University Health Network, Collaborative Research e-Infrastructure (Research infrastructure - INFRASTRUKTUR)

Application Number: ES467472 Project Number: -1

Applicant

Project Owner

Institution / company (Norwegian name)	Pål Barkvoll
Faculty	Faculty of Dentistry, University of Oslo
Institute	Institute of Clinical Dentistry
Department	
Address	P.O. Box 1109 Blindern
Postal code	0317
City	Oslo
Country	Norway
E-mail	pal.barkvoll@odont.uio.no
Website	http:/www.odont.uio.no/om/iko
Enterprise number	971035854
Auditor	Office of the Auditor General
eAdministration	

Project administrator

First name	Lars Olav
Last name	Skare
Position/title	Senior Advicor
Phone	+4722852211
E-mail	l.o.skare@odont.uio.no
Confirmation	✔ The application has been approved by the Project Owner

Project manager

University Health Network, Collaborative Research e-Infrastructure (Research infrastructure - INFRASTRUKTUR)

Application Number: ES467472 Project Number: -1

First name	Pål
Last name	Barkvoll
Institution / company (Norwegian name)	Universitetet i Oslo
Faculty	Faculty of Dentistry
Institute	Institute of Clinical Dentistry
Department	
Address	P.O. Box 1109 Blindern
Postal code	0317
City	Oslo
Country	Norway
Position/title	Professor - Chief E. Director
Academic degree	Dr.odont
Preferred language	Bokmål
Phone	+4722852226
E-mail	pal.barkvoll@odont.uio.no

Project info

Equipment

Project title	University Health Network, Collaborative Research e-Infrastructure

Primary and secondary objectives of the project

Primary and secondary objectives	Modern evidence-based medical research increasingly demands access to large quantities of coherent patient health information from local clinical practitioners, leading teaching hospitals and clinical research centres. There is currently no effective national or international mechanism for capturing and consolidating information across Public Health and professional organisations, no effective mechanism for information-sharing or collaborative multi-centre studies. UHN provides secure, exchange of close-to-patient health information, compliant with national ethical and data-protection requirements. Researchers will have access to a global resource-pool: - people, projects, datasets

- collaboration partners and teams
- multi-regional patient cohorts and control groups
- close-to-patient data on emerging diseases and pandemics in developing countries.

The prototype works and is validated by the 5 founding universities during 2011, ready for global launch and deployment in 2012

Project summary

Project summary

Building on the experience and commitment of five leading international centres, UHN is developing a global network of oral health teaching and research institutions which will:

- promote and support collaboration in medical research,
- transfer best-practice in medical education,
- enable sharing of information and resources, and
- develop IT standards and infrastructure to support best-practice in medical education and research.

First focus is exchange of oral health datasets between researchers, including data derived from e-dental records (EDR) and biobanks. The infrastructure is capable of normalizing disparate data, so they can adapt to any patient data system. Data will be made available for research locally, regionally and internationally.

The leading institute, IKO in Oslo, has been using EDR since 2005, and our four collaborating international centres have been developing their capability since 2007. During 2011, all five will be using the UHN software and will thereby validate the functionality, scope and effectiveness of the e-infrastructure, guiding its development from prototype to global deployment.

The project requires successful implementation of EDR in the other four colleges being fully operational from 2011. All four are committed; cf. the enclosed letters.

The R&D challenge of incompatible coding systems, e.g. for diagnoses, is addressed by the software´s data-mapping capabilities. This overcomes one of the scientists? most difficult issues regarding multi-centre collaboration.

After global launch in 2012, UHN will be accessible to dental schools, other research institutions and national public and private clinics, to provide best practice treatment based on UHN statistics, much prioritized in Norway; cf. Report to Parliament no. 7 (2008-09). Biobank data in UHN will support the

analyzes. UHN will also establish the necessary firm basis for research in developing regions of the world.

Funding scheme

Supplementary info from applicant

Programme/ activity	INFRASTRUKTUR
Application type	Research infrastructure
Topics	
Other relevant programmes/ activities/ projects	
Discipline(s)	Clinical Dentistry
If applying for additional funding, specify project number	
Have any related applications been submitted to the Research Council and/or any other public funding scheme	No
If yes, please provide further information	

Progress plan

Project period

From date (yyyymmdd)	20110501
To date (yyyymmdd)	20151231

Main activities and milestones in the project period (year and quarter)

Milestones throughout the project	From		To	
Cf. Project Description Chap. 10 Achieved	2011	2	2011	2
The 5 Partners review Prototype 2 (P2)	2011	2	2011	2
Implement P2 at 20 General Practitioners	2011	2	2011	3
Development General Availabilty (GA)	2011	2	2011	2

Release GA Version 1.0	2011	2	2011	2
Global implement. in 15 (?) Dental Schools	2011	2	2011	4
Implement. 1 Norw. Publ Dental Health reg.	2011	2	2011	4
Global Launch & Implementation 100 univ	2012	1	2013	2
Implementation National Biobanks	2012	1	2013	2
Extend to other Medical Disciplines	2012	1	2014	4
Intro universities S. Africa and Colombia	2013	1	2014	4
Laptop version for Peripatetic Therapists	2012	1	2013	4
Implement. at more univ. and corporations	2013	1	2014	4
Further Global extension to Primary Care	2015	1	2015	4
Further extension to Secondary Care Research	2015	1	2015	4
Extension to Care in Developing Countries	2015	1	2015	4
Extension to Norw. Public Health Reagions	2011	3	2015	4

Budget

Cost plan (in NOK 1000)

	2011	2012	2013	2014	2015	2016	2017	2018	Sum
Investment cost	995	700	775	540	910				3920
Operating expenses	16598	17260	14454	14943	17260				80515
Totalsum	17593	17960	15229	15483	18170				84435

Spesifikasjonsfelt	Investment cost is here the sum of expenses to hardware and the running og the project (journeys and board allowance for the central persons involved). Operating expenses: In this project it is most adequate to see the operative expenses as payment / compensation for the work of persons involved in the project as well as its development. The aqusition and the development of the UHN e-Infrastructure will involve on a co-operation between a large number

of persons in the consortium institutions as well as their cooperaration with the software developing company. This amounts to 90 Full Time Equivalents (FTEs) over the 5 years. As the Cost code table shows, almost 70 % of the project costs are incurred abroad, as IKO´s projects partners as well as the software developers are located abroad.

The UHN Consortium and its software development company have, as accounted for in the project description, already by the autumn of 2010 achieved the development of a software which currently (October 2010) is being tested by researchers in Oslo. Each member of the UHN Board wants to be responsive in organizing the contribution from the 4 universities cooperating with Oslo. Cf. the attached letters from these members.

A detailed calulation can also be seen in the project desription. So, here is just mentioned the categories of competence involved, and a short explanation how the numbers are calculated:

A) UiO researcher full time equivalents (FTEs) for: Data-recording standards definition, "core data" definitions, medical and other coding, system evaluation, requirements planning. Wage scale associated professor UiO low 57 and professor high wage scale. 98) Average wage scale gross 681 100 + 23 % indirect cost = NOK   837 753

B) Researchers at the other 4 UHN founder Universities full time equivalents (0,5 FTE x 4) for: Data-recording standards definition, "core data" definitions, medical and other coding, system evaluation, requirements planning. Calculated same average payment as UiO + VAT 25 %.

C) UiO IT staff for UHN support. Average wage scale 63 gross NOK 500 700 + 23 % indirect cost = NOK 615 861

D) IT staff at the other 4 UHN founder universities (x 4). Calculated same average payment as UiO + VAT 25 %

E) Developing software company (vendor) of the UHN software (London): FTE average NOK 700 000 per year included indirect cost + 25 % VAT

F) Project leader UiO: FTE per year NOK 944 300 gross + 25 % VAT = per year NOK 1 161 489, included indirect 23 % cost: NOK 1 274 527

G) Administration UiO; FTE wage scale 69 NOK 687 447 included indirect 23 % cost.

Cost code (in NOK 1000)

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	2011	2012	2013	2014	2015	2016	2017	2018	Sum
Trade and industry	0	0	0	0	0				0
Independent research institute	0	0	0	0	0				0
Universities and University Colleges	4659	4321	4773	5439	6894				26086
Other sectors	0	0	0	0	0				0
Abroad	12934	13639	10456	10044	11276				58349
Totals	17593	17960	15229	15483	18170				84435

Funding plan (in NOK 1000)

	2011	2012	2013	2014	2015	2016	2017	2018	Sum
Own financing	400	0	500	0	700				1600
International funding	0	1440	4008	6304	8256				20008
Other public funding	0	0	0	2000	7000				9000
Other private funding	0	0	0	0	0				0
From Research Council	17193	16520	10721	7179	2214				53827
Totals	17593	17960	15229	15483	18170				84435

Specification	Own financing: This is the funding from the 5 consortium institutions, in year 1, and then funding for the running of the infrastructure (after implementation) in year 3 and year 5. International funding: This is the calculated price for the other universities for access to the UHN e-Infrastructure; first an entrance fee, the an annual subscription rate. The calculations and plans altogether is an expression for the huge interest dental colleges globally show for the UHN project. Other public funding: According to the time schedule public health care as well as private health care in the region / country around each consortium

member institution will be sought recruited for implementation of the UHN e-Infrastructure. But at this stage one finds it not right to calculate earnings from such sectors into the project budget.

