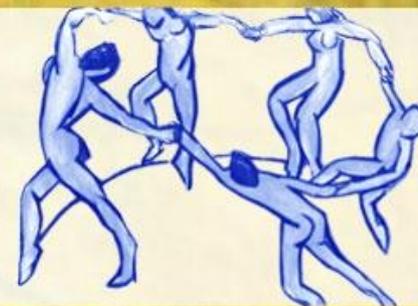


Divided we fall, united we inform
Building alliances for
a new European cooperation
Rome, Italy, 11 - 13 June 2014



Helping patients get up from their knees...

Ivana TRUCCOLO¹, Chiara CIPOLAT MIS¹, Emanuela FERRARIN^{1,2}, Mauro MAZZOCUT¹, Nicolas GRUARIN¹, Paolo DE PAOLI³

¹Scientific and Patients Library , IRCCS Centro di Riferimento Oncologico (CRO) National Cancer Institute, Aviano (PN), Italy,²CIFAV ONLUS, CRO Pharmacy

³CRO, MD Scientific Director



- ❖ The focus of my speech is the concept of **Empowerment in practice from a biomedical & health consumers librarian'** point of view.
- ❖ There is a big debate in the scientific literature about **the concept of Empowerment** and its theoretical and practical implications when applied to healthcare
- ❖ **This debate usually does not include the libraries/librarians** as potential co-actors...

Health librarians because of their knowledge of and skills in...

The librarian's role in the provision of consumer health information and patient education

*Policy Statement by the
Medical Library Association and the
Consumer and Patient Health Information Section
(CAPHIS/MLA)*

Health librarians, because of their knowledge of and skills in the identification, selection, organization, and dissemination of information, play an important role in both consumer health information services and patient education. The role of the librarian differs depending on the mission and policies of the organization. Librarians' activities in this area are oriented towards the goals of producing a healthy society and assisting the individual in making informed health decisions. This policy statement, approved by the Board of Directors of the Medical Library Association, was developed by the Consumer and Patient Health Information Section. It covers MLA policy, defines consumer health information and patient education, and identifies potential roles for librarians in these two areas.

Bull Med Libr Assoc 84(2) April 1996

- Building an authoritative collection of CHI and patient education materials in print and electronic form that meets the needs of the institution or community being served.
- Developing subject file collections on current topics of interest to consumers, etc.
- Maintaining a current collection of CHI and patient education materials which are routinely reevaluated and revised.

Knowledge and resource sharing

- Networking with other individuals, organizations, and agencies to facilitate resource-sharing of CHI and patient education materials.
- Consulting on the identification, selection, and organization of patient education materials in health care settings, e.g. hospital nursing units, ambulatory clinics, etc.
- Serving on institutional committees that address topics such as patient education, public health, community health education, quality assurance, medical



- ❖ The first goal is to expose the knowledge and skills that a librarian can use in order to play an active role in the patient education & empowerment process
- ❖ The second one is to demonstrate the methodology and some preliminary results of a practical experience of Patient Education & Empowerment, ie ...
- ❖ what happens when librarians are involved...

What is Empowerment

❖ **Power (psychology)**
is the preferred
term for
Empowerment in
the Mesh/PuMed
database



- ❑ **Patient empowerment = a** *process* that helps patients gain control over their lives, increasing their capacity to act on issues that they themselves define as important;
- ❑ a process through which patients *individually and collectively* are able to...

(Adapted from JA-PaSQ, 2012 by
Robert Johnstone, EPF/IAPO)

Some inspiring papers...



*...Robert Johnstone (of the International Association of Patients Organisations) says that “doctors should get down from their pedestals, but **patients must get up from their knees.**” Yet he adds: “**empowerment is not about trying to wrest power from the doctors, it is essentially helping people lead more proactive and fulfilling lives.....**”*



Lancet Editorial. Patient Empowerment:
who empowers whom, May 5, 2012

EDITORIALS

... (BMJ 2013;346:f2614)

Editorials are usually commissioned. We are, however, happy to consider and peer review unsolicited editorials

• See <http://resources.bmj.com/bmj/authors/types-of-article/editorials> for more details

bmj.com • Articles from the *BMJ* on shared decision making are at bmj.com/bmj-series/shared-decision-making

Let the patient revolution begin

Patients can improve healthcare: it's time to take partnership seriously

Tessa Richards analysis editor, *BMJ*, London WC1H 9JR, UK trichards@bmj.com

Victor M Montori professor, Knowledge and Evaluation Research (KER) Unit, Mayo Clinic, Rochester, MN, USA

