

WRAPIN: finding trusted health information on the Internet and empowering patients within personal health records

**Michel Joubert, Arnaud Gaudinat,
Célia Boyer, Antoine Geissbühler,
Marius Fieschi,
HON Foundation Council members**

HONcode

HON Code of Conduct

- **The HONcode for health Web sites addresses the reliability of information**
- **The HONcode is today the most widely endorsed set of ethical guidelines for site developers in the health domain**
- **It is made of eight items**



HONcode Items (1/2)

- **Authoritative**
 - Indicate the qualifications of the authors
- **Complementarity**
 - Information should support, not replace, the doctor-patient relationship
- **Privacy**
 - Respect the privacy and confidentiality of personal data submitted to the site
- **Attribution**
 - Cite the source(s) of published information, date of pages...

HONcode Items (2/2)

- **Justifiability**
 - Site must back up claims relating to benefits and performance
- **Transparency**
 - Accessible presentation, accurate email contact
- **Financial disclosure**
 - Identify funding sources
- **Advertising policy**
 - Clearly distinguish advertising from editorial content

CISMeF

Catalogue and Index of French-language Health Web Sites

Glioblastome - [2003]



Par : Dr Grill J - [Site éditeur : Orphanet base de données sur les maladies rares et les médicaments orphelins. Direction Générale de la Santé / INSERM]

description de la maladie, diagnostic, traitement, pronostic, autres sites Internet, consultations adaptées, projets de recherche, réseaux de professionnels, association de patients, essais cliniques, registres, médicament [France]

mots-clés : ➔ *glioblastome; *glioblastome/génétique;

types : conseil génétique; *registre; réseaux coordonnés; *structure recherche; *texte;

accès : http://www.orpha.net/consor/cgi-bin/OC_Exp.php?Lng=FR&Expert=360

UMVF

Virtual French-language Medical University

Sarcomes et autres cancers : Néphroblastome - [2002]



Par : Anatomie Pathologique, CHU Angers - [Site éditeur : Faculté de médecine d'Angers]

motsclés : ***sarcomes**; ***tumeur de Wilms**;

types : ***cours**;

accès : <http://www.med.univ-angers.fr/discipline/anapath/ed9/nephrobl/index.htm>

"Le Monde", édition du 21/02/2007

- **La loi d'août 2004 réformant l'assurance-maladie a chargé la Haute Autorité de santé (HAS) d' « établir une procédure de certification des sites informatiques dédiés à la santé »...**
- **A défaut d'une certification, la HAS s'oriente vers un partenariat avec le label HON (Health on the Net) - déjà existant mais peu connu du grand public - afin d'inciter les concepteurs de sites à respecter certaines bonnes pratiques...**

