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# Information Prescription: A New Trend in Biomedical Informatics to Manage Uncertainty in the Health Care System

## Data and Text Mining in Biomedical Informatics: MEBI 591C

Francisco Saavedra

# An Idea in the Horizon…

*A new kind of prescription can be filled online, but it does not involve using the Internet to order drugs.*[1] *Informaticists call the healing power of transforming medical data into personal health care answers an "information prescription."*

1. O'Neil J. Practice: information's healing power. The New York Times. 2004 Sep 7; Vital Signs.

# Uncertainty in the Health Care System: The (Real Life) Decision Making Process

**If you are ill**:

- the odds are that no matter what is your income, background, or education level,
- basic life-or-death decisions are being made for you by a profit-seeking health maintenance organization, and
- a physician you scarcely know, with a background with which you are unfamiliar,
- practicing in a facility whose track record in the management of your illness is a mystery (5,8).

# Uncertainty in the Health Care System : The (Real Life) Decision Making Process

## What would you do?

# Uncertainty in Medicine: The (Real Life) Decision-Making Process

**Medicine traditionally has identified several reasons for uncertainty**[2,3]

1. Gaps or defects in the knowledge of individual physicians.
2. Inadequacies in the profession's knowledge.
3. Every decision made about the future is inherently uncertain.
4. Medicine is especially fraught with uncertainly because it must operate in a world of generalities.
5. Every patient is a particular individual and therefore necessarily different in some respect from the general.

2. Evans L, Trotter DRM. Epistemology and uncertainty in primary care: an exploratory study. Fam Med. 2009;41(5):319-26.
3. Waymack MH. Yearning for certainty and the critique of medicine as "science". Theor Med Bioeth. 2009;30(3):215-29.

# Uncertainty in Medicine:
# The (Real Life) Decision-Making Process

## What would you do?

# How? The Concept

A mechanism that brings a direct connection between evidence-based biomedical literature and patient decision making is needed in routine health care to empower patients to make their own critical decisions based on thorough, reliable, and applicable biomedical information.

# Defining the Concept: "INFORMACY"

Physician-managed, patient-centered biomedical informatics consulting services (INFORMACY) would provide medical information tailored to individualized needs.

# The How—the Mechanics:

1. **Physicians would refer patients** to **INFORMACY** by completing an **INFORMATION PRESCRIPTION**, and then

2. The **patient would submit the prescription** to the **INFORMACY** Website.

3. In response, **INFORMACY** **would perform an extensive meta-search** and then critically appraise and summarize the results into a unique **information report** to be discussed further with the patient's physician (or team) of choice.

