

ANNEX I DESCRIPTION OF THE ACTION

1. OVERVIEW

1.1. Title

Institutional Treatment, Human rights and Care Assessment

1.2. Priority area and action

3. Health Determinants (HD2006)

3.2.4 Integrative approaches on lifestyles and sexual and reproductive health: mental health

1.3. Summary (objectives, methods, expected results)

Overview

ITHACA will identify and disseminate best practice to improve the protection of human rights and dignity, and the general health status of residents in health or social care institutions with mental ill-health, mental disability or dependency.

General objectives:

- (i) establish a European network of 15 sites committed to these actions
- (ii) pilot and finalise a usable method of assessing best practice in institutional settings in relation to (a) human rights and dignity, and (b) general health status
- (iii) ensure that these methods are suitable for wider EU use
- (iv) gather comprehensive data at the national and the local levels on factors necessary to ensure that practice is (a) brought up to minimally acceptable levels, and (b) then subject to continuing quality improvement.

Main outcome:

use multiple channels of knowledge transfer to successfully make the results of this project available to all those able to benefit from them in EU member states and in pre-accession states, including the Council of Europe, Commission services and all other key stakeholders with the involvement of the operators of national institutions and authorities.

2. OBJECTIVES

2.1. General objectives

This bid is in response to the follow call: *To identify and disseminate best practice to improve the protection of human rights, the dignity and the general health status of residents in health or social care institutions with mental ill-health, mental disability or dependency.*

There is widespread concern that conditions for many people with mental ill health, mental disability or dependency in institutions in Europe fall far short of standards compatible with agreed human rights treaties and conventions, and do not consistently prevent abuse. The ITHACA project will document the factors necessary to create and successfully implement policy to promote the human rights, dignity and general health status of residents in such institutions, both adults and children, based upon the best available evidence and experience.

The overall *primary strategic objective* of this proposal is to contribute to the improvement of conditions in institutions in Europe for people with mental ill health, mental disability or dependency, and to communicate these findings to all relevant stakeholders.

Our *methodological approach* is to do this by systematically identifying, collecting and disseminating information on the best known methods to provide such care. We shall carry out this work at both national level (or regional level where appropriate in federated states) and local level, as set out in detail in Section 4, including close communication with the operators of national institutions and authorities. The implementation of the project will consider checking on similar projects in order to avoid any overlap and to share any relevant crosscutting aspect.

Our *general objectives* are to:

- (i) establish a pan-European network of sites committed to action to improve the quality of care related to mental health institutions
- (ii) pilot and finalise a practical method of assessing best practice in institutional settings in relation to (a) human rights and dignity, and (b) general health status
- (iii) ensure that these methods are suitable for wider, future use throughout EU via an effective dissemination strategy for the project results to maximise the policy impact of the work in the context of the Green Paper 'Promoting the mental health of the population. Towards a strategy on mental health for the EU' (COM(2005) 484 final of 14 October 2005).

Our *strategic objectives* are to:

- (i) use these assessments to gather comprehensive information at the national and the local levels on what factors are necessary to ensure that practice is (a) brought up to minimally acceptable levels, and (b) then subject to continuing quality improvement
- (ii) use multiple channels of knowledge transfer to successfully make the results of this project available to all those able to benefit from them in EU member states, including the Commission services, and in pre-accession states, and
- (iii) to create a method of institutional assessment that can be used on an ongoing way in the future to assess whether care standards are improving as intended or not, and to support with evidence future recommendations for policy enhancement in this area of health and social care.

2.2. Specific objectives

The specific objectives and their relation to the 5 Workpackages described are:

Objective 1. Establish and manage an effective pan-European network committed to identifying and disseminating knowledge across the whole European region on good practice in the institutional care of people with mental health related disabilities (see Workpackage 1).

Objective 2. Complete a carefully co-ordinated dissemination process to ensure that the knowledge generated by this project is successfully made available to all those able to benefit from it across the European region (see Workpackage 2).

Objective 3. Conduct a detailed evaluation of the ITHACA project to determine how far it successfully meets its objectives and to establish learning on how such projects can be more effectively carried out in future (see Workpackage 3).

Objective 4. To establish a pragmatic and widely usable method to assess good practice relating to human rights and dignity at the national and at the local levels in relation to the improvement of conditions in institutions in Europe for people with mental ill health, mental disability or dependency and to use this method to assess good practice in this domain (see Workpackage 4).

