoints* was instead focused on the ethical, legal and social issues related to the bid topics. It included both peer reviewed articles (*Research articles*) and news (*Views*) items that comment on and analyse how brain science innovations could affect the evolution of society in an unprecedented manner and, conversely, how society changes the image of science and technology and influences their development.

The *Events* level offered a list of upcoming events related to the *bid* themes with a brief description and a link to the event page. The upcoming *bid* events were also announced on the second level of the section, as well as on the *Home Page*. In the final configuration of the website all *bid* past events were grouped under the section *events-bid past events*.

The section *Community&Links* was mainly targeted for patients and lay readers offering a list of European and national *Patients' associations*, useful *Links* and a selection of *Guidelines* related to brain diseases, brain technologies and brain science published by European and worldwide organizations.

The section *Press Room* provided journalists with informative material: the level *Media Resources* included information on the *bid* project in general and on *bid* activities, while in the *Press Releases* section journalists could access all *bid* press releases and register to the press mailing list.

In order to increase the visibility of the project and the website and foster the discussion, a Facebook page was also created under the name neuromediacorner with links to the project website or to interesting news, pictures of the *bid* events, comments.

The target audiences for the website ranged from neuroscientists to social scientist, to journalists and EU media, to patients and relatives, to institutions and the general public. Thus the *bid* team made use of different methods/tools to promote the neuromedia corner website: press releases, *bid* events, direct public relation activity, publishing and new media.

The website was regularly updated throughout the project and will be kept online for at least another two years to give access to the material collected.

4.1.4 The potential impact and the main dissemination activities

4.1.4.1 Potential impact

The *bid – brains in dialogue* project had the ambition to foster a true dialogue among key stakeholders in neuroscience and more specifically in brain imaging, brain devices and predictive medicine. This mission turned out to be as important as challenging to put into practice. An important step forward has been made but more initiatives like this one are needed.

The project's activities involved a very broad spectrum of stakeholders, including neuroscientists, clinicians, philosophers, sociologists, lawyers, delegates of patients' associations and industry, policy makers, science communicators and lay citizens, all with different interests, priorities and expectations.

The potential impact achieved varied with the nature of the activity and the type of involvement.

The highest impact was most likely reached with those stakeholders taking part in the three interdisciplinary workshops organised. They were given the opportunity to interact with experts from different disciplines for two days, through talks and activities but also over meals and free time in order to create an informal environment and create connections. From the evaluation forms collected, most of the workshops' participants enjoyed the opportunity of being part of such interdisciplinary and international debates even though the discussions in the lecture room clearly showed that many obstacles still persist for a true multidirectional discussion. Even though the debate was lively, not all stakeholders were equally involved at all stages.

The impression shared by some of the participants is that sociologists, patients, philosophers and other stakeholders are very interested in listening to scientists and learning from them, but the opposite is less true. Indeed scientists and some of the other stakeholders are mainly used to work and talk into a well-defined field of competences and in some cases the discussion was hampered by the use of technical terms that were not understandable to everybody. Despite the different levels of interest or scepticism, however all attendees were exposed to different perspectives and made a first step to the realisation of an open dialogue. In particular all attendees appreciated the involvement of patients and service-users and were surprised by the use of participatory activities and new dialogue formats.

Most participants expressed the will to repeat the experience and reproduce some of the activities in their own institutes or organisations. Moreover, those invited to contribute to outcome material were really enthusiastic to do so. These were very important achievements to make the interdisciplinary dialogue continue and improve after the end of the meeting.

Lay citizens were reached indirectly through the different communication activities and, directly, through several public events. The success of the latter initiatives strictly depended on the location and context in which they were collocated. The presence of the Café Scientifiques organized in Cambridge and Warsaw in the programme of the local Science Festivals allowed a wider and more enthusiastic participation, involving a wide number of young people. The experience turned out to be rewarding also for the speakers, who enjoyed the interaction and hopefully appreciated the importance of establishing a two way communication with the civil society.

A different level of impact was achieved with the several communication activities realised through the press office and the website. These allowed reaching the enlarged community interested in the *bid* topics and not just the representatives of the key-stakeholders attending the workshops. Different targets were reached through different initiatives, from researchers, to clinicians, patients, science journalists, policy makers or lay citizens.

The website itself offered a broad range of material. Most sections were targeted to all key stakeholders and lay citizens including the *News*, *Views*, *Events* and the list of *Research centres*. The key readings in the *Scientific areas* were mainly thought for scientists and clinicians even though reviews rather than research articles were chosen on purpose to make them more approachable by non-experts. The section *Community&Links* was targeted to the civil society and patients while the *Press Room* provided useful information and material for the media.