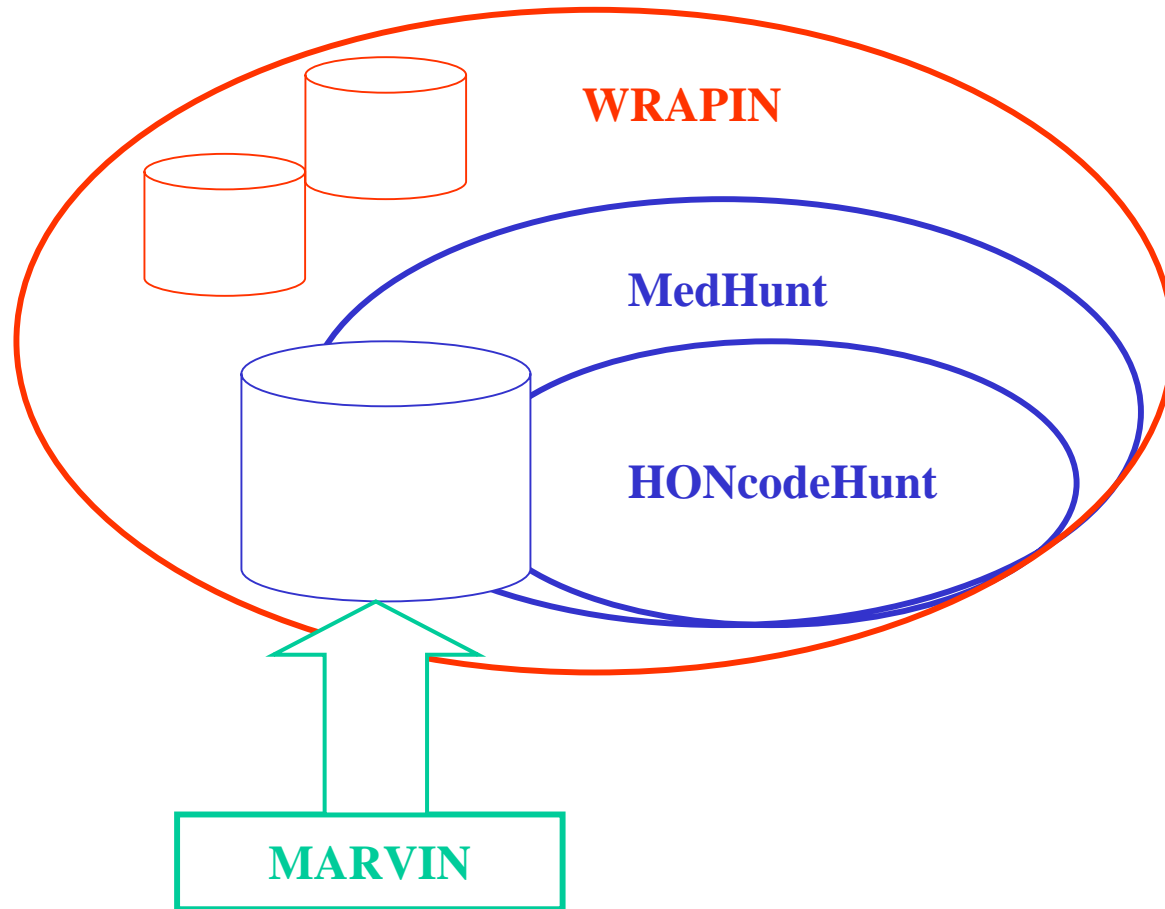


Worldwide online **R**eliable **A**dvice to **P**atients and **I**ndividuals

- **General Public: patients and citizens**
- **Health Professionals**
- **Responding to the demand for quality in e-health information**
- **Providing value-added services**

- **European project IST-2001-33260**

HON's Components



Finding Trusted Health Information on the Internet

- **WRAPIN has been designed to provide patients and citizens with trusted health information**

Copy and paste of a text submitted for analysis

Input **keywords**, **text** (with no limitation of length) or **URL** (<http://...>) to find relevant, **trustworthy** sources of additional information.

High grade gliomas are highly vasular tumors and have a tendency to infiltrate. They have extensive areas of necrosis and hypoxia. Often tumor growth causes a breakdown of the blood-brain barrier in the vicinity of the tumor. As a rule, high grade gliomas almost always grow back even after complete surgical excision.

Search

Clear

8 Tumor Types: Other Gliomas

Trusted Seal: [MedlinePlus](#)



..The rarest form of **glioma**, these **tumors** contain both glial cells and mature neurons. They ...
multiformeOptic Nerve **Glioma** . These **tumors** are found on or near the nerves that travel betwe ...
1.800.934.CURE . **Tumor** Types: Other **Gliomas****Brain** Stem **Glioma** . **Brain** stem **gliomas** account for
2 ... **tumors** and just short of 5% of adult **tumors**. They most frequently afflict children between th ...

URL: http://www.braintumor.org/patient_info/surviving/tumor_ty...

[Similar results](#)

Terms of the questions are automatically highlighted in summaries

- The query was: "ablation of a lung"

20 RFA (for Lung Tumors)



... interventional . Radiofrequency **Ablation** of **Lung** Tumors. Click image to view larger . What is Radi ...
If you undergo radiofrequency **ablation** of a **lung** tumor, you will have either a CT scan or a magnet ...
ablation may be used to debulk a **lung** tumor that is too large to remove surgically. In ... promising
alternatives to surgical removal of **lung** tumors is eliminating the tumor cells using heat. ...

URL: <http://www.radiologyinfo.org/content/interventional/rfalu...>

[Similar results](#)

Terms in the answers are automatically highlighted

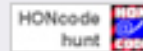
What is Radiofrequency ablation of lung tumors?

One of the most promising alternatives to surgical removal of lung tumors is eliminating the tumor cells using heat. The technique, called radiofrequency ablation (RFA), is performed by interventional radiologists and is much less invasive than open surgery. Guided primarily by computed tomography (CT) scanning, a small needle electrode is inserted through the skin and directly into the tumor tissue. Radiofrequency energy consisting of an alternating electrical current in the frequency of radio waves is passed through the electrode. The energy causes the tissues around the needle electrode to heat up, killing nearby cancer cells. At the same time, heat from radiofrequency energy closes small blood vessels and lessens the risk of bleeding. RFA usually causes little discomfort. It is usually done as an outpatient procedure that does not call for general anesthesia.