Objective 5. To establish a pragmatic and widely usable method to assess good practice relating to general health status at the national and at the local levels in relation to the improvement of conditions in institutions in Europe for people with mental ill health, mental disability or dependency and to use this method to assess good practice in this domain (see Workpackage 5)

These objectives will be achieved by the practical steps set out below, and from the substantive content of the data gathering in WP4 and WP5. The overall strategy will be implemented by paying close attention to the following cross-cutting **Core Themes**:

Core Theme A. Detailed identification of the relevant **legal** framework concerning:

- Disabled persons and discrimination acts
- Incapacity
- Guardianship
- Laws which are discriminatory
- Legal provisions relating to health promotion, illness prevention and access to care

Core Theme B. Detailed identification of the relevant **policy** framework concerning:

- Policies which formally promote discrimination
- Policies which aim to reduce discrimination against disabled persons
- The protection of disabled persons in relation to involvement in research
- the Green Paper 'Promoting the mental health of the population. Towards a strategy on mental health for the EU' (COM(2005) 484 final of 14 October 2005).

Core Theme C. Careful attention to the necessary framework for proper **reporting, governance and accountability** between the relevant national (or regional) and local responsible authorities, including a continuous link with the Commission services, and with the Council of Europe, all other key stakeholders with the involvement of the operators of national institutions and authorities.

Core Theme D. Attention to the relevant conditions necessary for **effective inspections** of institutions including:

- Setting of effective care standards
- Lines of accountability for inspectorates.

2.3. Indicators chosen

By indicators we mean variables which allow measuring of performance, and of success of the results, i.e. the quality of the deliverables, the completion of the deliverables, and their usability by wider target groups.

Task: Objective 1. Establish and manage an effective pan-European network committed to identifying and disseminating knowledge across the whole European region on good practice in the institutional care of people with mental health related disabilities (see Workpackage 1).

Indicator: Successful establishment of fully functioning ITHACA network (12 months)

Objective 2. Complete a carefully co-ordinated dissemination process to ensure that the knowledge generated by this project is successfully made available to all those able to benefit from it across the European region (see Workpackage 2).

Indicator: Completion of ITHACA webpage (12 months), Dissemination Strategy (24 months) and EU media launch of results (36 months), in association with key operators and via continuous link with Commission services. The Expert Advisory Group acts a peer review and monitoring function to ensure quality and timely completion of these deliverables.

Objective 3. Conduct a detailed evaluation of the ITHACA project to determine how far it successfully meets its objectives and to establish learning on how such projects can be more effectively carried out in future (see Workpackage 3).

Indicator: Completion of interim evaluation (18 months) and final evaluation (36 months). The Expert Advisory Group acts a peer review and monitoring function to ensure quality and timely completion of these evaluation reports.

Objective 4. To establish a pragmatic and widely usable method to assess good practice relating to human rights and dignity at the national and at the local levels in relation to the improvement of conditions in institutions in Europe for people with mental ill health, mental disability or dependency and to use this method to assess good practice in this domain (see Workpackage 4).

Indicator: Completion of human rights and dignity assessment schedule (18 months). The Expert Advisory Group acts a peer review and monitoring function to ensure quality, usability, and timely completion of the method.

Objective 5. To establish a pragmatic and widely usable method to assess good practice relating to general health status at the national and at the local levels in relation to the improvement of conditions in institutions in Europe for people with mental ill health, mental disability or dependency and to use this method to assess good practice in this domain (see Workpackage 5).

Indicator: Completion of general health status assessment schedule (18 months). The Expert Advisory Group acts a peer review and monitoring function to ensure quality, usability, and timely completion of the method.

2.4. Rationale and relative merits of the project

State of the Art in the Area

European Policy Context. In Europe only 55% of States have a national mental health policy, while mental health legislation has been enacted within 74% of countries in the European region in the last decade. In some countries mental health laws are at least 40 years old. In particular there are no effective policies across Europe to ensure that people with mental disorders are treated with equality in terms of physical health care. Specifically the ITHACA project supports the Green Paper 'Promoting the mental health of the population. Towards a strategy on mental health for the EU' (COM(2005) 484 final of 14 October 2005).

Observation of basic human rights and dignity. People with mental disabilities, especially those in institutions, may be subject to a number of violations of their human rights, for example being deprived of 'legal capacity'. People with intellectual disabilities or dependency face similar prejudice (*see Bartlett P., Lewis O. & Thorold O. (2006) Mental Disability and the European Convention on Human Rights. Martinus Nijhoff, Leiden*).

Need for Progress

In relation to **human rights and dignity** it is clear that progress is needed in rights to:

- education, property, marry, to found a family, and to respect family life, voting, associate with others, work, advocacy, and to access legal representation

In relation to **general health status** there is a need for progress with:

- identification of good practice for health promotion and illness prevention, including assessment of risk factors, screening and diagnosis of disorders, and for access to care.