When the laptop version of the infrastructure is developed, however, the UHN e-Infrastructure will also be extended to enable collection of close-patient data by peripatetic practitioners operating in developing countries. Then the UHN consortium Board believes that one can receive support from different public sources for developmental aid funding. Likely also from private organisations, but this is not calculated into this budget.

The UHN consortium Board has agreed upon avoiding private investment. The reason is that the 5 universities believe that this project will best serve the science and the societies by being steered solely by academia.

Private funding like earning from pharmaceutic industry is likely, but at this stage of time one has not found it right to calculate this a secure source for funding.

Partners

Partners under obligation to provide professional or financial resources for the implementation of the project

1

Institution/ company	University of London, Kings College
Department/ section	Dental Institute Guy's, King's College, St Thomas
Address	
Postal code	SE1 9RT
City	London
Country	UK
Enterprise number	
Contact person	Dean Nairn Wilson
Contact tel.	+44 20 7188 116
Contact e-mail	nairn.wilson@kcl.ac.uk
Partner's role	Financing and Research activity

2

University Health Network, Collaborative Research e-Infrastructure (Research infrastructure - INFRASTRUKTUR)

Application Number: ES467472 Project Number: -1

Institution/ company	Universidad de Complutense de Madrid
Department/ section	Faculty of Odontology
Address	
Postal code	ES-28040
City	Madrid
Country	Spain
Enterprise number	
Contact person	Dean Mariano Sanz
Contact tel.	+3491 3941 901
Contact e-mail	marianosanz@odon.ucm.es
Partner's role	Financing and Research activity

3

Institution/ company	University of Hong Kong
Department/ section	Faculty of Dentistry
Address	
Postal code	
City	Hong Kong
Country	Hong Kong
Enterprise number	
Contact person	Dean Lakshman P. Samaranayake
Contact tel.	+852 2859 0342
Contact e-mail	lakshman@hku.hk
Partner's role	Financing and Research activity

4

Institution/ company	University of Alabama, Birmingham
Department/ section	School of Dentistry
Address	
Postal code	AL 35294
City	Birmingham Alabama

University Health Network, Collaborative Research e-Infrastructure (Research infrastructure - INFRASTRUKTUR)

Application Number: ES467472 Project Number: -1

Country	US
Enterprise number	
Contact person	Dean Huw Thomas
Contact tel.	+1 205 934 4720
Contact e-mail	hft@uab.edu
Partner's role	Financing and Research activity

Attachments

Project description

Filename	101005 Project Description UHN e-Infrastructure.pdf
Reference	ES467472_001_1_Prosjektbeskrivelse_20101005

Confirmation from partner(s)

Filename	100922 Support Univ of London Kings College.pdf
Reference	ES467472_008_4_AktiveSamarbeidspartnere_20101005

Filename	100920 Univ Complutense Madrid Recommend.pdf
Reference	ES467472_008_5_AktiveSamarbeidspartnere_20101005

Filename	100929 Support Hong Kong Univ Faculty Dentistry.pdf
Reference	ES467472_008_6_AktiveSamarbeidspartnere_20101005

Filename	100920 Support Univ of Alabama.pdf
Reference	ES467472_008_7_AktiveSamarbeidspartnere_20101005

University Health Network, Collaborative Research e-Infrastructure (Research infrastructure - INFRASTRUKTUR)

Application Number: ES467472 Project Number: -1

Other items

Filename	Curriculum vitae short version PB.pdf
Reference	ES467472_010_3_Annet_20101005

Filename	IAN FINCH CV.pdf
Reference	ES467472_010_4_Annet_20101005

Filename	PAUL BEARD CV.pdf
Reference	ES467472_010_5_Annet_20101005

Research Council of Norway – Research Infrastructure
Call for proposals with deadline 13. October 2010

University Health Network (UHN) e-Infrastructure

Institute of Clinical Dentistry, University of Oslo
Coordinator/scientific contact person: Chief Executive Director, Professor Pål Barkvoll

Category

☐	Advanced scientific equipment/facilities (2-200 mill NOK)
☐	Scientific databases and collections (2-200 mill NOK)
☒	e-Infrastructure (2-200 mill NOK)
☐	Participation in international research infrastructure (e.g. ESFRI)

1.   Relevance

- **In relation to call for proposals**

Modern evidence-based medical research increasingly demands access to large quantities of coherent patient health information from local clinical practitioners, as well as from leading teaching hospitals and clinical research centres. In all countries, including Norway, there is currently **no effective mechanism for collecting and consolidating this information across multiple Public Health and professional organisations, and there is no effective mechanism for sharing this information to enable collaborative multi-centre studies.**

University Health Network (UHN) will establish an *International e-Infrastructure* to promote and support such projects by enabling secure, managed exchange of health information. This e-Infrastructure aims to enable rigorous compliance with national ethical, patient-confidentiality and data-protection regulations for exchange of research datasets derived from electronic patient records.

- **In relation to societal challenges**

Report to the Storting (Parliament) no. 7 (2008-2009) An innovative and sustainable Norway (St.meld. nr. 7 (2008-2009) *Et nyskapende og bærekraftig Norge*) emphasizes issues of increasing national importance and public debate in the light of current financial crises:

"Research policy mirrors the societal will to develop and use new knowledge. **The research and evidence based knowledge stamp development and will become continuously more important in the next few years.** The business sector as well as the public sector needs increased knowledge. Therefore, the government has ambitious goals for Norwegian effort in research in the next few years" (chapter 7).

The health care sector in Norway operates largely as a public service and consumes a large proportion of public funds. The 2008-2009 report (Chapter 8) particularly emphasizes the need to address research in "health-and-care", linking health to social security and welfare. Key words in chap. 8.2 "Prioritization of the health-and-care sector":

- "Innovation in the public sector generally, and in health-and-care especially"; "…that is, the job is carried out in a smarter way".
- "Facilitation for increased added-value based on good solutions in the public sector. An example from **IT as a tool for innovation** is increased use of e-ID."
- "… national investigation on citizens and systematic measurements of goal achievement and use of resources."
- "Encourage innovation in society generally by implementing **innovative solutions in the public services**."

This is followed up by chap. 8.2.1 "Need for innovation in the health-and-care sector":

The **ageing population** and **need for saving** is quantified in the Storting Report and shows an overwhelming need for communication, cooperation and unified effort which **the UHN consortium is convinced can be realised only through systematic clinical research based on high-volume close-to-patient recording**. As the Storting Report words this: "An important remedy to support electronic cooperation is the Strategy Plan 2.0 "National strategy for **electronic cooperation in the health- and care sector** 2008-2013".

Similar challenges are recognized across virtually all western societies.

The consortium behind the UHN project states that there is little or no national or international coordination of universally relevant medical and dental research. As a result, institutions often develop identical facilities or undertake redundant duplicated research in isolation, leading to **increased cost and time delays**. The aim of the UHN is to build on the expertise and reputation of 5 leading international dental centres to develop a global network of oral health teaching and research institutions to collaborate in medical research, transfer best practice in teaching and institutional administration and to share information and resources in the development of standards and infrastructure for information technology support of practice, teaching and research. **This corresponds exactly with the aim for the European Strategy Forum on Research Infrastructure (ESFRI).**

As a way of meeting a universal societal challenge, the UHN project has attracted strong support and commitment from its consortium members on three continents. They recognise the opportunity to create a coordinated knowledge infrastructure in which they can become the "hubs" for local, regional and national networks, which will link together to form a global platform for collaborative research projects, sharing close-to-patient data, scientific insight, and best practice. They will then be best placed to respond effectively to local and national needs, as well as being able to integrate resources and create pooled patient research cohorts to meet the challenges of major multi-centre international projects.

National associations of dentists or dental hospitals will be invited to participate in the networks making use of the UHN software.

Several reports to the Storting during the recent years have concluded that the best basis on which to conduct effective national research and evidence-based action is to recognize and draw on the strengths of the autonomous regional (sub-national) organizations. This principle applies to a wide range of research, from environmental and resource management to alternative sources of energy. References to the field of Health-and-care may be found in Reports to the Storting with the keywords "Reform by cooperation" (St.meld. nr. 47 (2008-2009) *Samhandlingsreformen*) and "Regional centres of competence".

Dentistry and oral health is a self-contained section of health care, which enables the world's dental colleges and oral research institutions to operate as a closely-knit global community. This offers an important benefit in terms of developing research e-infrastructure. Different national needs can be represented, and the development of the collaborative technology managed relatively easily. Once developed and proven within this well-defined global oral-health community, the same infrastructure can then be applied to general medicine research and health care as a whole.

The UHN e-Infrastructure project reflects a clear societal consensus: best practice in both medical research and healthcare delivery increasingly demands mechanisms for collaboration and inter-working between these two fields.