# How can we do that? The specifics…

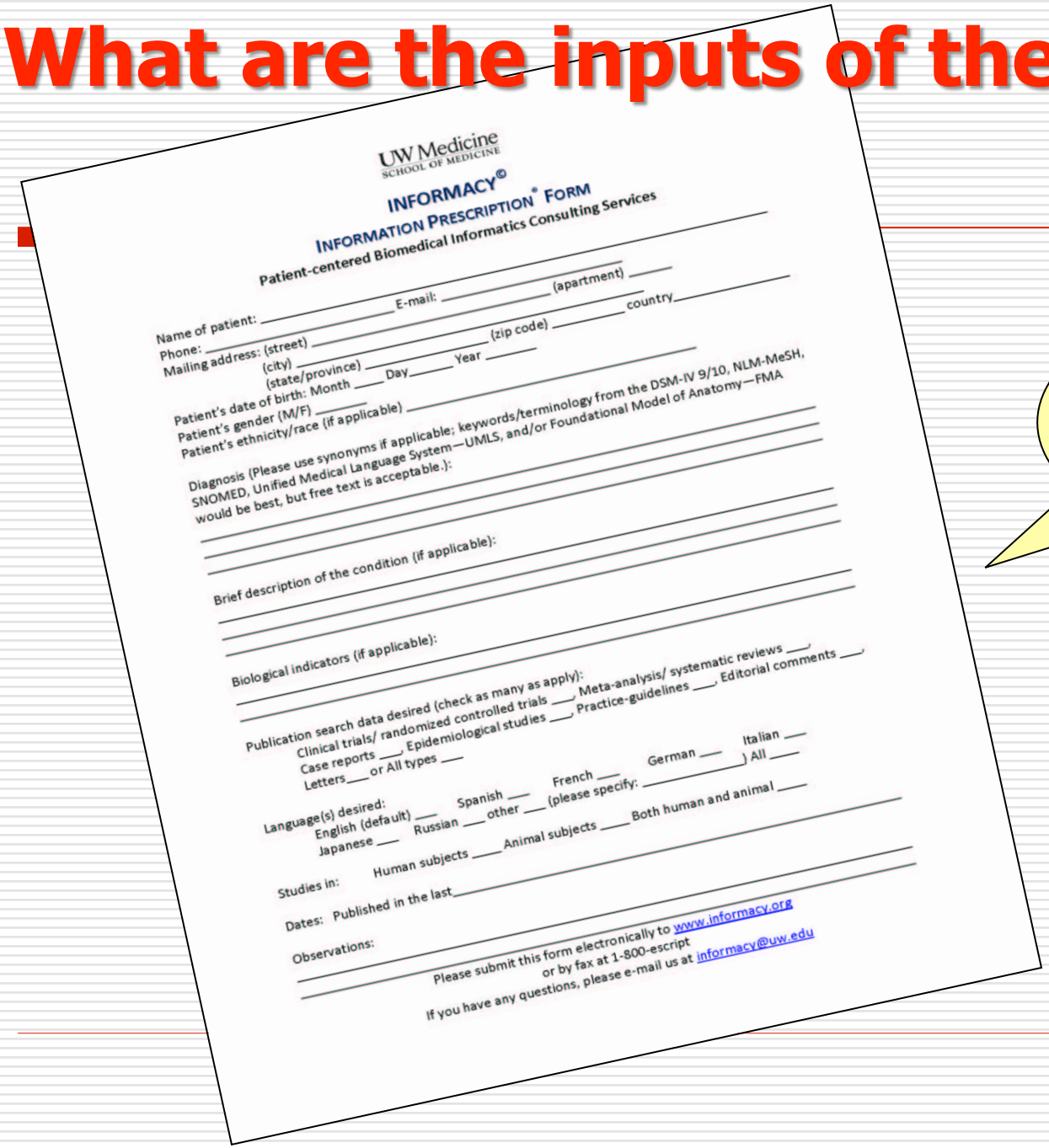
**This project requires the DEVELOPMENT OF TOOLS to:**

1. **Perform meta-searches** in different databases and systems;

2. **"Read" unstructured descriptions** of basic clinical data; and

3. **"Data mine"** to improve the relevance of the literature search and generate final postings tailored to patients' medical needs.

# What are the inputs of the System?



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**INFORMACY©**

**INFORMATION PRESCRIPTION® FORM**

**Patient-centered Biomedical Informatics Consulting Services**

Name of patient: _____ E-mail: _____

Phone: _____

Mailing address: (street) _____ (apartment) _____

(city) _____

(state/province) _____ (zip code) _____ country_____

Patient's date of birth: Month ____ Day____ Year ____

Patient's gender (M/F) _____

Patient's ethnicity/race (if applicable) _____

Diagnosis (Please use synonyms if applicable; keywords/terminology from the DSM-IV 9/10, NLM-MeSH, SNOMED, Unified Medical Language System—UMLS, and/or Foundational Model of Anatomy—FMA would be best, but free text is acceptable.):

Brief description of the condition (if applicable):

Biological indicators (if applicable):

Publication search data desired (check as many as apply):
Clinical trials/ randomized controlled trials ___, Meta-analysis/ systematic reviews ___,
Case reports ___, Epidemiological studies ___, Practice-guidelines ___, Editorial comments ___,
Letters___ or All types ___

Language(s) desired:
English (default) ___ Spanish ___ French ___ German ___ Italian ___
Japanese ___ Russian ___ other ___ (please specify: _____) All ___