How the Project Contributes to Fill Gaps

The ITHACA partnership builds upon already established networks of collaborators (in the INDIGO anti-stigma network). Key innovative features are:

- We are committed to **strong collaboration with service user and carer groups**, with the active participation in the Project Coordinating Centre (PCC) of the Service User Research Enterprise (SURE), which is a consumer led research group at Institute of Psychiatry in London, with close links with many related service user groups throughout Europe.
- **Track Record in Successful EU Collaborations.** ITHACA WP Leads have a very strong track record of successful EU and other international partnerships: in advising governments on national mental health policy, publishing in peer reviewed and other journals and periodicals, organising European conferences, talking and contributing to European Union, European Commission, WHO, Association of European Psychiatry and World Psychiatric Association. We have also collaborated over the last 11 years in ENMESH (European Network for Mental Health Service Evaluation).

We shall fill key information gaps by producing practical and **useful deliverables**, namely evidence-based materials to assist policy-makers at the local, national and the EU levels to set policies that better protect the human rights and dignity, and which promote the general health status of people in social and health care institutions. We shall specifically address examples of best practice in relation to 3 EU applicant states: Bulgaria, Romania and Turkey.

3. EXPECTED RESULTS

3.1. Outcome

These will be the key results suitable for dissemination for the 5 Specific Objectives and the 4 Core Themes

Objective 1. Establish and manage an effective pan-European network (see Workpackage 1). **Intended Result:** Creation of this network, dissemination of information about the network and invitation for participation for sites from other EU states to participate in the network in future projects.

Objective 2. Co-ordinated dissemination of results (Workpackage 2).
Intended Result. Successful knowledge transfer to make the results of the ITHACA project and their implications for improved health and social care practice available to all those in the EU and in pre-accession states who may be able to benefit from them.

Objective 3. Detailed evaluation of the ITHACA project (see Workpackage 3).
Intended Result. Interim and final evaluation report giving specific achievements of the ITHACA project and recommendations for further improved practice in future EU collaborations

Objective 4. Establish and use a method to assess good practice relating to human rights and dignity (see Workpackage 4).

Intended Result 1. A practical and useful European method to assess the improvement of human rights and dignity

Intended result 2. A clear summary report on the factors necessary to improve human rights and dignity, suitable for use by a wide range of operators and authorities, and to support policy formation in relation to the Council of Europe and Commission services.

Objective 5. Establish and use a method to assess good practice relating to general health status (see Workpackage 5).

Intended Result 1. A practical and useful European method to assess the improvement of general health status

Intended Result 2. Clear summary report on factors necessary to improve general health status

In relation to the project cross-cutting Core Themes, which apply both to the domains of Workpackages 4 and 5, the main results suitable for dissemination will be:

Core Theme A. The relevant *legal* framework concerning:

Intended Result. Short, and practical final reports of Workpackages 4 and 5 which show which types of national/regional laws which are necessary for the proper promotion and improvement of human rights and dignity, and general health status.

Core Theme B. The relevant *policy* framework concerning:

Intended Result. Short, and practical final reports of Workpackages 4 and 5 which show which types of national/regional policies are necessary for the proper promotion and improvement of human rights and dignity, and general health status.

Core Theme C. Arrangements necessary for proper *reporting, governance and accountability*

Intended Result. Short, and practical final reports of Workpackages 4 and 5 which show how these factors can be put into practice in different settings across Europe,

with multiple feature boxes of good practice, quotations from successful implementation sites, and resources and contact details including internet links.

Core Theme D. Relevant conditions necessary for *effective inspections* of institutions.

Intended Result. As for Core Theme C.

3.2. Deliverables

<i>Deliverable No</i>	<i>Deliverable title</i>	<i>Delivery date</i>	<i>Nature</i>	<i>Confidentiality level</i>	<i>Dissemination</i>
D 1	Detailed interim report to the Public Health Executive Agency on project progress (18 months) along with continuous links with Commission services and the Council of Europe.	M18	Report	Confidential in the first instance	Progress update to EU. Paper report
D 2	Coordination of data summaries, statistical analyses and assessment schedules to record practice in relation to human rights and dignity and general health status produced by Work packages 4 and 5	M36	Report	Public	Standardised assessment report. Paper, PDF & document
D 3	Briefing paper for the Commission's Platform on Mental Health to support the implementation of the Commission's mental health strategy	M24	Report	Public	Standardised assessment report. Paper, PDF & document
D 4	Final report to the Public Health Executive Agency with full details of ITHACA project conduct and results	M36	Report	Confidential in the first instance	Full report to EU. Paper report and PDF on website
D 5	Create an ITHACA webpage with relevant details about the ITHACA work and its products and deliverables and make the ITHACA institutional assessment form available as PDF files in all project language versions	M24	Website	Public	Full report to EU. Paper report and PDF on website