2. Vision and scientific goals

- **Long and short-term scientific goals**

UHN aims to form a network to connect a wide range of entities and individuals within health care and health research:

1. **An e-infrastructure for research**: Initially the system will facilitate exchange of research datasets including those derived from EDR (electronic dental records) systems as used by the 5 partners, and biobank systems. After global launch in 2012, extend to more dental research centres and colleges.

2. **The North-South Dimension**: Mobile solutions at an individual patient level, to be used in developing countries. This is planned when the UHN system in 2012-13 is sufficiently established and can represent best practice examples. At this stage the UHN founder institutions will seek cooperation with research centres in e.g. South Africa.

3. **Distance Learning**: Outreach upgrading of postgraduates and specialists. King´s College London has developed their IVIDENT system, launched stepwise under the name UDENTE in 2010. Oslo has ten years' experience of its own distance learning systems. UHN will augment this teaching with research evidence to underpin the didactic curriculum.

4. **UHN software** developed as a communication tool for public and private dental clinics nationally, providing a basis for practitioners to participate in clinical research projects organised by professional researchers. The network can be extended to other branches of general medicine by around 2014, by which time UHN will also be providing services for the pharmaceutical industry.

The initial scientific goals will be defined and achieved by the 5 consortium founders, recognising that as the UHN infrastructure and community evolves, it will be applied to a wide range of medical research and health care. The UHN system will include all researchers and students within every institution that joins the UHN community, and along with their clinician colleagues will have access to **invaluable knowledge, data and peer-group resources** enabling them to:

- Locate relevant people, projects, datasets and patient cohorts
- Establish standards – high quality, consistently coded, standardised and searchable data (in collaboration with national associated partners)
- Publish details of projects and datasets
- Comply with national data-protection regulation and hence facilitate ethical approval.

The software tool will make this possible through:

- Data extraction system (scheduling, quality check, protocols, etc.)

- Meta data (data repositories in a scalable environment)

- Data export facility (security, authorization, format control, payment/licensing, etc.)

In other words the objective of the project is to establish and operate an international e-infrastructure that provides data sharing and exploitation opportunities to scientists within the dental R&D area, as well as a platform for innovation and commercialization. The infrastructure all developed and provided out of Norway, will provide easy, secure and transparent access to distributed storage resources, provide aggregate capacities for storage and data transfer, and optimize the utilization of the overall resource capacity. This will be achieved by developing a new infrastructure consisting of following main components.

The e-infrastructure comprises also scalable storage (server architecture facilitating repositories) and internet based export/import data security and user authorization principles. Existing clinical software shall be integrated with the new e-infrastructure.

The UHN project is now in its second year, led by Institute of Clinical Dentistry (IKO) in Oslo in collaboration with 4 institutions. The e-Infrastructure prototype will be implemented and piloted by IKO´s project partners [1]) in 2011 enabling launch, commercialization and general global availability in 2012. Initial deployment will be within similar leading national oral health research institutions, followed by national and regional clinical networks and other oral research institutions. Within the period of this application (2011-2015), the e-Infrastructure will also be extended to enable collection of close-patient data by peripatetic practitioners operating in developing countries.

As a summary the long-term goals for the UHN infrastructure are:

- creation of a universally-accessible network of information resources for Norwegian and international research within dental science, resulting in improved R&D resource utilization, collaboration and results.

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[1]) University of London / King's College / Dental Institute at Guy's, King's College and St Thomas' Hospitals, University Complutense of Madrid / Faculty of Odontology, University of Alabama Birmingham / School of Dentistry, and University of Hong Kong / Faculty of Dentistry

- promote further development and widespread usage of the collaborative infrastructure within universities around the world, led by the Norwegian initiative. Participation in the UHN network (for which the prototype software is already in operation) will enable institutions to drive additional synergistic value from their underlying clinical systems, generating research data as a by-product of normal day-to-day operation
- commercialize the outputs of the project.
- encourage development of a global scientific fellowship, to include researchers who would otherwise be isolated from any collaborative community, particularly in remote areas and developing countries.
- be proactive in international collaboration in infrastructure and computational science.
- disseminate computational science as part of the dental education and research.
- cooperate with medical research in fighting widespread diseases, especially in developing regions of the world.
- offer an effective networking hub supporting patient care and associated research in remote medical centres, outreach clinics and community health centres, particularly in townships and poor rural areas.

- **Expected impact on Norwegian science, technology and innovation in an international perspective**

The impact nationally and internationally it is accounted for under clause 1 *Relevance,* but we emphasize that:

- At national level the **Norwegian Centre for Health Informatics** (KITH) will be an important partner for the institute leading the UHN project, Institute of Clinical Dentistry (IKO) at the University of Oslo.

- The University Health Network (UHN), will because it is based on internationally recognized needs, supply Norwegian health sciences with a tool for unified efforts through **multi-centres studies**. It will represent the content in the communication between academia, regional centres of competence and the practitioners. In the initial stages of national implementation this will come into use within oral health. In the next stages the same pattern or **device aims will be adapted to general public health research and –care**, probably initially within special fields of medicine, e.g. geriatrics and drug addiction care.

- Because of its device, especially the derivation of information at an individual patient level and safe exchange of datasets, UHN is well organized for international exchange and **communication** between single researchers and teams on one hand, and between them and single practitioners and teams of practitioners on the other hand.

3.   Scientific and technological status

- **Status of current research and technological development, main scientific challenges:** As this submission is written (on October 5th 2010), second prototype of the UHN software is under implementation at the Institute of Clinical Dentistry (IKO) in Oslo. It is developed in a cooperation between a small team of engineers based in London and a representative team of researchers at IKO. – The same team tested the first prototype of the UHN software, cooperated with the software developers on

March 17th-18th 2010, and shared their opinions with the UHN Board, as they at the same time had a Board meeting in Oslo. ooo

- **National and international "state-of-the-art" in the relevant disciplines, technologies and research themes, requirements for frontier research:** Clearly the most successful research is produced by teams across institutional and national borders. Each researcher within a team depends on close cooperation with colleagues situated at institutions spread throughout the world. The cohesion of each team is maintained through shared scientific interest and competence. Until now, these researchers have had only email for exchanging information. That is not what one needs to create a collaborative environment for effective sharing of collective data.

- **The scientific environment and development of Norwegian research activities in the field, relevance with respect to the priorities given in the call for proposals:** As it was called attention to in Chapter 1 *Relevance,* Norwegian health research needs a way to get a closer relation to practice: It must be put to use and get relevant feedback in return. The UHN project will aim to raise the competence among the practitioners by diminishing the gap between academia and health care in the regions.

- **The level of existing research infrastructure, the need for the new investment:** Apart from biobank data systems there is no existing internationally applicable system for collecting systemized data at an individual patient level, neither in oral health research nor in other fields of human health. The reasons for this are complex, which is explained under challenges in this description.

- **Scientific ambitions and relevance with respect to the existing national and international research agenda/strategies:** The main scientific aim for the UHN project is to provide for an electronic and user friendly tool for building of networks, within regions, between regions, nationally and globally. UHN will encourage development of a global scientific fellowship, to include researchers who would otherwise be isolated from any collaborative community, particularly in remote areas and developing countries. Also at a national level in the western world such a tool is missing, leading to e.g. institutions´ developing identical facilities or undertaking identical research in isolation. This is well described in the attached letter from King´s College London.

4. Description of the Research Infrastructure

- **Scientific, technological and physical description of the new development and its relation to existing national and international research infrastructure:** Collection of datasets derived in the first stages from electronic dental records (EDR). Beyond the dental environment medicine is also moving to electronic patient record (EPR) systems, and the same need for collaboration exits. With the time it is highly likely that this sector would wish to access the UHN system to facilitate this.

- **Description of the needs and relevance with respect to the technological and scientific challenges:** A scientific challenge is that researchers have no mechanism for sharing large quantities of coherent patient health information from clinical practitioners, leading teaching hospitals and clinical research centres. The UHN

system will make up for that. Worldwide and within the same health field, however, different coding systems are used for e.g. diagnoses. The UHN system will in each case all the same map the patient information into an unambiguous dataset. But as slightly different definitions lay behind the codes, such datasets may represent a source of error. To face this problem the researchers have to communicate across the borders of different coding systems, to make establish to what extent the dataset is reliable.

- **The concerns of the proposal:** The infrastructure concerns a new research infrastructure, it is both a national facility and part of an international network of connected and interoperable research facilities, and the infrastructure is localised, distributed and/or electronically accessible.

- **The national character of the new research infrastructure:**
  - Improved efficiency of utilization of resources (researchers, students and funding) and improved quality of R&D projects as access to data will be significantly extended.

  - The extended data content and aspects of it, can provide new Norwegian led R&D projects not being able to identify or conduct prior to the new e-infrastructure.

  - Areas of R&D can be extended to include data related to humans from other demographic and geographic areas.

  - Manifestation of the Norwegian leading position with dental science.

  - Provide facility for cross functional R&D, as other R&D institutions from life science can extend their perspectives of analyzes to include oral aspects.