Studies in: Human subjects ___ Animal subjects ___ Both human and animal ___

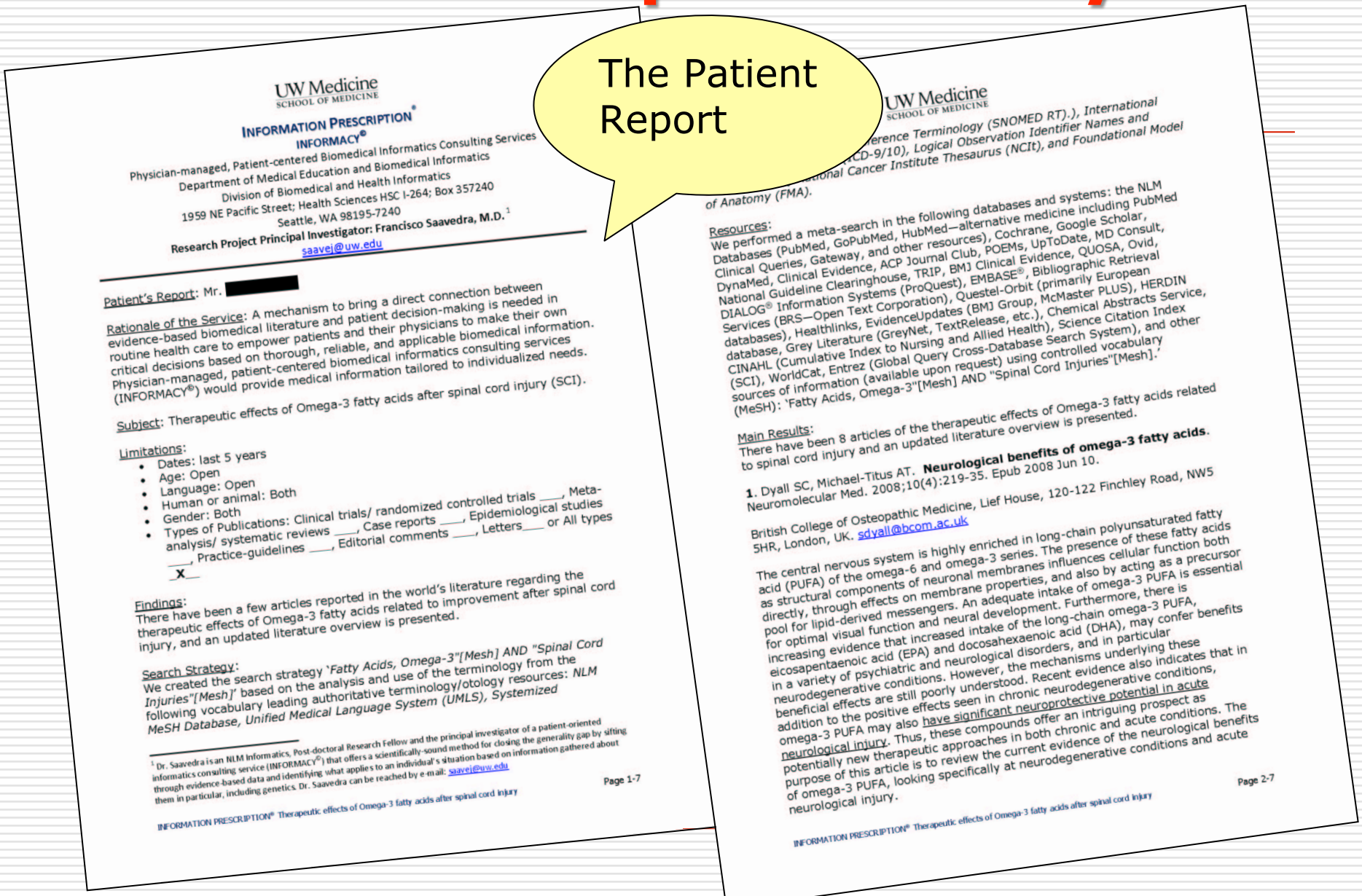
Dates: Published in the last_____

Observations:

Please submit this form electronically to www.informacy.org
or by fax at 1-800-escript
If you have any questions, please e-mail us at informacy@uw.edu

The Information Prescription

# What are the outputs of the System?



The Patient Report

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**INFORMATION PRESCRIPTION®**
**INFORMACY®**

Physician-managed, Patient-centered Biomedical Informatics Consulting Services
Department of Medical Education and Biomedical Informatics
Division of Biomedical and Health Informatics
1959 NE Pacific Street; Health Sciences HSC I-264; Box 357240
Seattle, WA 98195-7240
**Research Project Principal Investigator: Francisco Saavedra, M.D.** [1]
saavej@uw.edu

Patient's Report: Mr. [redacted]

Rationale of the Service: A mechanism to bring a direct connection between evidence-based biomedical literature and patient decision-making is needed in routine health care to empower patients and their physicians to make their own critical decisions based on thorough, reliable, and applicable biomedical information. Physician-managed, patient-centered biomedical informatics consulting services (INFORMACY®) would provide medical information tailored to individualized needs.

Subject: Therapeutic effects of Omega-3 fatty acids after spinal cord injury (SCI).

Limitations:
- Dates: last 5 years
- Age: Open
- Language: Open
- Human or animal: Both
- Gender: Both
- Types of Publications: Clinical trials/ randomized controlled trials ___, Meta-analysis/ systematic reviews ___, Case reports ___, Epidemiological studies ___, Practice-guidelines ___, Editorial comments ___, Letters___ or All types _X__

Findings:
There have been a few articles reported in the world's literature regarding the therapeutic effects of Omega-3 fatty acids related to improvement after spinal cord injury, and an updated literature overview is presented.

Search Strategy:
We created the search strategy '*Fatty Acids, Omega-3"[Mesh] AND "Spinal Cord Injuries"[Mesh]*' based on the analysis and use of the terminology from the following vocabulary leading authoritative terminology/otology resources: *NLM MeSH Database, Unified Medical Language System (UMLS), Systemized*

[1] Dr. Saavedra is an NLM Informatics, Post-doctoral Research Fellow and the principal investigator of a patient-oriented informatics consulting service (INFORMACY®) that offers a scientifically-sound method for closing the generality gap by sifting through evidence-based data and identifying what applies to an individual's situation based on information gathered about them in particular, including genetics. Dr. Saavedra can be reached by e-mail: saavej@uw.edu



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*...erence Terminology (SNOMED RT).), International ...CD-9/10), Logical Observation Identifier Names and ...ional Cancer Institute Thesaurus (NCIt), and Foundational Model of Anatomy (FMA).*

Resources:
We performed a meta-search in the following databases and systems: the NLM Databases (PubMed, GoPubMed, HubMed—alternative medicine including PubMed Clinical Queries, Gateway, and other resources), Cochrane, Google Scholar, DynaMed, Clinical Evidence, ACP Journal Club, POEMs, UpToDate, MD Consult, National Guideline Clearinghouse, TRIP, BMJ Clinical Evidence, QUOSA, Ovid, DIALOG® Information Systems (ProQuest), EMBASE®, Bibliographic Retrieval Services (BRS—Open Text Corporation), QuestelOrbit (primarily European databases), Healthlinks, EvidenceUpdates (BMJ Group, McMaster PLUS), HERDIN database, Grey Literature (GreyNet, TextRelease, etc.), Chemical Abstracts Service, CINAHL (Cumulative Index to Nursing and Allied Health), Science Citation Index (SCI), WorldCat, Entrez (Global Query Cross-Database Search System), and other sources of information (available upon request) using controlled vocabulary (MeSH): 'Fatty Acids, Omega-3"[Mesh] AND "Spinal Cord Injuries"[Mesh].'

Main Results:
There have been 8 articles of the therapeutic effects of Omega-3 fatty acids related to spinal cord injury and an updated literature overview is presented.