The *bid reporting sections* provided all the outcome material produced and collected after each main workshop. The aim was to foster the continuation of the dialogue started during the meeting summarising the topics covered and introducing some issues to discuss.

A full report with an analysis of the evaluation forms collected was provided together with all presentations from the speakers for those who could not attend the meeting.

A set of video interviews and press articles were edited to reach the civil society but also provide some educational material which became part of focused communicative sets on each topic. All video-interviews were also uploaded on the neuromediacorner's channel of YouTube to make the video more accessible and interesting for lay surfers.

To mainly reach and move the community of neuroscientists two special issues were edited for *Frontiers for Human Neuroscience* and *Frontiers for Integrative Neuroscience*. The issues included contributions from all stakeholders, including sociologists, lawyers, delegates of patients' association or industries in order to provide an interdisciplinary and unusual perspective for the Journal. The combination of mini reviews, perspectives and opinion papers and the publication on open-access journals was aimed at making the material accessible for lay readers too.

In order to increase the visibility of the project and the website and involve the younger generation, a Facebook page was also created under the name neuromediacorner with links to the project website or to interesting news, pictures and videos of *bid* events.

Overall it seemed clear that, with some exceptions, younger generations are more interested and open to an interdisciplinary dialogue and therefore future efforts should be focused on raising awareness and broadening the perspectives of young adults and researchers. Moreover, new forms of interaction, from participatory activities to digital communication, seem to be the most effective approaches to promote this type of "uncomfortable" debate.

4.1.4.2 Impact of the *bid* project at a National and European level

The implementation of the *bid* project started at a local and national level through the organisation of small local interdisciplinary meetings and the exploitation of the national contacts. Throughout the project the team broadened its contacts to a European level involving experts from the scientific community, clinicians, delegates of European patients' associations and industries, science journalists from international media.

The three main workshops were organised in different European countries – UK, Italy and Poland - to foster the participation of delegates from different member states. Speakers were chosen on the basis of their expertise, interest in the interdisciplinary dialogue and nationality in order to involve delegates of different European countries. Participants were restricted in number to allow an easier debate. They were always selected in order to guarantee a balance and variety of expertise and cultural background. Thanks to the experience acquired and the broader net of contacts established, the attendance to the workshops increased throughout the project. We had around 40 attendees from 9 European countries for the first workshop, 60 attendees from 15 European and non-European countries for the second and 70 attendees from 25 European and non-European countries for the last one. A great support in contacting the different national scientific communities was given by the Health National Contact Points which allowed promoting the events in different national universities, research centres and universities.

Each workshop finished with a public event that allowed us to raise public engagement on brain related issues and promote the project in the different countries. The opportunity and effort to be part of local Science Festivals turned out to be particularly successful to guarantee a good and active participation and reach in particular university students.

The press office worked to create a net of European journalists which were always informed of *bid* activities and, in some cases, had the opportunity to attend one the workshops as speakers, chairs or part of the audience. This allowed some of the *bid* activities to be covered also on international press or radio programmes and thus reach the civil society. A crucial contact to this purpose was the European Union of Science Journalists' Associations (EUSJA) which helped promoting *bid* events among its members.

In order to reach different stakeholders at the European and National level an intense public relation activity was also established with some of the European patient's associations and many of the European organisations related to brain science, such as FENS, EFNS, EDAB etc. These organisations were always contacted for promotional activities and also for support in identifying key stakeholders. Moreover the *bid* team also participated to several national and international conferences, such as the 10th and 11th International Public Communication of Science and Technology Conference (PCST), which were important occasions to develop face-to-face public relations and present the *bid* project.

4.1.4.3 Dissemination activities

As previously explained, the main goal of the *bid* project was to foster dialogue among key stakeholders in neuroscience and in particular:

- communicate the state of the art of brain imaging, brain devices and predictive medicine;
- discuss the expectations, benefits and risks of new therapies and technologies;
- build constructive discussions on the ethical, legal and social issues;
- foster communication among key stakeholders testing novel dialogue formats.

In order to achieve its scientific and communicative mission, *bid*:

- organized international workshops and public events on the three themes of interests;
- managed a press office active at the European level;
- managed the website neuromedia corner.

Thus the core activities of the project can be considered as dissemination activities even though they were targeted to different publics (See Section A2 below).

The organisation of workshops and public events over the three *bid* themes were aimed at communicating sound scientific information and foster the discussion on the ethical, legal and social implications of new technologies in brain science. These activities were targeted to all key stakeholders including the civil society.