  - Provide a standardisation of code systems for exchange and registration of data, enabling national and international collaboration.

- **The main user modes and research disciplines of the intended users:**
  - discover existing projects in a particular field of interest and establish contact for collaboration
  - discover and contribute datasets relevant to a particular field of interest
  - publicize and recruit collaborators for a new project
  - identify patient global patient cohorts matching a profile of diagnoses, treatments, lifestyle, etc. for prospective research projects, and establish appropriate contact with the clinicians responsible for those patients' care.
  - Initially, researchers and students in all aspects of oral health, particularly those engaged in patient interaction, although laboratory and biobank researchers will also benefit. Also clinicians providing close-patient clinical data, normally as a by-product of patient care. Later phases will move beyond dentistry and oral health to include all other medical disciplines.

- **Needs and requirements for the use and development of e-Infrastructure, such as resources for data storage, tools for data handling, electronic services and communication:** Each of the five UHN partners needs a server earmarked for the UHN software and exchange of datasets. Most of the current work associated with Electronic Patient Records and the coding standards associated with diagnosis and treatments have been concentrated on issues of financial and insurance related administration, reporting and patient mobility. There is currently little published material related to the e-enablement of oral health research through the capture, standardisation and sharing of close patient data between leading international institutions. The main technological challenge is seen as ensuring that the procedures for anonymising, storing and sharing the research data are sufficiently robust to be

accepted as both ethical and legal in the jurisdictions of all participating institutions. This part of the project will draw on proven and accepted practice for the anonymisation of patient data in use within the participating universities.

- **Critical factors of the project are associated strategic challenges in the following relationships:**

- **Research scientists – working with – Technologists and Software Developers:** Academic researchers across the four institutions need to understand the objectives of, and collaborate with, their fellow scientists in the other institutions in order to contribute their competence and experience to produce unambiguous structured requirements in a form which the developers of the system can use effectively. This is a challenge for management, which will be overcome by the fact that the coordinators and drivers of the project are the top clinical and academic executives of the four leading institutions.

- **Dentistry and Oral Health – part of but separate from – Medicine:** The identity of Dentistry and Oral Health as a science in its own right is somewhat ambiguous; in some parts of the world, dentistry is a branch within medicine. The challenge is to consolidate dentistry as a science of its own, whilst at the same time promoting cooperation between associated medical fields on the one hand and dentistry on the other.

- **Dentistry and Oral Health – working with – Commerce:** Dentistry depends on related industrial organisations for pharmaceutical products, materials and advanced equipment. These enterprises depend on research, which can be carried out by universities as well as commercial research institutions in return for funding. The independence of such scientific research may be compromised, unless the integrity of individual research teams is reinforced by a "global scientific dental identity".

- **Dental Science – operating within – Research Ethics and Patient Care considerations:** As research techniques become more advanced, dental research must continually review and revise the framework of ethical protocols within which it is carried out, recognising the evolving concerns and legal constraints within various cultures and jurisdictions around the world. Biological material and associated data originate from human beings for whom respect and wellbeing must be the primary concern. The UHN Research Infrastructure must enforce appropriate measures to ensure appropriate patient consent and protect personal information. Collaboration between the institutions leading dental research will enable more secure definition of best practice with respect to ethical research as a whole.

5. Impact on science, technology and innovation

- **Impact on the recruitment to science:**
- Increased possibilities for international collaboration and exposure will increase the attraction of science as a subject.
- The opportunity of using internet technology to participate in multiple collegiate groups of like-minded scientists is in keeping with increasing use by young people of social networking sites such as Facebook and Twitter.

- **Impact on internationalization of Norwegian science:** On-going programme of multi-regional oral health research projects

- **Examples of potential results, other possible use of expected results, contribution from and benefits for all partners:**

- Framework for consistent multi-centre definition of research projects and associated data collection and processing

- Adoption of global standards for data definitions, protocols, patient-record inter-working, security and authentication

- Collection of consistent multi-centre close patient data

- Consistent multi-centre definition of patient cohorts, medical questionnaires, data extraction criteria

- Framework for establishing and utilizing a global biobank database, including interfaces to existing biobank systems.

- Opportunity for universities to access research data on diseases and conditions prevalent in developing countries but not yet widely observable in Europe or USA

- Seamless exchange of researchers, educators and students between universities, based on use of consistent infrastructure

- **New research opportunities for the Norwegian and international scientific community:** UHN will provide framework for bidding for international public and privately-funded research projects which none of the participating universities could undertake individually

- **Impact on future innovation, value creation and national competitiveness:**

- The access to extended database or biobank will represent a strong source for development of new products and services for dental and life science health. Examples can be e.g.:
    - New drug for tooth or oral treatments
    - New diagnostic traits of diseases, related to oral conditions
    - New dental tests to be incorporated as part of the commercial dental activities, reducing potential problems at a later stage
    - Provide data for commercial R&D
    - Provide new elements for the purpose of education

- The outcome will represent new opportunities for commercialization like spin-out's or licensing.

6. User groups

- **Justification of the level of national interest and participation:**

  Within its global context, the UNH network will also provide a Norwegian communications infrastructure to facilitate consistent, coherent, secure transfer and appropriate sharing of health data across universities, regional health agencies, local clinics and practitioners. It will also stimulate and support national collaborative research groups.

- **The needs and interests of national research teams and user groups:**

  National research teams and user-groups will increasingly need access to large coherent data samples in order to generate meaningful epidemiological quantitative analyses and statistically sugnificant patient cohorts Economically, such data sets can only be derived as a by-product of normal clinical patient care. This requires coherent data-capture, secure transmission and data-management, all of which are provided by the UHN network.

- **How the new research infrastructure may create new international research collaboration, its attractiveness for high quality international research groups, the added value of such collaboration, Nordic and European dimension:**

  The new UHN research infrastructure will stimulate the formation of top-quality international research groups as follows:

  Researchers with interests in common can get access to each other's personal, project and dataset details in a sufficiently secure collegiate environment to enable much fuller disclosure than would be possible on open websites.

  Easy-to-use mechanisms for secure, encrypted, anonymized interchange of close-to-patient data in compliance with national data-protection and confidentiality regulations are essential for practical international research collaboration. They do not currently exist.

  At a Norwegian level, there is a current recognised problem in getting dental practitioners to record and transmit their patient datasets back to University of Oslo Institute of Clinical Dentistry for analysis by researchers in a secure, coherent, consistent and economically affordable manner. The UHN network will solve this problem.

  From a European perspective, universities in Norway, Spain, UK and Ireland are using electronic patient record systems which are compatible with the UHN research infrastructure; the UHN standards-definition work will provide a platform to coordinate and promote European interests.

- **Users from industry and/or the public sector, nature of the collaboration and use of research results for innovation:**

  Multi-national industrial corporations such as Colgate and Unilever supplying the global market for oral healthcare products, will be able to commission the kind of multi-regional research made possible by the UHN network. Other examples are

Nobel Biocare, AstraZeneca, Straumann, and Zimmer supplying the rapidly-developing global markets for implant technology.

- **Nature and goals of relevant ongoing and future projects. List examples of relevant funded current national and international research projects:**

The Norwegian Government's NORAD, along with agencies from the UN, the EU and from other developed countries (USAID, DFID, Irish Aid, etc) have already funded projects in sub-Saharan Africa which assemble health information at a district or regional level. This provides for initial epidemiological research, and the UHN network can leverage this investment by enabling health information collection at the individual level necessary for treatment planning and delivery, or for more analytical research.

Funding would be sought for an oral-health project based on the use of the UHN research infrastructure as a way of building on these earlier projects, and will be the next logical step in a multi-phase project. NORAD works alongside other agencies such as CIDA, UNICEF, the Bill and Melinda Gates Foundation, USAID, the Doris Duke Charitable Foundation, WHO and the World Bank in programmes such as "The Catalytic Initiative"

- **Estimation of the total use, annual number of Norwegian and international scientific users, industrial/public users:**

Users	2011	2012	2013	2014	2015
Norway					
- Researchers	50	100	100	200	300
- Hospital Clinicians	300	300	400	600	800
- Local Dentists	100	200	500	1000	1000
International					
- Researchers	250	500	1000	2000	4000
- Hospital Clinicians	100	200	400	800	1600
- Local Dentists	10	200	1000	2000	4000
Industrial					
- Researchers	0	10	20	30	50
Public Sector					
- Epidemiologists	0	10	20	50	100
Total	*810*	*1520*	*3440*	*6680*	*11850*

7. Partners

- **Description of the scientific consortium, the research groups, institutions, possible partners from industry or public institutions, international partners:**

The initial scientific consortium will consist of multi-centre project teams and departmental liaison groups from the UHN founding institutions:

- o University of Oslo, Faculty of Dentistry, Institute of Clinical Dentistry
- o University of London / King's College / Dental Institute at Guy's, King's College and St Thomas' Hospitals

- University Complutense of Madrid / Faculty of Odontology,
- University of Alabama Birmingham / School of Dentistry
- University of Hong Kong / Faculty of Dentistry

This initial consortium will extend as follows:

- Other Dental Schools and hospitals in Norway and regions with ties to the founding partners: Scandinavia and Northern Europe, Southern Europe, USA and Canada, China, South-East Asia and Australasia, sub-Saharan Africa and South America.
  - Other Dental Schools and hospitals in other regions.
  - Public Health Authorities in Norway and internationally
  - General Dental Practitioners in Norway and internationally
  - Researchers in major corporations supplying dentistry and oral health products
  - Medical schools, teaching hospitals, universities and other academic institutions involved in medical research in Norway and internationally
  - Peripatetic therapists delivering healthcare in developing countries.