**1.** Dyall SC, Michael-Titus AT. **Neurological benefits of omega-3 fatty acids.** Neuromolecular Med. 2008;10(4):219-35. Epub 2008 Jun 10.

British College of Osteopathic Medicine, Lief House, 120-122 Finchley Road, NW5 5HR, London, UK. sdyall@bcom.ac.uk

The central nervous system is highly enriched in long-chain polyunsaturated fatty acid (PUFA) of the omega-6 and omega-3 series. The presence of these fatty acids as structural components of neuronal membranes influences cellular function both directly, through effects on membrane properties, and also by acting as a precursor pool for lipid-derived messengers. An adequate intake of omega-3 PUFA is essential for optimal visual function and neural development. Furthermore, there is increasing evidence that increased intake of the long-chain omega-3 PUFA, eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), may confer benefits in a variety of psychiatric and neurological disorders, and in particular neurodegenerative conditions. However, the mechanisms underlying these beneficial effects are still poorly understood. Recent evidence also indicates that in addition to the positive effects seen in chronic neurodegenerative conditions, omega-3 PUFA may also have significant neuroprotective potential in acute neurological injury. Thus, these compounds offer an intriguing prospect as potentially new therapeutic approaches in both chronic and acute conditions. The purpose of this article is to review the current evidence of the neurological benefits of omega-3 PUFA, looking specifically at neurodegenerative conditions and acute neurological injury.

# How can we do this? More Specifics…

**This project requires the DEVELOPMENT OF TOOLS to:**

1. **Perform meta-searches in different databases and systems;**
2. "Read" unstructured descriptions of basic clinical data; and
3. "Data mine" to improve the relevance of the literature search and generate final postings tailored to patients' medical needs.

# How can we do this?
# More Specifics... META-SEARCH

**This project requires the DEVELOPMENT OF TOOLS to:**

1. **Perform meta-searches in different databases and systems;**

Resources: The NLM Databases (PubMed, GoPubMed, HubMed—alternative medicine including PubMed Clinical Queries, Gateway, and other resources), Cochrane, Google Scholar, DynaMed, Clinical Evidence, ACP Journal Club, POEMs, UpToDate, MD Consult, National Guideline Clearinghouse, TRIP, BMJ Clinical Evidence, QUOSA, Ovid, DIALOG® Information Systems (ProQuest), EMBASE®, Bibliographic Retrieval Services (BRS—Open Text Corporation), Questel-Orbit (primarily European databases), Healthlinks, EvidenceUpdates (BMJ Group, McMaster PLUS), HERDIN database, Grey Literature (GreyNet, TextRelease, etc.), Chemical Abstracts Service, CINAHL (Cumulative Index to Nursing and Allied Health), Science Citation Index (SCI), WorldCat, Entrez (Global Query Cross-Database Search System), and others...

# How can we do this?
# More Specifics... META-SEARCH (Cont...)

**This project requires the DEVELOPMENT OF TOOLS to:**

1. **Perform meta-searches in different databases and systems;**

**Other Resources**: Clinical Evidence—British Medical Journal Publishing Group: the international source of the evidence for effective healthcare, Project CORK (Comprehensive bibliographies in drug misuse), BIDS (Bath Information and Data Services--bibliographic service for the academic community in the UK), PSYCLIT (Literature Reference for Psychology), PsycINFO (Psychological Abstracts), ERIC (Educational Resources Information Center), ASSIA (Applied Social Sciences Index and Abstracts), FAMILY-RESOURCES-DATABASE, HEALTH-PERIODICALS-DATABASE, BIDS, Dissertation-Abstracts, SIGLE (System for Information on Grey Literature in Europe), DRUG-INFO, SOMED (multilingual literature database in the field of Social Medicine and Public Health- mostly German and English), Social-Work-Abstracts, National-Clearinghouse-on-Alcohol-and-Drug-Information, Mental-Health-Abstracts, DRUG-database and ETOH databases; as well as other resources such Doctor's Guide Publishing Limited—weekly edition: physicians helping physicians to identify need-to-know science; Wonka—World family doctors-caring for people: Global Family Doctor Daily Alerts; Medscape—Family Medicine MedPulse; Breast Cancer Research—Source for peer-reviewed biological and translational research and opinions relevant to breast cancer; Veritas Medicine—Resource providing access to clinical trials and information about therapies in development for serious medical conditions; and Peer View Institute—NTK/Watch: A collaboration between more than 290,000 physician-members to identify need-to-know science.