The press office was in charge of carrying on the public relation activity to promote the project but also of producing and managing different types of communication materials targeted to different stakeholders.

Before each major event the team edited and circulated at the international level a press release which lead to the publication of some press articles on the Italian press and the participation of a team member to radio programmes. In occasion of ESOF2010 it also prepared a bookmark with information on the project and website to distribute during the following activities. The participation to different national and international conferences, in particular, was also used for promoting the project and establishing new contacts.

After the three major workshops the *bid* team edited different types of written and video material which were then made available on the website. This included reports, video interviews (also available on neuromediacorner's channel of YouTube), communicative sets, articles for scientific and lay magazines, special issues on open access scientific journals containing mini reviews, perspectives and opinion papers from different stakeholders. Additional press articles and radio programmes were produced by some of the European science journalists attending the meeting.

All major *bid* publications were distributed on USB keys during the final conference after receiving editors' permission.

The project website was the main tool of the press office for its promotion and dissemination activities providing a selection of news, views and scientific reviews which were considered particularly relevant and new in the field of brain imaging, brain devices and predictive medicine. It presented themed reporting sections containing the outcome material from each workshop in order to spread the results of the debates and the success and criticalities of the formats tested. Most of the material proposed was targeted to a broad public with few sections mainly focused for neuroscientists, academics, patients or the media. A Facebook page and a YouTube channel were also created to give visibility to the project and more easily involve the younger generations.

4.1.5 The address of the project public website and relevant contact details

Project website: neuromedia corner <http://www.neuromedia.eu>

E-mail: bidinfo@neuromedia.eu

Project coordinator: Prof Vincent Torre

E-mail: torre@sissa.it



The *bid* team:

Chiara Saviane E-mail: saviane@sissa.it

Donato Ramani E-mail: ramani@sissa.it

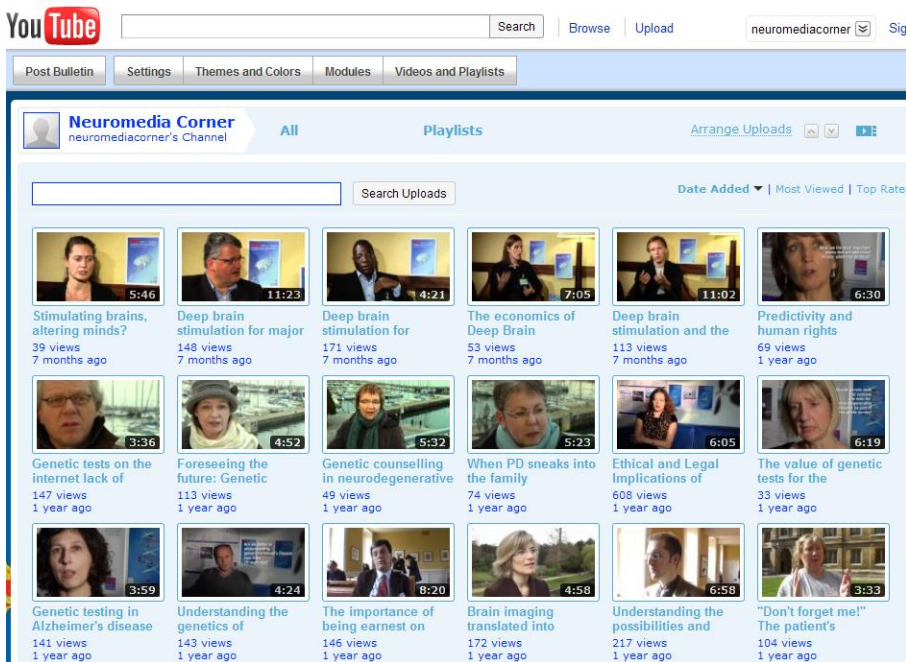
Emiliano Feresin E-mail: feresin@sissa.it



A snapshot of the website homepage (www.neuromedia.eu)



A snapshot of the Facebook page (<http://www.facebook.com/neuromediacorner>)



A snapshot from the neuromediacorner's channel on YouTube (<http://www.youtube.com/user/neuromediacorner>)



Cambridge, UK; 18 March 2009
Can we read minds?



Trieste, Italy; 29 January 2010
bid workshop brains in dialogue on genetic tests



Warsaw, Poland; 21 September 2010
bid workshop brains in dialogue on deep brain stimulation



Brussels, Belgium; 6 July 2011
bid final conference – dialogue to dialogue