- **Documentation of the scientific and technological competence of all partners, their roles, expertise, responsibilities and commitments (as partner, host, contributor), priorities with respect to their individual strategies:**

The founding UHN consortium members all represent research-based universities recognised internationally as leaders in the field of medical research in general and oral health research in particular. These institutions will continue to lead the specification of the research infrastructure functionality, definition of medical and other coding systems, etc., and will be the pilot users. The Deans of these institutions have written endorsement letters indicating their recognition of the value of the UHN project and the strength of their commitment to it.

A working prototype of the software and communications technology has been developed by Ian Finch & Associates, a small international project team, all of whom have specialist knowledge and extensive experience in the field of dental and oral health IT technology. The team was brought together specifically for, and is entirely dedicated to the UHN project. The team is liaising with specialists within Microsoft Health Solutions Group, regarding use and potential development of specific Microsoft products and technologies relevant to the UHN project. The prototype is being used and evaluated by the five UHN founding universities in order to validate the functionality and design, and to prove its security, authentication and data-encryption capabilities.

- **Describe specifically the institutions involved and expertise needed in the relevant phases of design, construction and/or operation of the new or upgraded research infrastructure:**

See above for the institutions involved. The expertise needed includes:

- Software development and global deployment, maintenance and support
- User-interface design in a clinical/research environment
- Medical research methodologies, terminology and processes, initially with particular reference to dentistry and oral-health
- Ethical and patient-confidentiality regulations and requirements

- o Electronic patient record databases
- o Clinical data interpretation, repair and cleansing
- o Medical coding systems and their application
- o Public-key encryption systems and digital certification
- o Secure international data-communications and messaging
- o Project management

8. Project management

- **Project management, administration of roles, competence and contribution of the partners in the relevant phases of design, construction and/or operation:**

  Overall management of the project including funding, participation of other universities and institutions and timescales will be the responsibility of the UHN Board, chaired by Prof. Pål Barkvoll (University of Oslo), with the Deans of the other founding institutions serving as Board Members.

  Within the framework determined by the UHN Board, project management of the technical infrastructure development will be the responsibility of the developers (Ian Finch & Associates). The CVs of the individual concerned demonstrate extensive senior management and project management in the relevant fields. Most of the founding institutions have worked with the key individuals over a period of several years. Delivery of an excellent working prototype of the infrastructure in a remarkably short timeframe is the best possible verification of the necessary competence and commitment.

- **Justification of suggested localisation, host institution(s), alternatives that have been considered, opportunities and risks:**

  The UHN project was conceived and initiated by the University of Oslo, which acts as the "host" of the project only for management and governance purposes and for custody of Intellectual Property on behalf of UHN. Operationally, the UHN global research collaboration infrastructure has been designed to operate as a peer-to-peer information resource network rather than as a central "data-warehouse" so its operations are not specifically "localised" to any of the participating institutions. This architecture avoids possible extra-territoriality problems regarding transmission and storage of sensitive personal data, and similarly avoids any "single point of failure". It opens up the opportunity for the participating universities to act as "hubs" for outreach clinics, general dental practitioners and public health organisations. The UHN network architecture allows the participating universities to collect and supply coherent data to and from their "satellite" institutions with the same degree of security and control as for the interaction between the universities themselves.

  The UHN network management centre will initially be situated in London and operated by the software development team. This centre manages the distribution of software updates, and hosts a log file which records digitally-signed agreements of the roles and responsibilities of multi-centre collaborators on a project, terms and conditions under which collaborators may have access to each other's data, etc. This UHN network management centre is not involved in the transmission or storage of any sensitive data, which takes place entirely on a peer-to-peer basis.

- **How the research infrastructure will be managed subsequent to the project period, responsibilities for construction, operation and upgrade, how the new research infrastructure fits into the host institutions long term planning and research strategy:**

  Subsequent to the project period, development priorities and control of membership will continue to be managed by the UHN Board. This Board will also determine license fees, subscription rates and allocation of funds thereby raised.

  Software development and support, and management of the UHN infrastructure will be contracted out on a commercial basis.

  Exploitation of the research opportunities opened up by the UHN network will play a fundamental part in the evolution of research strategies and plans on the part of participating institutions:

  - o closer integration of research with clinical patient care
  - o accessibility of vastly larger volumes of close-to-patient data
  - o ability to compare and contrast findings from patient research cohorts from different regions and ethnicities
  - o access to world-leading subject-specialist researchers and clinicians
  - o appropriate and secure access to datasets resulting from past projects
  - o access to close-to-patient data from developing countries with endemic disease patterns not yet epidemiologically significant in developed countries
  - o opportunities to create "rapid reaction" global research teams in response to emerging pandemics, with the possibility of direct access to detailed, accurate relevant clinical data.

9. Plan for access and use, data and knowledge management

- **How access to the new research infrastructure will be effectively managed, principles of project selection, capacity issues:**

  Individual user's access to the UHN network is controlled by a series of "permissions" administered by their university or other institution. This will ensure that the infrastructure is only used for projects and purposes which are approved by appropriately senior and qualified staff. It is, however, up to each institution to set its own priorities and to encourage researchers in the other UHN member institutions to support and collaborate in the projects it nominates and registers on the network.

  The peer-to-peer architecture of the network ensures that there are no technical limits to its scalability in terms of the number of participating institutions or the volumes of data shared.

- **Knowledge management, transfer and utilization in innovative environments, how data and knowledge are generated, managed and made available for research and innovation, the transfer of knowledge and results to academic, industrial and public partners:**

  "Knowledge management, transfer and utilization in innovative environments" is the essence and purpose of the UHN network. Careful consideration and significant development resource has therefore been applied to:

  Tools for searching and discovering people, projects, datasets and patient cohorts

Facilities for requesting, generating and supplying specific datasets

Systems for protecting intellectual property, ideas and methodologies particularly when associated with commercial projects, and/or for managing the appropriate timing for disclosure and publication.

Systems for protecting confidential patient data, including the identification and authentication of the named individuals who accept responsibility for appropriate access and use of other institutions' data, and the third-party logging and recording of the associated mutually-signed agreement documentation.

- **Policies for publications, patents and the dissemination of research results:**

This remains entirely a matter for agreement between collaborating institutions. The role of the UHN research infrastructure is solely the logging and recording of such agreements, along with the terms and conditions governing any associated subsequent clooaborative activity transacted using the UHN network.

- **Use of electronic services and portals, databases, sample and publication archives, etc.:**

A design principle of the UHN network is that it should interact with and make use of any other internal or external systems, rather than attempt or require their replacement or duplication. This principle can be observed in the working prototype, which uses existing email systems, electronic dental record systems and external search engines such as PubMed and Google.

10. Time-schedule and deliverables
- **Detailed time-schedule for the main activities and progress of the project:**

Activity	Schedule Dates	Status
Creation of the UHN founder consortium	2008 - 2009	Achieved
Development of requirements and commissioning of initial demonstration prototype ("P1")	2009	Achieved
Delivery and review of P1	Mar 2010	Achieved
Commissioning of second (working) prototype ("P2")	Apr 2010	Achieved
Delivery and implementation of P2 in Oslo	Oct 2010	Achieved
Usage and review of P2 in Oslo	Nov/Dec 2010	In plan
Implementation, usage and review of P2 in London, Birmingham Alabama, Madrid, Hong Kong	Dec 2010 – Mar 2011	In plan
Recruitment of and implementation in ~20 General Dental Practitioners in Norway	Jan 2011 – Apr 2011	In plan
Development of GA ("General Availability") software package based on P2	Jan 2011 – Mar 2011	In plan
Release of GA V1.0	Apr 2011	In plan
Recruitment of and implementation in ~25 "Phase 2" university dental schools globally	Apr 2011 – Dec 2011	In plan
Implementation in a regional public dental health authority in Norway	Apr 2011 – Dec 2011	In plan
Recruitment of and implementation in ~100 "Phase 3" university dental schools globally	2012	To be planned

Recruitment of and implementation in national biobanks	2012	To be planned
Extension of infrastructure to include other medical disciplines	2012 - 2014	To be planned
Implementation in universities in South Africa and Colombia	2013	In plan
Development of laptop-based peripatetic therapist version of software, including clinical data-gathering	2012 - 2013	To be planned
Recruitment of and implementation in more universities and in corporations	2013 - 2014	To be planned
Further global extension to primary and secondary care research institutions, developing countries, public health authorities, corporations	2015 and beyond	To be planned

- **Milestones and project deliverables in relation to the relevant phases of the design, construction, installation, test periods, operation and/or possible upgrades and decommissioning:** See table above.