# How can we do META-SEARCHERS?
(Cont…)

# Ideas?

# How can we do this? The specifics… "READ" UNSTRUCTURED DATA…

**This project requires the DEVELOPMENT OF TOOLS to:**

1. Perform meta-searches in different databases and systems;

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# How can we do this? The specifics…
# "READ" UNSTRUCTURED DATA…

## This project requires the DEVELOPMENT OF TOOLS to:

## 2. "Read" unstructured descriptions of basic clinical data:

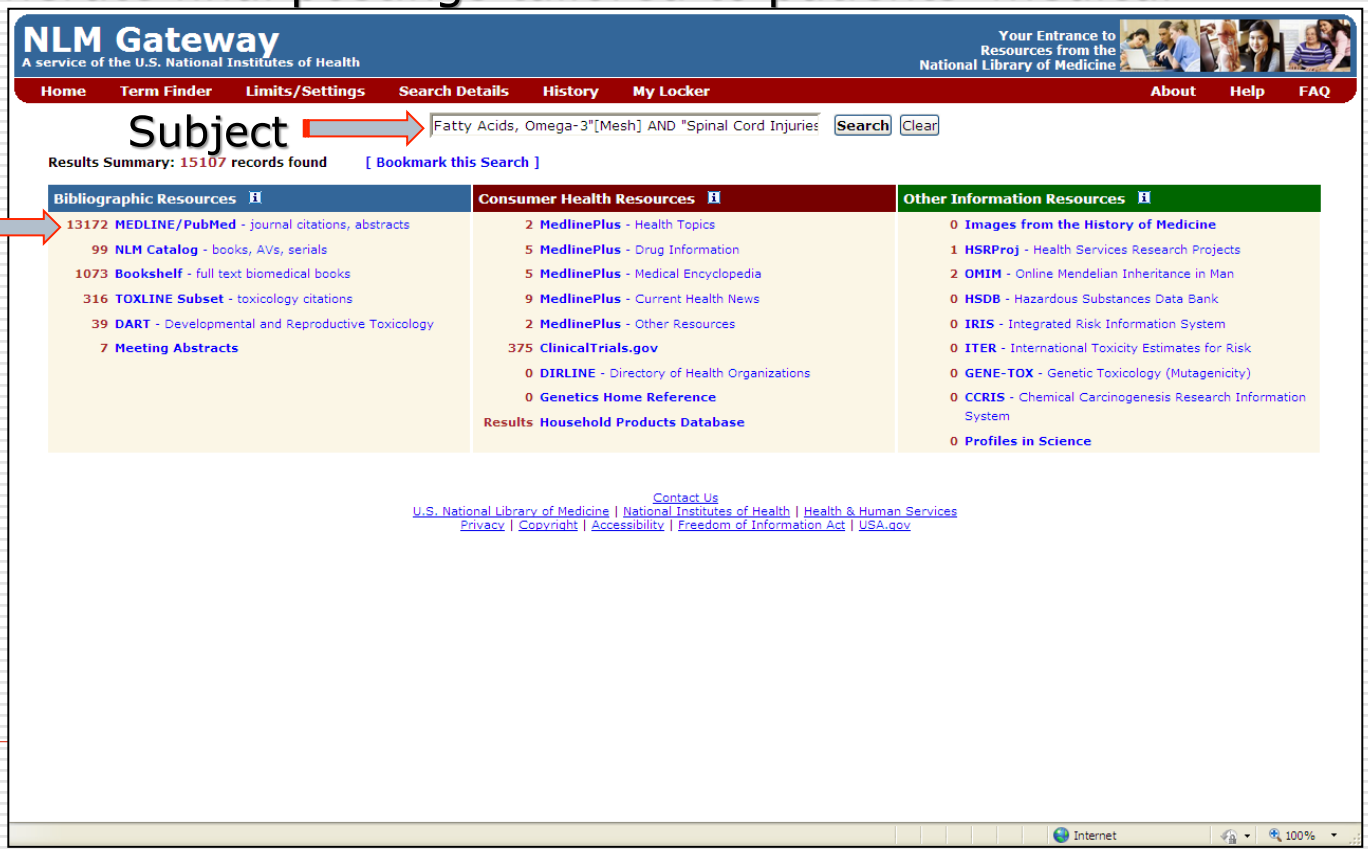
Huang WL, King VR, Curran OE, Dyall SC, Ward RE, Lal N, Priestley JV, Michael-Titus AT. **A combination of intravenous and dietary docosahexaenoic acid significantly improves outcome after spinal cord injury.** Brain. 2007 Nov;130(Pt 11):3004-19. Epub 2007 Sep 27.Neuroscience Centre, Institute of Cell & Molecular Science, Queen Mary Universityof London, UK. w.huang@qmul.ac.uk. Previous studies have shown that omega-3 polyunsaturated fatty acids such as alpha-linolenic acid and docosahexaenoic acid (DHA) are neuroprotective in models of spinal cord injury (SCI) in rodents. However, the mechanism of action underlying these effects has not been elucidated, and the optimum treatment regime remains to be defined. We have therefore carried out a detailed analysis of the effects of DHA in adult rats subject to thoracic compression SCI. Saline or DHA (250 nmol/kg) was administered intravenously (i.v.) 30 min after compression. After injury, the saline group received a standard control diet for 1 or 6 weeks, whereas DHA-injected animals received either a control or a DHA-enriched diet (400 mg/kg/day) for 1 or 6 weeks. Other groups received a DHA-enriched diet only for 1 week following injury, or