Fiona Godlee editor in chief

Peter Lapsley patient editor, *BMJ*, London WC1H 9JR, UK

Dave Paul secretary of the patient advisory group, Knowledge and Evaluation Research (KER) Unit, Mayo Clinic, Rochester, MN, USA

A hundred years ago George Bernard Shaw lambasted the medical profession as a conspiracy against the laity.¹ Today, disease and doctor centric health systems that are costly, wasteful, fragmented, and too often uncaring are provoking similar ire.²

Despite the best intentions and undoubted skill of many who work within healthcare, access to care, and its quality, vary markedly, and most people in rich countries access a confusing smorgasbord of tests and treatments whose merits are hyped and harms underplayed.³ Patients lack information on practice variation, the effectiveness of their care, and the extent of medical uncertainty. Practice is informed by an

interventions. Discussion groups of patients, carers, and clinicians led by the James Lind Alliance in the United Kingdom, and the Patient Centered Outcomes Research Institute in the United States, are shedding light on the mismatch between the questions that patients and doctors want answers to and the ones that researchers are investigating. Joint discussions have helped build a database of uncertainties about the effects of treatment (www.library.nhs.uk/duets/).

Patients and doctors are also collaborating to design new services and information systems.⁷ Leaders in innovative partnership include ReshapeHealth (www.radboudreshapecenter.com), which is pioneering patient led and “crowdfunded” research. A growing number of healthcare organisations are giving patients access to, and in some cases control over, their medical records.⁷ At the Mayo Clinic a free app gives patients full access to their medical notes, pathology reports, and radiology reports; and because a shift in power depends on establishing a common lexicon, work is under way to reduce the medical jargon in these resources.

ment is seen as a way to help health systems become sustainable. Some have argued that it is the “blockbuster drug of the century” and will deliver equivalent dividends.¹⁰

But partnering with patients must be seen as far more than the latest route to healthcare efficiency. It's about a fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems. We need to accept that expertise in health and illness lies outside as much as inside medical circles and that working alongside patients, their families, local communities, civil society organisations, and experts in other sectors is essential to improving health. Revolution requires joint participation in the design and implementation of new policies, systems, and services, as well as in clinical decision making.

Much remains to be discovered, evaluated, and implemented to achieve meaningful partnership with patients. There is also a need to embed shared decision making into routine practice.^{11,12} At an open meeting in June in Peru (www.isdm2013.org), which can be followed



Empowerment & some related concepts (MeSH)

There are some *related concepts*:

- ✓ **Patient Education (as Topic)**: *The teaching or training of patients concerning their own health needs (uncomplete)*
- ✓ **Health literacy**: *Degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (uncomplete)*
- ✓ **Patient Participation**: *Patient involvement in the decision-making process in matters pertaining to health.*
- ✓ **Personal Autonomy**: **Self-directing freedom and especially moral independence**

Mosconi P. et al., 2012

Consumer Health Information vs Patient Education

- ❖ *[....] Consumer health information (CHI) and patient education overlap in practice, since patient behavior may change as a result of receiving health information materials.*
- ❖ ***Patient education and CHI often differ in terms of the setting in which the process occurs, rather than in terms of the subject matter...***

The librarian's role. Bull Med Libr Assoc, 1996



Taking part of a Research Project



- ❖ **Patient Education & Empowerment is the aim of a collaborative multicentric 3years Research Project granted by the Italian National Health Authority**
- ❖ **Centro di Riferimento Oncologico of Aviano (CRO) is leading this project based on the program and activities of a local Patient Education & Empowerment Group (PEEG)**

EXTENDING COMPREHENSIVE CANCER CENTERS EXPERTISE IN PATIENT EDUCATION: THE POWER OF PARTNERSHIP WITH PATIENT REPRESENTATIVES

Project Code:RF-2010-2308141

CRO, Aviano
Leader

BURLO, TS
partner

INT, Milano
partner

IOV, Padova
partner

**Oncologico,
Bari** partner

ASMN, Reggio Emilia
collaborator

AIMaC and ANGOLO
(cancer patients
associations) partner

Negri, Milano –
collaborator

IRST, Forlì –
collaborator

**Cannizzaro
Hospital, Catania**
collaborator





The Patient Education & Empowerment Group



- ❖ **The CRO PEEG (2010-) is a multi-professional, trans-disciplinary, non-hierarchical Work Team including patients, their representatives, and volunteers along with members of clinical, research and technical staff**
- ❖ **Its program is part of the CRO Annual Plan**



