

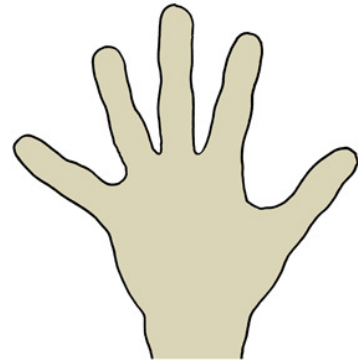
PROJECT DELIVERABLE

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Navigate and Develop Socially

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Summary:

This deliverable reports on the establishment of the Ethics Board within the Hands-project and on the activities of the board during Year 3 of the project period.

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Overview

The function of the Ethics Board (EB) is described in section 2.1.4 in the Description of Work approved by the Commission (Appendix A). This Annual Report reports on the activities of the EB during Year 2.

The EB has been supported administratively by the main project partner AAU who has allocated Dr. Thomas Ploug, an expert in IT-Ethics to act as the secretary to the EB.

The membership of the EB has not changed in Year 3.

Meetings and other activities

The EB has not held any meetings, but have discussed one project application via Moodle.

The Chair of the EB has held two meetings with the Project Co-Ordinator.

Discussions and approvals

During year 2 the EB had a general discussion about introducing a GPS functionality in HANDS and outlined a set of general guidelines that should guide the implementation:

“GPS functionality

In relation to GPS activated functionalities the EB sees an important distinction between continuous logging of GPS data, and location specific activation of functionalities with discrete logging of data concerning the activation. Continuous logging potentially infringes spatial privacy in significant ways.

The EB further discussed who should have access to activation data and decided that a policy should be developed for each participating school.

In discussion with the consortium the EB developed the following principles for ethical use of GPS in the HANDS toolset:

1. Continuous logging of GPS data should not be implemented in the HANDS toolset

2. GPS controlled activation of HANDS functionality should be negotiated with users and only be used with consent from both users and parents
3. Location specific logging of GPS data should only be activated in cases where a functionality is activated, it should not be used for monitoring whether a user visits an 'undesirable' location
4. Each school should adopt an explicit policy concerning parents' possibility to request specific information about logged GPS information. This policy can be either:
 - a. Teachers can disclose logged GPS information to parents, but only if the parents specifically request such disclosure
 - b. Teachers cannot disclose logged GPS information to parents if the parents specifically request such disclosure

The policy should apply across the school to all users and parents."

In Year 3 a specific proposal was put forward to implement a GPS functionality that checks whether a user was present at the location of the School at the beginning of the School day.

The EB judged this proposal against the previously agreed general guidelines and approved it.

Appendix A – Description of the Ethical Board in the approved “Description of Work”

The Ethical Board (EB)

As part of the HANDS project an Ethical Board (EB) will be established. The board will follow the practical system development as well as the empirical sub-projects in HANDS from beginning to end. In order to do so, it is essential that the members of the Ethical Board include

- i) respected members of the scientific community and industry, without violating any IPR or regulations in the CA,
- ii) specialists in the care and the education [of] children and young people with ASD,
- iii) persons qualified in computer ethics and ethical theory in general,
- iv) persons representing the interests of the young people with an autism diagnosis and their families,
- v) members independent of the research within HANDS.

EB should consist of 6-8 members elected by the HANDS project leader and the chairman of EB in agreement. The chairman of the EB will be Professor Søren Holm, Director of the Centre for Ethics, Law and Society, Cardiff University (see CV in Appendix I).

All partners will be asked to propose persons to be considered for membership of the EB. The members will be appointed by the chairman of the EB and the project coordinator in cooperation.

It will be the responsibility of EB to

- i. discuss general ethical questions related to HANDS
- ii. discuss and ethically evaluate the system requirements of the systems which are supposed to be tested and used by children and young people with an autism diagnosis
- iii. discuss and ethically evaluate all clinical tests involving children and young people with an autism diagnosis (including practical plans and questions regarding consent).

The EB is supposed to report all discussion and evaluations to the coordinator of Hands. In addition there will be an annual report from EB.

There will be separate EB meetings organised by the Project Management in cooperation with EB chairman. In addition, the members of the EB will be invited to the general project meetings. EB is expected to hold 3-4 meetings

through the project. The Project management will provide secretarial assistance for the EB meetings. The minutes from the EB meetings including all advices regarding tests and experiments will be sent to the Project Management who will take further action.

EB should during the entire project period carry out a constructive dialogue with the members from the groups involved in the “hands on” practice and with the HANDS researchers working with ICT ethics.

All partners are supposed to describe all ethically relevant problems in a format which makes it possible to discuss the problems at the EB meetings. In some cases EB will probably also be able to discuss the problems over e-mail or using video conferences. In particular, all clinical tests involving young people with an autism diagnosis should be presented and approved by EB before they are carried out. All decisions made by EB on ethical issues must be followed by the consortium members. In question of doubt the project board makes the final decision.

In case of clinical trials and experiments involving young people with an autism diagnosis the responsible researchers will be asked to report to EB. In particular, it will be important that all ethically relevant events during the empirical research are reported.

The members of EB monitor the global trends in their fields, and the tasks of the EB is to provide HANDS / the Commission with a brief yearly review of the project, to focus on the long-term vision of the project and to make strategic recommendations to the project management board. The EB will in addition to this, oversee the implementation of the projects activities with regards to the research, networking of researchers, dissemination of information and exploitation of results as well as the integration of these four components. It is envisioned that the EB on top of their formal tasks also will provide HANDS with more informal advices.

Appendix B – overview of relevant research regulation in the countries involved in HANDS

The HANDS project raises a number of ethical issues that have been discussed extensively in the HANDS Ethics Board. The table in this appendix provides an overview of whether and how HANDS research is legally regulated in the countries involved in HANDS.

Because the research is not health related it falls outside the scope of national implementations of the Good Clinical Practice Directives (Directive 2001/20/EC & Directive 2005/28/EC); and also outside of the scope of the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS 164) and its protocols¹. This means that the research is not subject to approval by the research ethics committee systems set up to handle biomedical research in any of the four countries involved in the project.

	Is research ethics committee approval required?	Is parental consent required? <i>On the assumption that the young person is legally a minor</i>	Is consent from the young person required? <i>On the assumption that the young person is legally a minor</i>	What are the regulatory implications of the research participants having autism-spectrum disorder?	What are the regulatory implications of the research taking place in a school setting?
Denmark	No	Yes, in accordance with the national implementation of the Data Protection Directive (Directive 95/46/EC) because the project collects personal data	No legal requirement. Obtaining assent is standard practice.	No specific regulations	No specific regulations. As gatekeepers the school leadership have to act with the interests of the children as the paramount consideration
Hungary	?	See above	?	?	

¹ This Convention has been signed and ratified by Denmark and Hungary, signed but not ratified by Sweden, and not signed by the United Kingdom

Sweden	No	See above	No legal requirement. Obtaining assent is standard practice.	No specific regulation	See above
United Kingdom	No legal requirement, but UK universities require staff to seek REC approval	See above	No legal requirement, but a competent minor can consent independently. Obtaining assent is standard practice.	No specific regulations	See above