- **Emphasise critical dates with respect to funding and commitments, the technical and scientific development:** Cf. table above: Critical dates are most likely the ones connected to recruitment of private corporations and industry.

11.   Budget and funding plan

**Kostnader forbundet med innkjøp og etablering av infrastrukturen /
Expenses related to Purchase and Implementation of the Infrastructure**

In 1000 NOK:

	Year 1	Year 2	Year 3	Year 4	Year 5	Sum
Lønn og indirekte kostnader / Payment and indirect Expenses 1)	16598	17260	14454	14943	17260	80515
Direkte kostnader til utstyr / Direct Expenses for Equipment 3)	500	180	250	0	350	1280
Andre kostnader / Other expenses 2)	495	520	525	540	560	2640
Totalt / Total	17593	17960	15229	15483	18170	84435

1) This line relates to heading A) below; Compensation related to Full Time Equivalents (FTEs).
2) This line relates to heading B) below; Other expenses = journeys / allowances for board.
3) This line relates to heading C) below; Hardware.

A) *Calculated Payment / Compensation related to Full Time Equivalents (FTEs)*

Assumptions according to the Categories of Personnel A) – G) (Cf. left column below)

A)   **UiO Researcher** Full Time Equivalents (FTEs) for: Data-recording standards definition, "core data" definitions, medical and other coding, system evaluation, requirements planning. Wage scale associated professor UiO low 57 – professor high wage scale. 98) Average wage scale gross 681 100 + 23 % indirect cost = NOK 837 753

B)   **Researchers at the other 4 UHN Founder Universities** Full Time Equivalents (0,5 FTE x 4) for: Data-recording standards definition, "core data" definitions, medical and other coding, system evaluation, requirements planning. Calculated same average payment as UiO + VAT 25 %.

C) **UiO IT Staff** for UHN support. Average wage scale 63 gross NOK 500 700 + 23 % indirect cost = NOK 615 861

D) **IT Staff at the other 4 UHN Founder Universities** (x 4) Calculated same average payment as UiO + VAT 25 %

E) **Developing Software Company** (Vendor) of the UHN software (London): FTE average NOK 700 000 per year included Indirect cost + 25 % VAT

F) **Project Leader UiO**: FTE per year NOK 944 300 gross + 25 % VAT = per year NOK 1 161 489, included indirect 23 % cost: NOK 1 274 527

G) **Administration UiO**; FTE wage scale 69 NOK 687 447 included indirect 23 % cost.

In general: Payment put to 2010 level for 2011, then 3 % annual rise in payment from 2012. All persons paid per invoice to UiO. In the year of launching 2012 more activity calculated.

Category of Personnel	Year 1 2011	Year 2 2012	Year 3 2013	Year 4 2014	Year 5 2015	Total FTEs
A: FTEs	2,35	2	2	1,75	2	10,1
Amount A	1,968,720	1,725,772	1,777,545	1,602,012	1,885,797	
B: FTEs	2	2	2	2	2	10
Amount B	2,094,383	2,157,214	2,221,931	2,288,589	2,357,247	
C: FTEs	0,7	0,6	0,6	0,6	0,6	3,1
Amount C	431,103	380,602	392,020	403,781	415,894	
D: FTEs	8,4	8,8	4,4	2,4	2,4	26,4
Amount D	6,464,858	6,975,890	3,592,583	2,018,379	2,078,930	
E: FTEs	5	5	5	6	7	28
Amount E	4,375,000	4,506,250	4,641,438	5,736,817	6,893,741	
F: FTE	0,2	0,2	0,3	0,8	1	2,5
Amount F	232,298	239,267	369,667	1,015,353	1,307,267	
G: FTEs	1,5	1,8	2	2,5	3	10,8
Amount G	1,031,170	1,274,527	1,458,625	1,877,980	2,321,183	
Total	16,593,532	17,259,522	14,453,809	14,942,911	17,260,059	90,9

B) *Other expenses* = *journeys / allowance for board*

In General: Some more costs in the year of launching. Except that annually 3 % rise of costs. 2 annual UHN Board meetings included secretary. 2 annual meetings for 10 involved researchers and Developing Software Company representative

Year 1: NOK 495 000
Year 2: NOK 520 000
Year 3: NOK 525 000
Year 4: NOK 540 000
Year 5: NOK 560 000

C) *Hardware:*

Year 1: Investment NOK 100 000 x 5 sites = NOK 500 000
Year 2: Demo-equipment for launching: kr. 180 000
Year 3: Upgrading IT: NOK 50 000 x 5 sites = NOK 250 000
Year 4: NOK 0
Year 5: Upgrading IT: kr. 70 000 x 5 sites = NOK 350 000

Finansiering av infrastrukturens innkjøp og etablering/
Funding for the Purchase and the Implementation of the Infrastructure

In 1000 NOK:

	Year 1	Year 2	Year 3	Year 4	Year 5	Sum
Konsortiets egenfinansiering / The Consortium´s own Funding	400	0	250 *	0	350 *	400
Internasjonal finansiering / International Funding	0	1440	4008	6304	8256	20008
Annen offentlig finansiering / Other Public Funding	0	0	0	2000	7000	9000
Annen privat finansiering / Other Private Funding	0	0	0	0	0	0
Fra Forskningsrådet / From the Reserch Council	17193	16520	10721	7179	2214	54427
Totalt / Total	17593	17960	15229	15483	18170	84435

*
Finansiering av infrastrukturens drift (etter at denne er etablert) /
Funding for the Running of the Infrastructure (after Implementation) is
included in the table above.

Funding / Revenues:

Year 1: UiO pays NOK 400 000 Other UHN-founder members pay 0,- New UHN members: 0 = Total 400 000

Year 2: New UHN members: 4. Each pays 45 000 Euro = NOK 360 000. Total in: 1 440 000

Year 3: New UHN members: 12. Each pays 41 000 Euro = NOK 328 000. Total in: 3 936 000. Total number of UHN members except the UHN-founders: 16. 4 UHN members Pay annual subscription rate: 3 000 euro = NOK 24 000 x 4 = 72 000. Total in: NOK 4 008 000

Year 4: New UHN members: 20. Each pays 37 000 Euro = NOK 296 000. Total in: 5 920 000. Total number of UHN members except the UHN-founders: 36. 16 UHN members pay annual subscription rate: 3 000 euro = NOK 24 000 x 16 = NOK 384 000. Total in: NOK 6 304 000

Year 4: Developmental Funding: NOK 2 000 000

Year 5: New UHN members: 28. Each pays 33 000 Euro = NOK 264 000. Total in: 7 392 000. Total number of UHN members except the UHN-founders: 64. 36 UHN members pay annual subscription rate: 3 000 euro = NOK 24 000 x 36 = NOK 864 000. Total in: NOK 8 256 000

Year 5: Developmental Funding: NOK 7 000 000

12.   **Environmental and ethical perspectives**

- **Potential consequences on the natural environmental of the infrastructure and research activities:**

    Possible consequences for the environment are entirely positive:

    o   Use of the UHN network will avoid waste and duplication of effort
    o   Collaboration via electronic networks will help to reduce the need for international travel

- **Potential ethical issues related to the research infrastructure, the research projects, or the results from the research:**

    Utilization of data from developing countries with weak policy

    Strictly speaking, the infrastructure itself is neutral with respect to ethical considerations – ethics must be primarily the concern of the collaborative projects which are making use of the infrastructure.

    However, the emphasis implied by the UHN network's focus on functionality related to enabling good governance, transparency, auditability, patient confidentiality, "permissions" and observance of levels of authority can be expected to engender more rigorous universal adherence to ethical guidelines, and a transference of "best ethical

practice" to regions and countries which aspire to join the UHN community of prestigious medical research establishments.

Professor NHF Wilson
CBE FKC
Dean and Head of
Dental Institute
Deputy Vice Principal
(Health Schools)

Central Office
Floor 18, Tower Wing
Guy's Hospital
London SE1 9RT
Telephone +44 (0)20 7188 1164
Fax +44 (0)20 7188 1159
nairn.wilson@kcl.ac.uk

KING'S
College
LONDON

To whom it may concern
Norwegian Council of Research

23 September 2010

Re: University Health Network

King's College London Dental Institute (KCLDI) is part of King's College London which is one of the leading universities of the world (2010 QS international world rankings), *The Sunday Times* 'University of the Year 2010/11' and the fourth oldest in England. A research-led university based in the heart of London, King's has nearly 23,000 students (of whom more than 8,600 are graduate students) from nearly 140 countries, and some 5,500 employees. King's is in the second phase of a £1 billion redevelopment programme which is transforming its estate.

King's has an outstanding reputation for providing world-class teaching and cutting-edge research. In the 2008 Research Assessment Exercise for British universities, 23 departments were ranked in the top quartile of British universities; over half of our academic staff work in departments that are in the top 10 per cent in the UK in their field and can thus be classed as world leading. The College is in the top seven UK universities for research earnings and has an overall annual income of nearly £450 million.