D 6	Disseminate an Executive Summary for policy makers and parliamentarians at the EU level and in member states	M36	Report	Public	Full report to EU. Paper report and PDF on website
D 7	Disseminate an ITHACA project summary relevant for professional and other staff at health and social care institutions	M36	Report	Public	Summary report to EU and sent to national level professional organisations and user groups
D 8	Disseminate a project summary version suitable for service users and family members and make the results available in peer-reviewed journals and in the professional, vocational and NGO press, and we shall speak about the project results at relevant meetings and congresses to policy, staff, and service user and carer audiences, as well as issue press releases in Project Partner Site country states to gain wider circulation, discussion and debate of the main findings.	M36	Report	Public	Summary report to EU and sent to national level professional organisations and user groups
D 9	Final evaluation report, focusing on the achievement of the project's objectives and to be enclosed to the Final Report	M36	Report	Public	Full report to EU. Paper report and PDF on website
D 10	A practical and useful European method to assess the improvement of human rights and dignity of residents in institutions with mental ill-health, mental disability and dependency with a clear summary report on factors necessary to improve human rights and dignity	M24	Report	Public	Standardised assessment report. Paper & PDF document
D 11	We shall produce initial data summaries and statistical analyses for discussion by staff of the PCC, Project Partner Sites, and the Expert Advisory Group	M30	Report	Public	Interim report for ITHACA staff

D 12	Produce a consensus statement on the key features of best practice across Europe at the national and the local levels to publish in our final report and in other dissemination channels and media	M36	Report	Public	Full report to EU. Paper report and PDF on website
D 13	A practical and useful European method to assess the improvement of general health status of residents in institutions with mental ill-health, mental disability and dependency with a clear summary report on factors necessary to improve general health status	M24	Report	Public	Full report to EU. Paper report and PDF on website
D 14	We shall produce initial data summaries and statistical analyses for discussion by staff of the Project Coordinating Centre, Project Partner Sites, and the Expert Advisory Group	M30	Report	Public	Interim report for ITHACA staff
D 15	Reach a consensus on the key features of best practice across Europe at the national and the local levels to publish in our final report and in other dissemination channels and media	M36	Report	Public	Full report to EU. Paper report and PDF on website

4. METHODOLOGY

4.1. Methods used, references, significances

The project will consist of the following 5 stages.

Stage 1. Design of the data collection schedules

The methodology, methods and means used by ITHACA are:

In Workpackage 4 (human rights and dignity) and Workpackage 5 (general health care) to:

- (i) Conduct literature review of relevant publications
- (ii) EU survey through participating EU & national service user groups
- (iii) Data collection exercise from members of the Expert Advisory Group
- (iv) Contact with relevant organisation including the Council of Europe and the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)
- (v) Design the 2 draft data collection schedules to identify best practice for (a) human rights and dignity, and (b) general health care, to be used at the national and at the local levels.

Stage 2. Schedule Piloting

The Project Coordinating Centre (PCC) will:

- (i) Circulate draft to 15 Partner Sites with guidelines for the adaptation of the schedule to the local language via translation, backtranslation and use of local focus groups to check for correct translation of meaning in each local language version
- (ii) Co-ordinate the piloting on a limited scale of the two data collection schedules to establish clarity, relevance and ease of use
- (iii) Copy the two data collection schedules to the members of the Expert Advisory Group for their comments
- (iv) Collate feedback from these sources and revise the draft versions for final versions of the national and the local data collection schedules

Stage 3. Collection of data on best practice in the key area of (i) human rights and dignity and (ii) general health status

The 15 Project Partner Sites will use these data collection schedules for data on: (i) human rights and dignity and (ii) general health status:

- (i) National data collection schedule will be applied either at the national level (or regions where relevant for devolved mental health related laws and policies)
- (ii) Local data collection schedule aims to identify best practice rather than representative practice, so each Partner Site will use its local service user, professional and NGO networks to identify 6 institutions across the relevant range of health and social care institutions for people with mental ill-health, mental disability, and dependency (to a total of 90 institutions across all 15 sites)
- (iii) We will conduct focus groups with service users in each participating site. These will be organised through a member of ENUSP via their website. Full compliance with necessary local ethical approvals will be gained where appropriate.

Stage 4. Data co-ordination and analysis

The PCC will co-ordinate data from all Partner Sites from the 2 data collection schedules. We shall produce initial data summaries and statistical analyses for discussion by staff of the PCC, Partner Sites, and the EAG Group to reach a consensus on the key features of best practice across Europe at the national and the local levels.