- ❖ **The senior librarian, because of his competence in patient information, is the coordinator of this Team.**
- ❖ **A young librarian is the project manager of the collaborative Research Project (half time work)**
- ❖ **Another young librarian is involved in the surveys and networking**
- ❖ **The library is the pivot of patients' involvement.**

✓ The CRO Aviano (PN) is the North-Eastest Italian Cancer Comprehensive Center (1 out of 9): **research & care & high education**

✓ medium size



Cignoweb.it
L'informazione che cura

Home - Cos'è - Chi siamo - Collaborazioni - Qualità dei documenti - Contatti - Versione accessibile

Cerca

Ricerca avanzata | Ricerca per indici | Ricerca medicinali | Testimonianze | Storico ricerche

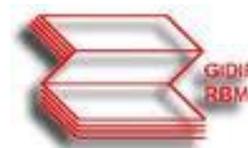
Cignoweb.it
Risorse informative di qualità per pazienti, familiari e cittadini in oncologia e ambito sanitario.

I contenuti sono in continuo aggiornamento, eventuali

Hal bisogno di supporto?
Associazioni
Helpline

Cerchi un istituto di cura? Consulta...
Libro bianco AIOM
Oncoguida
Sportello Cancro
Libro Bianco FAVO sulla riabilitazione oncologica

CRO 14



"Two libraries in one"



The program of the PEEG includes many different activities related to the areas of

❖ Research

❖ Education, both patient and health care workers education

❖ Information & Communication



Nothing for the patients without patients



❖ To involve patients and their representatives in as many formal and informal situations as possible, where initiatives for patients are planned.

motto of the Cancer Patients Associations
“Nothing for the patients without patients”

Our hypothesis is that “**patient empowerment**”,
*i.e. the process of helping people to discover
and use their own innate ability to gain
mastery over their illness condition*

(operational definition, Crit Care Nurs Q 2004, 27 (2): 201)

cannot be effective if it doesn't also mean:

- ❖ “doctors empowerment”
- ❖ “health care workers empowerment”
- ❖ “health care organisation empowerment” as
health is like life, a complex matter

Our observations are based on

- the analysis of the free comments, discussions and narrations both of patients (pts) and Health Care Workers (HCW),

but also

- on the periodical Reports of our Patient Education Activities drawn by the Lib-Coordinator

PEEG-Organizational meetings	Classes with patients about health topics	PE handout	National Literary Competition "Scriviamoci con cura" 2 nd edition	Continuing Education Courses (CEC)
<p>10 formal ,but many other informal ad hoc meetings involving about 50 people – HCW , patients ,volunteers...</p>	<p>25 classes, about 30 HCW, expert patients and volunteers as teachers, about 15 topics such as:</p> <ul style="list-style-type: none"> • “How to manage the adverse effects of chemotherapy” • “Eating well” • “Diet and cancer” • “How to deal with cancer emotions” • etc <p>The topics are both proposed by the HCW</p>	<p>10 booklets involving 26 HCW as authors,</p> <ul style="list-style-type: none"> - 6 people for the editing and - almost 30 patients as “reviewers” 	<p>35 patients and HCW participated in as author-writers (39 only patients participants in 2012). (Part of a Narrative Medicine Global Program)</p>	<p>25 out 195 CEC –ECM and not-(13%) were focused on improving the patient-physician relationship (Narrative Based Medicine etc..) vs 5% in 2012</p>



- ❖ Important **increase of activities and participation** both of HCW and patients since 2011 until now,
e.g. pts participating to the classes: 50 (2011)
vs 365 (2013)
- ❖ **Increase of the Library impact on the organization/s**
- ❖ **Change of priorities** as result of giving voice to the patients perspective

❖ health care workers (HCW):
– about 30% of the HCW involved in this process had
“enthusiastic insight”
since the beginning of the program

- because of personal beliefs and/or
- previous experiences at international centres



- about 30% of the HCW were quite **sceptical at the beginning**, e.g. not prepared for these kind of interactive mini-conferences during their daily care activities...

“I didn’t believe that there were in-treatment patients participating in these classes...”

I don’t believe that a narrative approach is a dependable approach...”

“I didn’t believe so many people were interested in the diet and CAM topics...”

- About 15% of HCW honestly participating in the different activities but apparently **scarcely involved** in the “cause” of the Patient Education & Empowerment process

these classes are sometimes like a beautiful concert for a few auditors



This is our diagnostic and clinical path and the patients have to accept it!

The attitude of these HCW is changing but this change is not an easy matter...

- about 15% (of the HCW involved in the Patient Education & Empowerment process) **feel their work as a “human adventure”**, they like to know their patients as human before patients and to put themselves on the line.