received acute DHA (250 nmol/kg; i.v.) treatment delayed up to 3 h after injury. We also assessed oxidative stress and the inflammatory reaction at the injury site, neuronal and oligodendrocyte survival and axonal damage and the locomotor recovery. At 24 h, lipid peroxidation, protein oxidation, RNA/DNA oxidation and the induction of cyclooxygenase-2 were all significantly reduced by i.v. DHA administration. At 1 week and 6 weeks, macrophage recruitment was reduced and neuronal and oligodendrocyte survival was substantially increased. Axonal injury was reduced at 6 weeks. Locomotor recovery was improved from day 4, and sustained up to 6 weeks. Rats treated with a DHA-enriched diet in addition to the acute DHA injection were not significantly different from the acute DHA treated animals at 1 week, but at 6 weeks showed additional improvements in both functional and histological outcomes. DHA treatment was ineffective if the acute injection was delayed until 3 h post-injury, or if the DHA was administered for 1 week solely by diet. Our results in a clinically relevant model of SCI show that significant neuroprotection can be obtained by combining an initial acute i.v. injection of DHA with a sustained dietary supplementation. Given that the safety and tolerability of preparations enriched in omega-3 fatty acids is already well-documented, such a combined DHA treatment regime deserves consideration as a very promising approach to SCI management…

etc…

# How can we do this?
# The specifics… "DATA/TEXT MINE"…

**This project requires the development of tools to:**

**3. "Data mine"** to improve the relevance of the literature search and generate final postings tailored to patients' medical needs.