Stage 5. (see Section 3.1)

Approach Adopted by ITHACA to collaboration

A key methodological consideration is how we shall approach collaboration between sites, organisations and nations. Our approach to a fair and productive creative environment for a long-term collaboration is that of Sartorius (1988) with 10 requirements for cross-cultural collaborative research:

- (1) Problem to be tackled must be recognised and defined jointly by all those who participate,
- (2) Solution to the problem must be of clear relevance to the needs of all the participating centres, agencies and countries,
- (3) Collaboration should not harm any of the parties, either directly or indirectly,
- (4) Collaboration should leave behind a structure for future joint work,
- (5) Collaboration should not exhaust resources of a centre or team,
- (6) In research, investigators should share their tasks on an equal-status basis,
- (7) Researchers should use their data in scientific publications and also in the promotion of collaboration and understanding among centres,
- (8) Rules of the ethical review committee in the country which has the strictest regulation should be enforced on the entire collaborative network,
- (9) Manner of collaboration should be agreed upon by all concerned and take into account culture-specific requirements even if this means a certain reduction of efficiency and longer periods of preparation for studies, and
- (10) Rules which will govern collaboration, use of data, authorship, publication of results, should be discussed, agreed upon and clearly spelt out in writing before the project starts.

Practical Arrangements for Successful Collaboration.

We shall translate these principles into practice through:

- Establishing regular *phone conferences* and *email correspondences* between the *participants*, as the primary policy setting body, to agree the overall direction of the project work and the allocation of resources.
- Holding three annual meetings of all *Partner Site Leads and key staff* to set policies, agree targets and review progress. The venue of these meetings will rotate around sites.
- We shall agree a *publication protocol* early at these meetings so that the participants in the ITHACA programme, including Site Heads, Site Co-ordinators and Project Workers can all expect a reasonable share of authorships of project papers, reflecting their relative contributions to the project.
- We shall also agree *programmes to disseminate the findings* of the project through professional, clinical/social care and policy related meetings, offering particular opportunities for younger staff to gain experience of presenting papers at international meetings and of meeting senior research and policy colleagues in this way.

The design of the ITHACA Programme is deliberately multi-disciplinary and the applicants include the following specialities: psychology, health economics, psychiatry, sociology, law and human rights, mental health policy, consumer and family member involvement, stigma and discrimination, and statistics.

4.2. Analysis of the risks and contingency planning

1A Risk Identified

Poor project co-ordination

1A Risk management strategy

Close project management by ITHACA Co-ordination Centre

ITHACA will use an iterative process, with drafts of scales being developed, piloted, and commented on by the EAG. The ITHACA PCC is responsible for:

- Coordination of the technical activities of the project and knowledge management
- The overall legal, contractual, ethical, financial and administrative management
- Overseeing the promotion of gender equality in the project and the science and society issues
- Drafting and maintenance of a consortium agreement
- Production of a Project Guide Book (PGB) for all participants and all major subcontractors

2A Risk Identified

Lack of consensus in identification of project aims / methods

2A Risk management strategy

Clear lines of responsibility, accountability and governance

A **Project Management Team (PMT)** with all participants will be established, consisting of the Project Coordinator (GT) as Chairperson and one representative of each of the participants. The PMT has the full responsibility for the ITHACA project considering all administrative and project decisions (financial, administration, management, monitoring, evaluating, and controlling any intellectual property rights). Since the nature of the task asks for multidisciplinary, the PCC will create the EAG for monitoring the development of the best practice report.

3A Risk Identified

Lack of clear communication between all stakeholders

3A Risk management strategy

Clear project communication strategy

The **communication between the PMT** and with the sub-contractors will include:

- Information exchange via a project's website
- Schedule for meetings, sometimes including special sub-contractors
- Clarifying that each of the participants is responsible for its own Workpackage
- Monthly teleconferences for all Heads of Sites
- Quarterly meetings of Hubs Site Heads, rotating between Project Sites
- Annual meetings between Hub Site Co-ordinators and their nominated Partner Site(s)
- We shall produce a regular *ITHACA Project Newsletter* for all staff.
- Regular meetings between project worker and his/her *Tutor*
- Annual meetings of the *Heads of all Project Sites*
- Regular *email* communication to seek consensus decisions within the network co-ordinated for administrative matters by the ITHACA PCC
- Create an *ITHACA website* for communication between project staff and others.

The **Project Guide Book** will contain:

- Planning and Management Overview
- Responsibilities of all parties concerned

- Ethical issues (gender, minorities, politics, ethics committees in relevant countries)
- Templates for contracts between participants and sub-contractors
- Information on accounting and payment system
- Templates for Time Sheets
- Evaluation Questionnaires
- Schedule of meetings
- Agreements on intellectual property

4.3. Work package overview

<i>Work-package (WP) No</i>	<i>Work package title</i>	<i>Lead partner</i>	<i>Number of person days</i>	<i>Global cost (€)</i>	<i>Starting date</i>	<i>Ending date</i>	<i>Deliverable No</i>
WP 1	Coordination of the project	Institute of Psychiatry, King's College London	945	478,166	1/4/2007	31/3/2010	D 1-4
WP 2	Dissemination of the results	Ludwig Boltzmann Gesellschaft	217	64,121	1/4/2007	31/3/2010	D 5-8
WP 3	Evaluation of the project	STAKES	48	22,701	1/4/2007	31/3/2010	D 9
WP 4	Human Rights and Dignity	MDAC	1476	257,461	1/4/2007	31/3/2010	D 10-12
WP 5	General Health Status	Universita' di Verona	1485	287,697	1/4/2007	31/3/2010	D 13-15
WP 6							D
WP 7							D
WP 8							D
WP 9							D
WP 10							D

5. WORK PACKAGES DESCRIPTION

5.1. Work package n° 1: Coordination of the project

5.1.1. List of partners involved

All partners

5.1.2. Description of the work

The WPI Lead will manage the project in the following ways:

(i) Establish the **ITHACA Project Co-ordinating Centre (PCC)** in London with the proper technical and administrative support.