Rephrasing a query

"glioblastoma"

5 Glioblastoma Multiforme



... in the white matter of the right **temporal lobe** and extending into the parietal and occipital **lobes**. ... often in the frontal **lobes** than the **temporal lobes** or basal ganglia) but almost never in the cerebel ... **Glioblastoma Multiforme**. George M Wu, MD . Liangge Hsu, MD . August 1, 1994 Presentation. A 36-year ... this study. Differential Diagnosis. **Glioblastoma multiforme** is the most likely diagnosis given the ...

URL: <http://brighamrad.harvard.edu/Cases/bwh/hcache/14/full.html>

[Similar results](#)

- Glioblastoma
- Brain Neoplasms
- Astrocytoma
- Glioma
- Carmustine
- Receptor Epidermal Growth Factor
- Temporal Lobe
- Corpus Callosum
- Receptors Growth Factor
- Astrocytes
- Central Nervous System Neoplasms
- Radiotherapy
- Epidermal Growth Factor
- Alkylating Agents
- Nervous System Neoplasms

Use of pre-defined Categories

- **Categories related to entities of the medical domain, e.g. « disease »**

Query:

Search

Clear

[Query details](#) | Same medical terms in: [Fr](#) [De](#) [It](#) [Pt](#) [Sp](#)

[glioblastoma](#): [Overview](#) | [Causes & Risk Factors](#) | [Screening & Diagnosis](#) | [Complications](#) | [Treatment](#) | [Prevention](#)

Results in English: 1-10 of 657 found documents

- 1 **Treatment of glioblastoma multiforme in the elderly in functionally non-critical areas.**
Clinical remarks on 22 patients.



"... Although several studies report a poor outcome in elderly patients with **glioblastoma**, in the light of our experience, **treatment** of elderly patients with **glioblastoma** in non-critical areas and Karnofsky Performance Status > 60 should be just as aggressive as in younger patients. ..."

URL: <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retriev...>

[Similar results](#)

Multilingualism

Query:

exérèse d'un cancer du poumon

Search

Clear

Query details | Same medical terms in: **En De It Pt Sp**

Results in French: 1-10 of 63 found documents

1 MEDHUNT



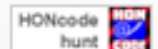
... DU SEIN METASTASE (principale) **CANCER DU POUMON** EPIDERMOIDE METASTASE (principale) ADENOCARCINOME ... chimio et radiothérapeutiques. **CANCER DU POUMON A PETITES CELLULES** (principale) **CANCER DU LARYNX** ... MELANOME (principale).Après **exérèse**. **CANCER DU FOIE** (à confirmer) Effets secondaires . REACT CORYNEBACTERIUM PARVUM. Introduction dans BIAM : 18/2/1992. Dernière mise à jour : 6/7/1999. Et ...

URL: <http://www.biam2.org/www/Sub1798.html>

[Similar results](#)

Results in English: 1-10 of 5678 found documents

1 eMedicine - Neoplasms, Lung : Article by Peter T Porrello, MD



... cancer is growing. Among all **cancers, lung cancer** now has the highest mortality rate in most countr Mortality/Morbidity: Of all **cancers, lung cancer** is estimated to be responsible for the greatest n ... bronchogenic carcinoma, **lung cancer, lung** malignancy, adenocarcinoma, squamous cell carcino ... important etiologic factor linked to **lung cancer** and is responsible for as many as 85% of cases. P ...

URL: <http://www.emedicine.com/emerg/topic335.htm>

[Similar results](#)

Trustworthy Medical Databases



HONcode : data base of HONcode-certified medical web sites (multilingual)



Medline : a data base of over 15 million medical and scientific articles (most of them in English) indexed from the sixties to date, made available by the NLM (National Library of Medicine USA)



Medhunt : all the medical web sites indexed by HON (multilingual)



Drug FDA : information in English about medicines issued by the Food and Drugs Administration (USA)



Clinical Trials : a data base of clinical trials in English made available by "the National Institute of Health" developed by the NLM (National Library of Medicine USA)



Uro : scientific articles in French covering the domain of Urology, made available to WRAPIN by "Association Française d'Urologie"



Oeso : scientific articles in English specializing in the diseases of the oesophagus, made available by the Oeso Fondation



HONnews : daily medical news in English from HealthDay

Empowering Patients within Personal Health Records

- **Information technology may provide patients to access their personal health records**
- **It can also be used by patients to understand and check diagnoses and treatments**
- **All the previous functionalities may be used by patients and citizens**
 - **Reliability of health sources**
 - **Copy-past of part of personal health record**
 - **Explanations and definitions**
 - **Multilingualism**
 - ...