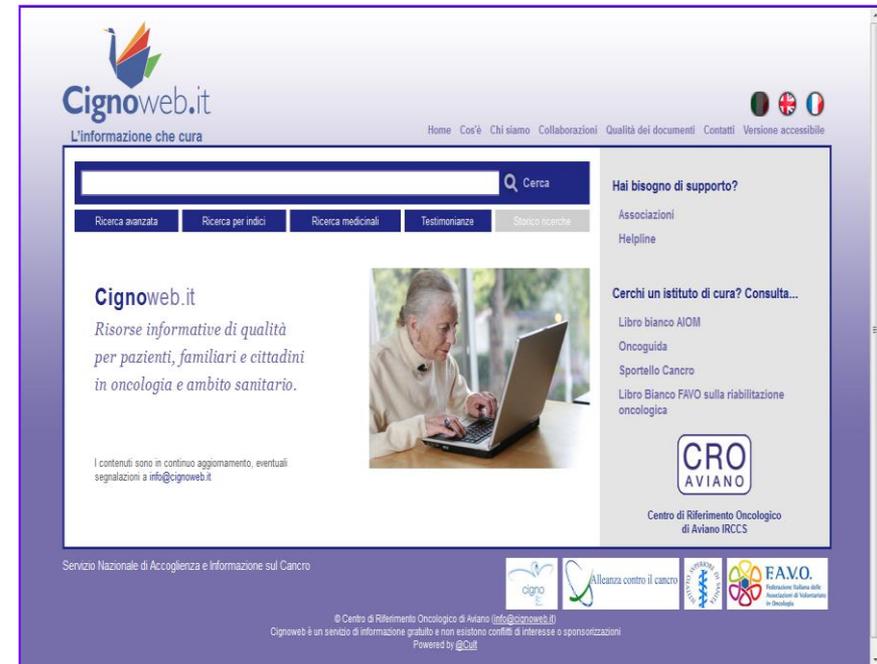


Lesson learned: The expert patient



Patients:

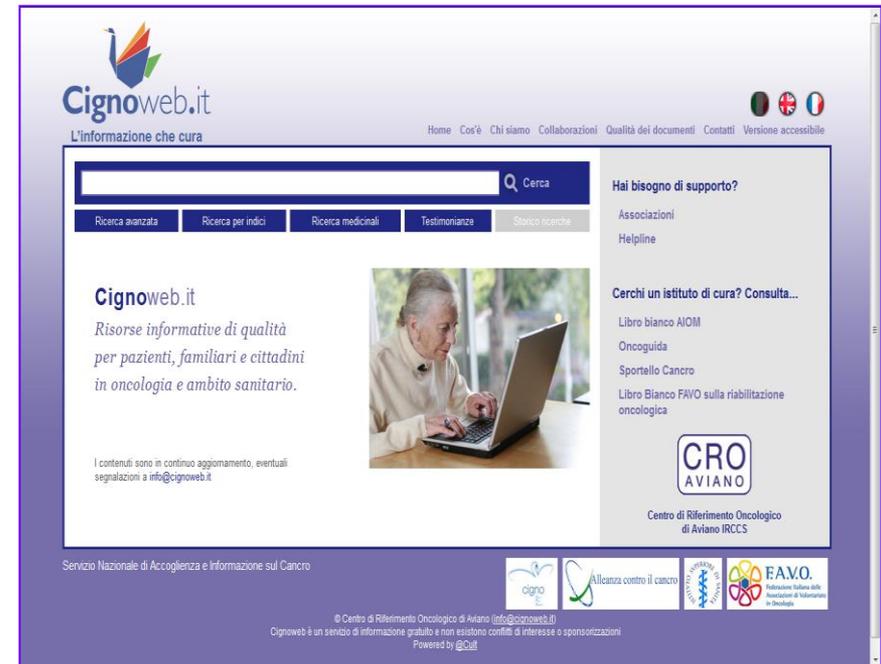
❖ **the expert patient**, i.e. the patient who decides to become expert and make available his own expertise, plays an important role in driving other patients.