(ii) Create and manage the **ITHACA Project Team (IPT)** consisting of the Leads for all 5 WPs with the Project Co-ordinator, with monthly phone conferences.

(iii) Create, manage and support **ITHACA Heads of Sites Team (HST)** for heads of all 15 sites, and ensure that Heads of Sites are responsible for proper local technical, financial and administrative management at individual sites and report back to PCC progress of work. Coordinate annual meetings for HST.

(iv) Invite collaborating partners (see section 7) and the Commission to join and establish the **Expert Advisory Group (EAG)** to offer regular advice to the PCC, IPT and HST on the methods, aims and operations of the project; how best practice and results of the study are disseminated; and related developments in the field of mental health internationally.

(v) Support the involvement of junior project staff and their mentoring to gain experience to assist their career development, and so **build capacity** in this field of European activity for the future.

5.1.3. Milestones

<i>Date</i>	<i>Milestone</i>
At 18 months	detailed interim first year report to the Public Health Executive Agency on ITHACA progress with copies to the Commission and the Council of Europe
At 24 months	Briefing paper for the Commission's Platform on Mental Health to support the implementation of the Commission's mental health strategy
At 36 months	- detailed final report to the Public Health Executive Agency on ITHACA progress with copies to the Commission and the Council of Europe - coordination of data summaries, statistical analyses and assessment schedules to record practice in relation to human rights and dignity and general health status produced by Work packages 4 and 5

5.1.4. *Deliverables*

D1 Detailed interim report to the Public Health Executive Agency on project progress (18 months) along with continuous links with Commission services and the Council of Europe.

D2 Coordination of data summaries, statistical analyses and assessment schedules to record practice in relation to human rights and dignity and general health status produced by Work packages 4 and 5 (36 months)

D3 Briefing paper for the Commission's Platform on Mental Health to support the implementation of the Commission's mental health strategy (24 months)

D4 Final report to the Public Health Executive Agency will full details of ITHACA project conduct and results (36 months)

5.2. **Work package n° 2: Dissemination of the results**

5.2.1. *Overall strategy and methods*

We shall undertake the project dissemination strategy with a combination of the following methods; (i) direct advice to EU/EC, WHO-Copenhagen and WHO-Geneva; (ii) advising our respective governments on national mental health policy; (iii) publishing in peer reviewed scientific journals; (iv) organising international conferences; (v) giving invited lectures at international meetings; (vi) contributing to European Union, European Commission, WHO, Association of European Psychiatry and World Psychiatric Association meetings and working parties, and have written policy and discussion papers for these organisations; (vii) taking part in international project to produce standardised outcome measures of mental health treatment and service interventions; (viii) liaising closely with user and carer groups and NGO's in our respective countries.

5.2.2. *Objectives*

We aim to disseminate our findings via:

- conferences and congresses
- peer-reviewed journals
- books and book chapters
- the ITHACA web page
- professional publications
- direct communication of the project results with policy makers and news organisations
- close links with Commission services

5.2.3. *Description of the dissemination work*

We are confident that we can successfully disseminate the results of our work because each of the project Partners has an established record of;

- advising the EU/EC, WHO-Copenhagen and WHO-Geneva
- advising our respective governments on national mental health policy

- publishing in peer reviewed scientific journals
- organising international conferences
- giving invited lectures at international meetings
- contributing to European Union, European Commission, WHO, Association of European Psychiatry and World Psychiatric Association meetings and working parties, and have written policy and discussion papers for these organisations
- taking part in international project to produce standardised outcome measures of mental health treatment and service interventions
- liaising closely with user and carer groups and NGO's in our respective countries
- close involvement of the operators and national institutions and authorities.

5.2.4. *Milestones and deliverables*

D5 Create an ITHACA webpage with relevant details about the ITHACA work and its products and deliverables and make the ITHACA institutional assessment form available as PDF files in all project language versions

D6 Disseminate an Executive Summary for policy makers and parliamentarians at the EU level and in member states

D7 Disseminate an ITHACA project summary relevant for professional and other staff at health and social care institutions

D8 Disseminate a project summary version suitable for service users and family members and make the results available in peer-reviewed journals and in the professional, vocational and NGO press, and we shall speak about the project results at relevant meetings and congresses to policy, staff, and service user and carer audiences, as well as issue press releases in Project Partner Site countries states to gain wider circulation, discussion and debate of the main findings

5.2.5. *List of stakeholders*

EU/EC, WHO, WHO-EURO, governments, professional organisations such as Association of European Psychiatry and World Psychiatric Association, national and international user groups, carer groups, NGO's.