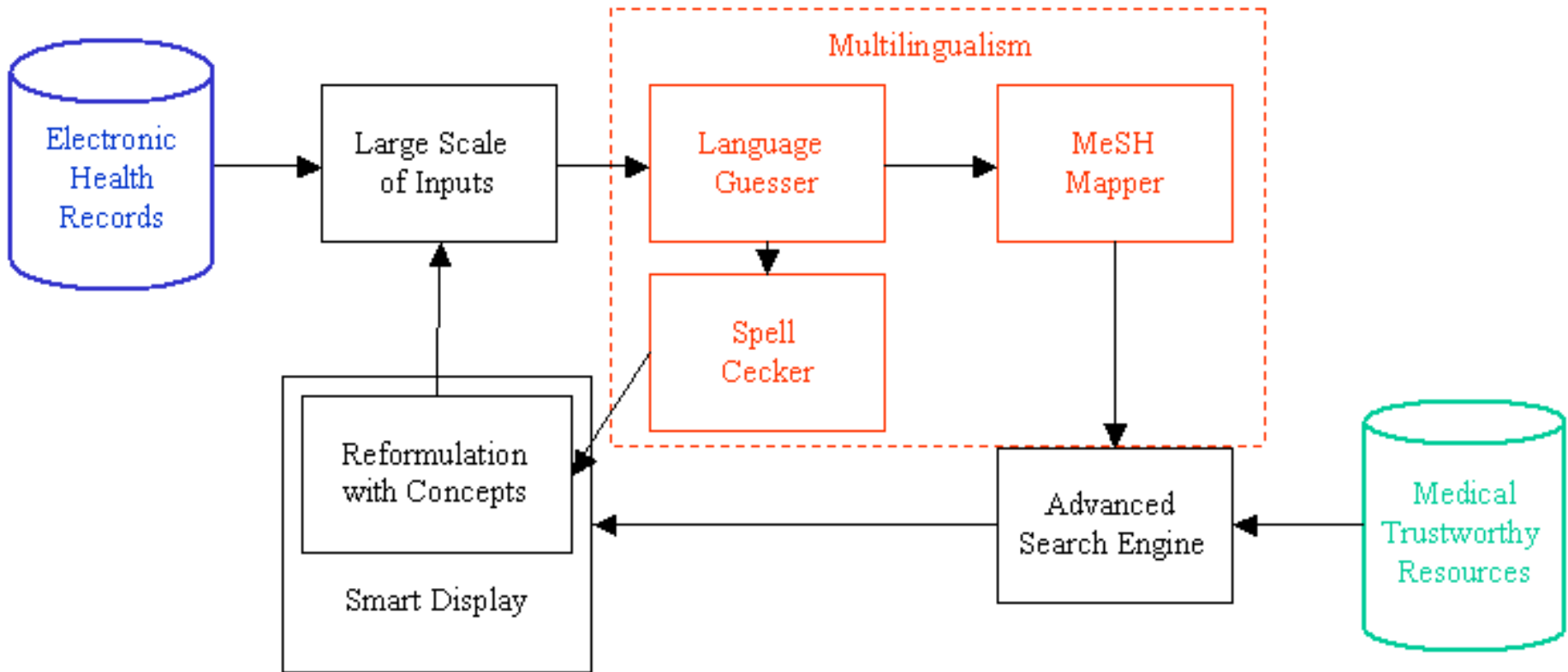
A tool for patient empowerment within EHR

- **A French-language answer to a copy-paste from a patient dossier: "ablation of a glioma ... associated with a radiotherapy"**

Traitement La chirurgie d'exérèse permet l'ablation de la tumeur quand celle-ci est particulièrement bien localisée. Ce traitement s'applique spécifiquement aux astrocytomes et aux craniopharyngiomes. Il existe néanmoins quelques risques de récurrence dépendant de la localisation de la tumeur. Ainsi, le gliome et les tumeurs hémisphériques (situées dans chaque moitié du cerveau) sont parfois enlevées partiellement.

La radiothérapie se fait généralement complément du traitement précédent également dans le but de prévenir les récurrences.

EHR as an input to the WRAPIN search process



Conclusion

- **Querying facilities**
 - copy-paste of text, e. g. patient record
 - rephrasing queries
 - multilingualism
- **Health literacy**
 - information categorized by its source
 - access to definitions
- **Transparency**
 - non commercial, non-governmental

Summary

- **WRAPIN has been designed to provide patients and citizens with trusted health information**
- **Responding to the demand for quality in e-health information**
- **It can be used by patients to understand and check diagnoses and treatments recorded in their personal health records**