The Dental Institute
The substantial reputation of KCLDI attracts students and staff from across the globe. As the largest dental academic centre in Europe, we teach over 800 undergraduate students, 260 graduate taught students including 160 on distance learning programmes, and over 70 graduate research students to a high international standard.

Students admitted to dentistry and allied courses of study benefit from innovative curricula taught by internationally renowned staff at some of the most famous hospital campuses including Guy's, King's and St Thomas' Hospitals. In the last Teaching Quality Assurance Subject Review the Institute achieved the top grade of 24/24.

The 2008 Research Assessment Exercise (RAE) confirmed King's eminent position in the 'golden triangle' of research-intensive universities in London and Oxbridge. Indeed using the 'research power' analysis, where the average point score for each unit of assessment in the RAE is multiplied by the total number of full-time equivalent staff entered, the Dental Institute was ranked first in the country. The total of 68 principle investigators coupled with the RAE result provides strong evidence of research excellence and critical mass within the Dental Institute.

In the wider setting of the Health Schools in 2006-7 King's received more new awards from the Medical Research Council than any other UK university, and in 2007-8 received more new awards for health sciences research than any other university in the country.

Need for UHN
Generally translational medical and dental research is organised by individual research institutions with little, or no, national or international coordination of such activities. As a result of this several institutions may be developing identical facilities or undertaking identical research in isolation leading to increased cost and time delays. The aim of the University Health Network (UHN) is to build on the expertise and reputation of 5 leading international dental centres to develop a global network of of oral health teaching and research institutions to collaborate in medical research, transfer best practice in teaching and institutional administration and to share information and resources in the development of standards and infrastructure for information technology support of practice, teaching and research. This is entirely in keeping with the aim of the European Strategy Forum on Research Infrastructure (ESFRI) and is highly supported by KCLDI.

With time new centres will join which will link to, and build upon, the best practice example of the established founder centres which KCLDI would welcome. At the same time each founder centre will develop an efficient national coordination (which will be via the ADH's in the UK) with the aim of integrating existing resources to provide a better infrastructure to be best placed to respond to local, national or international demands.

In the United Kingdom the Department of Health has championed the development of bioinformatics and is anxious to see the development of this area. The aim of this is to enable all patient data to be captured and made available for research locally, regionally, nationally and internationally. Within the Association of Dental Hospitals (ADH) this is taking the form of improved infrastructure and the implementation of an Electronic Dental Record (EDR) system, using the same supplier and with agreed minimum data set requirements. King's Healthcare Partners (KHP), one of the UK's five Academic Heath Science Centres, which brings together King's College London with three leading NHS Foundation Trusts (Guy's and St Thomas', King's College Hospital and South London and Maudsley) have stated that they wish to deliver International calibre research and foster translational research. KHP are therefore firmly committed to the principle of the UHN which they see as key to achieving these aims.

Within KCLDI all principle investigators will have access to the UHN system as will all research students and those on taught masters programmes (under the guidance of their supervisor). The UHN will offer these individuals invaluable assistance in maximising the opportunities afforded by the data collection by providing the ability to:

- Locate relevant people, projects, datasets and patient cohorts
- Establish standards – high quality, consistently coded, standardised and searchable data *(in collaboration with the ADH)*
- Publish details of projects and datasets
- Comply with applicable security and hence facilitate ethical approval.

It will therefore enable researchers to identify, at the outset, whether a particular project is viable within the host institution, requires external collaborators or is not feasible.

Public utility
The development of EDR systems within the ADH will greatly improve the homogeneity of data collected within the group and potentially facilitate collaboration. For this to occur researchers must be able to seek out appropriate collaborators and share data securely which is an area that the UHN software is uniquely positioned to support.

The system also provides an opportunity for those in primary care settings to contribute to research. This is likely to be of great interest to those working in dental public health whose research would be greatly facilitated by the advent of the UHN.

Beyond the dental environment medicine is also moving to electronic patient record (EPR) systems and the same need for collaboration exists. With time it is highly likely that this sector would also wish to access the UHN system to facilitate this.

Access
Whilst the software is being developed for, and led solely by, academia it is likely to be of significant interest to many other bodies and groups. These would include the Department of Health, Welcome Trust, National Institute of Health (NIH), International Association for Dental Research (IADR) and British Society for Oral and Dental Research (BSDR) and many specialist societies. Similarly health care industries are likely to wish to have access particularly where specific patient cohorts or clinical expertise were required.

Development
The UHN is a long-term project which will require the ongoing feedback of users during development. To achieve a fully integrated and user friendly system which if "fit for purpose" this involvement must be from an early stage. This approach would also ensure that researchers felt a degree of "ownership" which is likely to enhance acceptance an uptake of the tool. KCLDI is fully supportive of this approach and has identified a lead principal investigator to co-ordinate the necessary support for the project at all stages of development.

Hurdles
The principal rate determining step in the project is the implementation of the NPFIT, EDR programme within the host Dental Hospitals: Guy's and St Thomas' NHS Foundation Trust (GSTT) and King's College Hospital NHS Foundation Trust (KCH).

The current situation is that full funding is available for this at GSTT during the 2010-2011 financial year and at KCH during the 2011-2012 financial year. The proposal is therefore to deploy the EDR system at GSTT in the first quarter of 2011 following which a pilot trial of the system will be undertaken during the 2nd and 3rd quarters before full roll out in the 4th quarter. During this period a fully integrated system will be established at KCH.

Further UHN developments will facilitate the implementation and application of this resource and enhance its value to the host imstitutions.

Future
The development of the UHN software is an exciting, timely project which offers the possibility for greatly enhanced collaboration both nationally and internationally. In the United Kingdom it comes at a time when all of the University Dental Hospitals are investing in information technology infrastructure including EDR which will provide the basis for data collection. This process is ideally timed to dovetail with the UHN developments which will provide much needed structure and assistance in developing quality data collection and secure transmission of selected extracts both nationally and internationally, whilst maintaining appropriate levels of security. The outcome will be a much needed contribution to the development of evidence-based practice.

In view of the above KCLDI is pleased to lend its unqualified support to the UHN project and its application for funding to the Norwegian Council of Research for this innovative and much needed strategic development.

Yours sincerely

Professor Nairn Wilson

UNIVERSIDAD COMPLUTENSE DE MADRID
FACULTAD DE ODONTOLOGIA

DECANATO
Plaza Ramón y Cajal s/n, 28040 Madrid
Teléfono: +34 913941901
e-mail: decanato@odon.ucm.es
http://www.ucm.es/centros/webs/fodon

Madrid, September 20ᵗʰ, 2010

NORWEGIAN COUNCIL OF RESEARCH, E- INFRASTRUCTURE

Dear Sirs,

The University Complutense of Madrid (Spain) through its Faculty of Odontology fully supports the application of the project: UNIVERSITY HEALTH NETWORK made by the Institute of Clinical Dentistry from the University of Oslo

Our Dental Faculty will prioritize this research project and all necessary e-infrastructure will be implemented in order to assure the appropriate research setting at our end.

We strongly believe that modern health research demands high-quality patient information in order to gather the necessary evidence to support our diagnostic, preventive and therapeutic decisions.

We are looking forward to having the possibility to test the proposed e-infrastructure prototype that will be enable us to network and share our patients information data in order to fulfil our research objectives.

With this letter, the Faculty of Odontology at the University Complutense of Madrid fully supports the application to the Norwegian Council of Research, E-Infraestructure by the Institute of Clinical Dentistry from the University of Oslo.

Sincerely,

Mariano Sanz
Dean

BY FAX & MAIL
+ 47 22 85 23 06

September 29, 2010

TO WHOM IT MAY CONCERN

Recommendation for the Project University Health Network (UHN)

As the Dean of the Faculty of Dentistry at The University of Hong Kong, I hereby confirm that my Faculty is a member of the consortium of five dental colleges with the project University Health Network (UHN), and I have no hesitation to recommend that this most promising project is supported by a grant to its leading university, The University of Oslo, Institute of Clinical Research.

Key Information about Faculty of Dentistry at The University of Hong Kong:

We train 250 dental students in total, and graduate annually 50 dentists. Our postgraduate programme is perhaps the largest in Asia with students from some 30 countries. We annually graduate about 20 PhD candidates, and 150 candidates are enrolled in our taught postgraduate programmes in seven sub-disciplines of specialization.

Our key academic personnel comprises 45 Faculty members (full Professors, Assistant and Associate Professors). The fields of research in which the Faculty of Dentistry at The University of Hong Kong is rated high are biomedical and tissue engineering, infection and immunity, and public health and healthy ageing. Indeed, we publish the largest number of ISI publications per research active staff amongst all ten faculties of The University of Hong Kong, which is consistently rated as the top university in Asia (by the Times Higher Education Supplement Survey of UK).

The Need for the UHN Software:

Our best researchers collaborate with research teams both within the community of Hong Kong, regionally and globally. Our clinical research is highly dependent on maintenance of a flawless, dependable and a highly accessible database derived from the patient records and their biobanks.