5.3. **Work package n° 3: Evaluation of the project**

5.3.1. *List of parties involved*

All partners

5.3.2. *Description of the work and methodologies*

The ITHACA Evaluation WP will be systematically evaluated by STAKES, a partner with extensive experience from DG SANCO projects. Evaluation of the project is an integrated part of the project and is an ongoing process through all phases of the project.

The evaluation process will consist of the following steps implemented by the workpackage leader:

- to establish an evaluation plan
- the evaluator will participate in project meetings to ensure continuous quality improvement and evaluation
- the evaluator will continuously monitor the achievement of milestones
- the evaluator will alert the project coordinator in any case of non-achievement
- the evaluator will assess the achievement of the stated general and specific objectives
- the evaluator will collect qualitative data from the associated partners for a process evaluation
- the evaluator will analyse the collected data to identify barriers and success factors in the project
- the evaluator will produce an interim and final evaluation report

5.4. Work package n° 4: Human Rights and Dignity

5.4.1. *List of partners involved*

All partners

5.4.2. *Objectives*

To establish and disseminate across Europe a pragmatic and widely usable method for assessing good practice in human rights and dignity at both national and local level in order to improve the conditions of residents in institutions for people with mental ill health, mental disability or dependency in relation to physical health promotion, physical illness prevention, and access to health care.

5.4.3. *Description of the work*

This Workpackage contributes to ITHACA with the assessment and dissemination of good practice in relation to human rights and dignity of residents in institutions for people with mental ill health, mental disability or dependency in Europe. Furthermore, it will develop practical proposals for implementing across Europe best practice connected with these areas among people with mental illness/disability and dependency who are resident in health /social care institutions.

The Workpackage consists of the following steps:

1. Conduct a thorough literature review of relevant publications on this topic
2. Undertake an international survey of current inspection assessment schedules through participating EU and national service user groups to identify state-of-the-art and related work, e.g. inspection tools in production that have been piloted or developed in institutions, prisons and detention centres, upon which the ITHACA tool can be built
3. Make a data collection exercise from members of the Expert Advisory Group
4. Contact with relevant organisations including the Council of Europe and the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)
5. Design a data collection schedule to identify best practice in relation to human rights and dignity to be used at the national and local levels
6. Assess, through the use of inspections using a new assessment method to be organised at 15 Project Partner Sites, the condition of residents in institutions in relation to human rights and dignity conducted by staff at the local Partner Sites. Specifically we shall identify and disseminate:
 - what policies are followed, where responsibility lies for the proper assessment of mental capacity of people in the institutions studied, both for adults and children
 - what policies are followed, where responsibility lies for the proper provision of guardianship arrangements for people in the institutions studied
 - the necessary and sufficient ingredients for good practice in terms of human rights and dignity especially related to:
 - privacy and freedom from involuntary treatment
 - rights to marry or divorce

- right to own, manage, bequeath and inherit property
 - sign a legal contract
 - right to give evidence in a court of law or in other judicial circumstances
 - rights in relation to childcare, fostering and adoption
 - ability to buy insurance (health, travel, life, property)
 - rights to travel, have a passport, gain usual travel visas
 - register and vote in elections
 - make a valid will
 - access financial services such as take out a loan
 - rights to paid employment
7. Conduct focus groups with service users in each participating site organised through a member of ENUSP via their website. Full compliance with necessary local ethical approvals will be gained where appropriate.

5.4.4. *Deliverables and links with other work packages*

D10 A practical and useful European method to assess the improvement of human rights and dignity of residents in institutions with mental ill-health, mental disability and dependency with a clear summary report on factors necessary to improve human rights and dignity

D11 We shall produce initial data summaries and statistical analyses for discussion by staff of the PCC, Project Partner Sites, and the Expert Advisory Group

D12 Produce a consensus statement on the key features of best practice across Europe at the national and the local levels to publish in our final report and in other dissemination channels and media.

5.5. **Work package n° 5: General Health Status**

5.5.1. *List of partners involved*

All partners

5.5.2. *Objectives*

To establish and disseminate across Europe a pragmatic and widely usable method for assessing good practice in general health care at both national and local level in order to improve the conditions of residents in institutions for people with mental ill health, mental disability or dependency in relation to physical health promotion, physical illness prevention, and access to health care.