# Current Pilot Project Concept: Step-by-Step…

The Prescription goes here

| *STEP 1* | *STEP 2* | *STEP 3* | *STEP 4* | *STEP 5* |
|---|---|---|---|---|
| **Identification: Patient's Information Needs** | **TOOL #1: COMPUTERIZED META-SEARCHES** | **Gathering of Information Units** | **TOOL #2: DATA EXTRACTION** | **Synthesis and Dissemination of Information** |
| Plan strategy for Searching, data standards, and Vocabulary (controlled, syntaxes, ontologies, and semantics): | Meta-Searches in *Bibliographic Databases***, and *Biological Databases/ Systems (11)**** | Information Obtained | Data/ Text/ Knowledge Mining: In-silico Medical Text Analysis | Generation of Patient's Report and creation of the *Selective Dissemination of Information System* (SDIS) interface |
| Resources:<br>**MeSH** Database, Foundational Model of Anatomy (**FMA**),(9) * National Cancer Institute Thesaurus (**NCIt**), Unified Medical Language System (**UMLS**), Systemized Nomenclature of Medicine-Reference Terminology (**SNOMED RT**), International Classification of Disease (**ICD-9/10**), and Logical Observation Identifier Names and Codes (**LOINC**) | Databases/ Systems:<br>Biological data can be found from certain sources: text formats are provided by PubMed and OMIM; sequence data are provided by GeneBank for DNA and UniProt for protein; and protein structures are provided by PDB, SCOP, and CATH. | Different studies/ Documents:<br>Data from molecules, genes, proteins, pathways, tables, key delimited records, XML structures, case series, cohort trials, case control studies, randomized controlled trials, systematic review, meta-analyses, etc.<br>Biological data comes in many formats:<br>Text, sequence data, protein structure, and links. | Types of documents to cover:<br>Articles,<br>Textbooks,<br>Manuals,<br>Guidelines,<br>Book chapters,<br>Technical-scientific reports,<br>Books,<br>Grey literature,<br>Molecules, Proteins, Genes, Sequences, etc. | Tailored patient report: and<br>SDIS:<br>1. The electronic medical records systems (EMR)<br>2. The Diagnostic Decision Support system (DDSS)<br>3. Problem-Knowledge Coupler (PKC) |

# What does this project really offer? A Needed Clarification

It is important to emphasize that the response INFORMACY brings to uncertainty is not based on having all the answers (because this is not feasible), but the assurance that comes with knowing all the basic factors a physician could practically indentify are represented in the compilation of individualized information from the latest findings medical science has to offer.

# In this context: How can we approach data/text mining?

**Ideas?**

# Evaluation of INFORMACY :

Evaluation of the INFORMACY system and the development of standards could be conducted via both qualitative and quantitative follow-up analyses focused on:

1. Patient's satisfaction,
2. Improved QoL, and
3. Overall health outcomes.

# Values of the System…

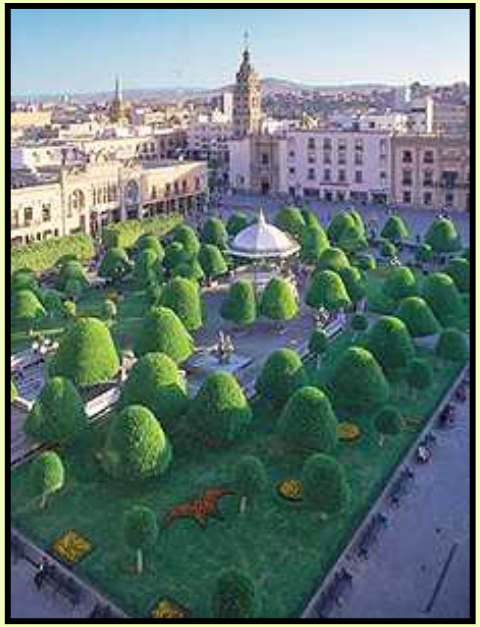
- The Healing Power of Information
- Its Meaningful and Relevant Use
- Empowering Patients
- Democratization of Scientifically-Sound Information

# Conclusions:

- I theorize that INFORMACY would meet the critical needs of patients for specific and reliable information, whereby empowering them to make decisions about their care with confidence, and result in statistically-improved health outcomes.

- I believe this service would also provide an effective tool for facilitating the integration of research-based evidence into the management of uncertainty in complex patient care, which would, in turn, foster physicians' engagement with biomedical literature.

- Thank You



POLIFORUM LEON
CONVENTIONS AND EXHIBITIONS

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