..../2

- 2 -

The collection, collation and archiving such data is resource-intensive, and laborious. The UHN will make it possible to access rapidly the required datasets not only from our local patient population and the recording system, but also from data systems in use worldwide including the current UHN members and the future participants.

Undoubtedly, the novel system will enable researchers to exchange and create large-scale datasets, among the five UHN institutions. As more entities are given access our University can collaborate with clinics and research institutions in Asia and worldwide to synergize important clinical research.

Access, Availability and Process:

As per the proposal it is envisaged that in its first phase UHN will focus on collaboration among the five UHN member institutions. This is to ensure that its software meets the needs of researchers from different regions of the world. As proposed after a phase of two years, access will be given to other institutions, which from then on will take part in the continuously increasing community for exchanging datasets.

As a member of the UHN Board, I provide full support to this proposal for the foregoing reasons. Please do not hesitate to contact me if you require further amplification of the above.

Yours sincerely,

Professor L.P. Samaranayake
Dean of Dentistry
Tam Wah Ching Professor in Dental Science

September 20, 2010

NORWEGIAN COUNCIL OF RESEARCH, E-INFRASTRUCTURE

Dear Council Members,

Please accept this letter affirming the University of Alabama at Birmingham School of Dentistry's support for the UNIVERSITY HEALTH NETWORK (UHN) by the Institute of Clinical Dentistry from the University of Oslo. We believe that the clinical and research communities can benefit greatly from such a project that provides us with a standard platform for collaboration and exchange.

Our university thrives on research and the use of our clinical information system brings with it great potential for data mining and exploration. This potential is maximized if we can compile our data with data from other universities. The prospect of assembling and consolidating data across organizations is currently not an option despite the need for it. The proposed UHN project expands the capability to use clinical data and to combine this data within joint research alliances with other universities. Furthermore, it is important that an international e-infrastructure be established to address concerns over security and research ethics as a prerequisite to information exchange, and the UHN proposes a mechanism to accomplish this. Our university will assist this process by providing technical security and ethics standards requirements for our region.

This project will pose some challenges as the organizations involved must come to some agreements regarding the meaning and use of the data and this will take several years to define as the technical portions of the tool continue to be developed. However, we have been involved in similar such efforts and it is doable with diligent effort and dedicated teams such as ours involved in the project. The outcome will prove to be well worth the effort, yielding a tool which will serve as the perfect supplement to the Electronic Dental Record (EDR). We are pilot testing our EDR now, and hope to be able to implement the full EDR with the UHN international e-infrastructure.

In summary, to conclude, the University of Alabama at Birmingham School of Dentistry fully supports the application to the Norwegian Council of Research E-Infrastructure by the Institute of Clinical Dentistry from the University of Oslo.

Sincerely,

Huw F. Thomas, BDS, MS, PhD
Dean, School of Dentistry

Curriculum vitae: Pål Barkvoll

Professor dr.odont. (Oral Surgery and Oral Medicine)
Chief Executive Director Institute of Clinical Dentistry

Born in Oslo, Norway May 16, 1959.

Present positions:

Chief Executive Director – Institute of Clinical Dentistry (1999 – present)
Professor in Oral Surgery and Oral Medicine (1995 – present)

Education:

- Cand.odont - DDS. University of Oslo (UiO), 1984
- Dr. odont. (PhD) University of Oslo, 1991. Thesis "Actions and interactions of sodium lauryl sulfate and chlorhexidine in the oral cavity"
- Specialty training – oral surgery and oral medicine 1988-1992
- The Executive Officer Course, The Norwegian National Defense College 1997

Research:

36 scientific papers published in international journals
3 book chapters
55 scientific abstracts - presented at different scientific meetings
25 papers in Norwegian journals and papers (popularization of scientific material)
Main supervisor for 3 doctoral degree students.
Supervisor for post graduate students and master students. 8

Experience as a Chief Executive Director for the Institute of Clinical Dentistry from 1999 and until today .

The institute was established in 1999 after a reorganization of the Dental Faculty at the University of Oslo. 13 clinical and preclinical teaching and research departments (oral surgery and oral medicine, pediatric dentistry, pharmacology, orthodontics, periodontics, endodontics, oral and maxillofacial radiology, geriatric dentistry, cariology, phrostodontics, biomaterials, public dental health and pathology) were included in this new institute together with 3 operative clinics and one clinical research laboratory. The institute has 55 000 patients visits a year and for the moment almost 450 employees. 91 scientific papers were published in well known international journals during the year of 2007. The teaching activity includes 180 dental students in the clinical terms; 60 dental hygienists, 35 PhD students and 50 post graduate students.

I was chairing the reorganization process before the institute was established in cooperation with the employees, the unions, the students and the authorities. I was furthermore appointed as the first Chief executive director and top responsible for all activity at the Institute in 1999. I still held this position.

During this almost 10 years I have been concerned about effective operations and teaching in the clinics, funding of research for the scientific departments, building up an international network of other Dental Schools. The last year I have been giving lectures

in Hong Kong, USA, South Africa, Ireland and Sweden based on the experience of an electronically based dental record (EDR) and an administrative system. I have been central in the development of this system from 2001. In Oslo this has been a success as a steering tool giving a lot of information regarding the student and patient activity. Information from the system could easily be used in research. We were going live with system on all clinics in 2005. The patient income increased by 100 % from 2005 to 2007 based on better control routines given by the EPD (Electronic patient diary). Implementation and operation of this EDR has been done under my strict supervision. Almost 50 % of the student Masters Degrees are based on information from the
In April 2008 I was the host for an International Meeting on theme "Electronical Dental Records (EDR) in Dental Education and Operation – based on the global leading role we have experienced for the moment. A lot of Dental Schools from a around the world participated in this meeting.

IAN FINCH - CV

CEO of Ian Finch & Associates Ltd.

M.A., Jesus College Cambridge – Mathematics & Moral Sciences
15 Carmalt Gardens, London SW15 6NE, U.K. Tel: +44 7970 891171
Date-of-Birth: 18/12/1947

An experienced senior consultant and executive manager in the telecoms and IT industry, with
extensive international experience in electronic information exchange, particularly in healthcare.

He has held senior management positions in IBM, GE, C&W and a specialist software company
serving UK hospitals, and has been CEO of several international businesses. He has a strong
reputation for innovative marketing, company growth and sound operations.

Two Ten Health – CEO of company providing specialist software for Dental Schools.

Cedar Group – Marketing responsibility for company providing specialist administrative and financial
management software for the majority of acute hospitals throughout the UK.

PFA Limited – Co-founder of a company specializing in e-commerce consulting, education and research. Personally managed project to develop and deliver an education programme for the UK National Health Service supporting secure electronic interchange of clinical data between primary care institutions (general practice family doctors) and secondary care (acute hospitals and pathology labs). Europe-wide research programme for IBM on healthcare telematics, and Europe-wide data-interchange project for the European Commission.

Two-Ten Health CEO 2006 – 2008

Cimax B.V. (Holland) CEO (Process Modelling Software) 1998 – 1999

Cedar Group Group Marketing, Europe/Asia Operations 1999 – 2002

Cable & Wireless Divisional Marketing Director 1990 – 1992

PFA Limited Co-founder 1988 – 1998

G.E. Info. Services UK Sales Manager, International Marketing Director 1985 – 1988

IBM (UK & USA) Systems Engineer, Sales, Marketing 1968 – 1985

PAUL BEARD – CV

Main associated of Ian Finch

Born: 4th August 1954 Education: M.A., Jesus College Cambridge - Computer Sciences
66 Devonshire Road, London, U.K. Tel: +44 7711 548314

An experienced IT professional with a track record of successful management and delivery. He has worked in senior technical positions for SD Scicon, Cable & Wireless, GlaxoSmithKline and Motorola and has experience of creating and managing successful technical teams in technology start-up companies. He has over 25 years experience in the I.T. and Telecommunications industries..

Independent Consultant 2007 – date

Two Ten Health - Requirements definition of a membership system for the Royal College of Surgeons. Functional Specification for new Finance sub-system for the Salud product. Advice on process and procedure adoption for customer requirement specification.Consultancy on platform choice and development strategy for updating the Salud product.
Capita plc. - Procurement of Capita U.K. and Internationl network (£30M contract value). Technical and business requirements, commercial and contract negotiations.

Vodafone - In depth study on technical deployment and cost of ownership on Remote Access network
facilities for five of Vodafone's major corporate customers.

BT Wholesale - Study into technical suitability, market position and competitive pressures on BTWholesale core product offerings. Report on competitive market position of BT-Wholesale Ethernet and IPVPN products in the carrier wholesale market.
Bid Management Limited Technical Director 2002 – 2007

Motorola Drector of Global Account Management 1999 – 2002

Glaxo Welcome Telecommunications Manager 1998 –1999

Cable & Wireless Director of Technology (Regional Bus.) 1996 - 1998

General Manager, Information 1994 – 1996

General Manager, Consultancy 1991 – 1994

Integral Technology Ltd. Technical Director 1989 – 1991

SD-Scicon Manager 1978 – 1989

International Computers Limited Systems Programmer 1976 – 1978