5.5.3. *Description of the work*

This Workpackage contributes to ITHACA with the assessment and dissemination of good practice in relation to general health care of residents in institutions for people with mental ill health, mental disability or dependency in Europe. Furthermore, it will develop practical proposals for implementing across Europe best practice connected with the promotion of general health care of people with mental illness/disability and dependency

who are resident in health / social care institutions, and for access to any necessary care.

The Workpackage consists of the following steps:

1. Conduct a thorough literature review of relevant publications on this topic
2. Undertake an international survey of current inspection assessment schedules through participating EU and national service user groups to identify state-of-the-art and related work, e.g. inspection tools in production that have been piloted or developed in institutions, prisons and detention centres, upon which the ITHACA tool can be built
3. Make a data collection exercise from members of the Expert Advisory Group
4. Contact with relevant organisations including the Council of Europe and the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)
5. Design a data collection schedule to identify best practice in relation to general health care, to be used at the national and local levels
6. Assess, through the use of inspections using a new assessment method to be organised at Project Partner Sites, the condition of residents in institutions in relation to general health status conducted by staff at the local Partner Sites. Specifically we shall identify and disseminate:
 - what policies are followed, where responsibility lies for the proper assessment and treatment of the physical and dental health needs of people in institutions and identify best practice
 - the necessary and sufficient ingredients for good practice in terms of general health care
 - good practice in relation to health promotion and illness prevention, including assessment of risk factors, screening and diagnosis of physical disorders/illnesses and provision of appropriate care especially related to
 - Pulmonary and cardiovascular diseases
 - Obesity
 - Diabetes
 - Hypertension
 - Infectious disease, e.g. HIV/AIDS, and treatment resistant TB
 - Dental care
 - Ophthalmic correction and care
 - Hearing assessment and aids
 - Nutritional status and dietary intake
 - Alcohol and drug misuse
 - Smoking reduction/cessation
 - Gastro-intestinal infections
 - Mobility aids
7. Conduct focus groups with service users in each participating site organised through a member of ENUSP via their website. Full compliance with necessary local ethical approvals will be gained where appropriate.

5.5.4. *Deliverables and links with other work packages*

D13. A practical and useful European method to assess the improvement of general health status of residents in institutions with mental ill-health, mental disability and dependency with a clear summary report on factors necessary to improve general health status

D14. We shall produce initial data summaries and statistical analyses for discussion by staff of the PCC, Project Partner Sites, and the Expert Advisory Group

D15. Reach a consensus on the key features of best practice across Europe at the national and the local levels to publish in our final report and in other dissemination channels and media.

6. MEASURES TO ENSURE VISIBILITY OF COMMUNITY CO-FUNDING

We consider it good practice to fully acknowledge the funding organisations which support ITHACA. We shall therefore give full credit to the European Commission at every opportunity in our knowledge transfer and dissemination activities. These will include:

- Naming the EU as the commissioner of this work in published papers and reports
- Where appropriate using the EU logo to denote the EU support we have received for presentations at local, national and international levels
- Stressing EU funding when giving interviews to the mass media
- Including clear mention of EU support in our institutions webpages and newsletters
- Emphasising in our dissemination work to policy, professional, service user, family member and other audiences that the work took place by virtue of EU support.

Managing sponsor acknowledgments. As contractors we shall submit at, or before, the end of the Project, a technology implementation plan acceptable to the Commission. It will include a summary of the project, the forecast of the intentions of each contractor and description of achievements regarding use of the knowledge (including timetable). The coordinator shall provide, a one-page publishable summary of the project which can be easily disseminated and distributed to the public. In addition, no later than the first report, the coordinator shall provide to the Commission a publishable poster targeted to a non-specialist audience and summarising the main features of the entire project. Each of these knowledge transfer actions will fully acknowledge the EU as the source of funding.

Examples of our knowledge transfer activities in which high EU visibility will be ensured:

- The WPA Global Stigma Programme has well established programmes in 20 countries across the world with professional input to assist with transfer of knowledge. The web site www.openthedoors.com will be used by ITHACA to host: evaluation discussion boards, training materials, lecture notes, research summaries, consumer perspectives on ITHACA.
- Bi-annual ENMESH congresses bringing together colleagues from across the whole of Europe to discuss mental health service improvement and evaluation
- Regular, high visibility and high-impact press releases and media campaigns by Mental Disability Advocacy Centre on reports highlighting the need to improve (i) mental incapacity and (ii) guardianship arrangements across many countries in Europe.
- Regular, targeted newsletters summarising key findings from our recent completed projects, such as the IoP Health Services Research newsletter Towards Mental Health, at www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/1_4_hsr_research_report.pdf. Show EU support in the spread of the project results through our partners organisations such as the European family member mental health organisation EUFAMI via: <http://www.eufami.org>.

7. LIST OF COLLABORATING PARTNERS

<i>Collaborating organisation</i>			<i>Contact person</i>			
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