The screenshot shows the homepage of Cignoweb.it, a website for cancer information. The header includes the logo and navigation links like Home, Cos'è, Chi siamo, Collaborazioni, Qualità dei documenti, Contatti, and Versione accessibile. A search bar is prominently displayed. Below the search bar, there are tabs for 'Ricerca avanzata', 'Ricerca per indici', 'Ricerca medicinali', 'Testimonianze', and 'Storico ricerche'. The main content area features the text 'Cignoweb.it Risorse informative di qualità per pazienti, familiari e cittadini in oncologia e ambito sanitario.' and a photo of an elderly woman using a laptop. On the right side, there is a sidebar with sections for 'Hai bisogno di supporto?' (Associations, Helpline) and 'Cerchi un istituto di cura? Consulta...' (Libro bianco AIOM, Oncoguida, Sportello Cancro, Libro Bianco FAVO). The footer contains logos for various organizations and the text '© Centro di Riferimento Oncologico di Aviano (Info@cignoweb.it) Cignoweb è un servizio di informazione gratuito e non esistono conflitti di interesse o sponsorizzazioni. Powered by @Call'.

www.cignoweb.it can help!!!

❖ **A biomedical librarian, expert in handling with consumer health information - and patient information & communication needs - can help both doctors, in “learning” from their patients, and patients in asking & understanding and searching & finding.**



The screenshot shows the homepage of Cignoweb.it, a website dedicated to cancer information. The header includes the Cignoweb.it logo, navigation links (Home, Cos'è, Chi siamo, Collaborazioni, Qualità dei documenti, Contatti, Versione accessibile), and a search bar. The main content area features a search bar, navigation tabs (Ricerca avanzata, Ricerca per indici, Ricerca medicinali, Testimonianze, Storico ricerche), and a central section with the text: "Cignoweb.it Risorse informative di qualità per pazienti, familiari e cittadini in oncologia e ambito sanitario." Below this, it states: "I contenuti sono in continuo aggiornamento, eventuali segnalazioni a info@cignoweb.it". The right sidebar contains a "Hai bisogno di supporto?" section with links to "Associazioni" and "Helpline", and a "Cerchi un istituto di cura? Consulta..." section with links to "Libro bianco AIOM", "Oncoguida", "Sportello Cancro", and "Libro Bianco FAVO sulla riabilitazione oncologica". The footer includes the CRO AVIANO logo, the text "Centro di Riferimento Oncologico di Aviano IRCCS", and various partner logos (Cigno, Alleanza contro il cancro, FAVO, etc.).

www.cignoweb.it can help both patients and librarians, public and health librarians, and HCW...

❖ A biomedical librarian's expertise in the **management of scientific literature** can support patients in their need of a proper information but also help them get more cautious on certain controversial and deceptive issues.

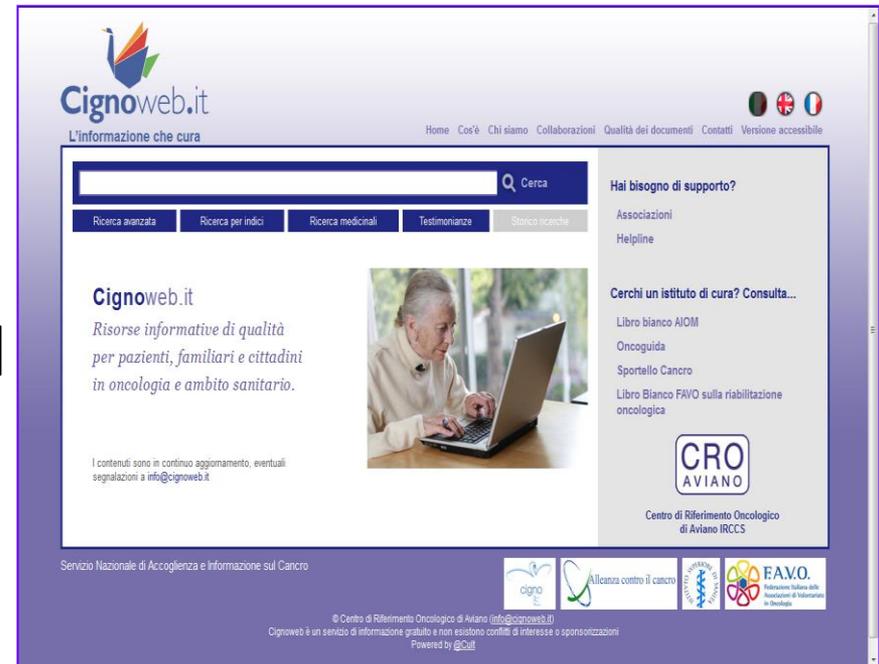


The screenshot shows the homepage of Cignoweb.it, a website for the Centro di Riferimento Oncologico di Aviano IRCCS. The page features a search bar at the top with a 'Cerca' button. Below the search bar are navigation tabs for 'Ricerca avanzata', 'Ricerca per indici', 'Ricerca medicinali', 'Testimonianze', and 'Storico ricerche'. The main content area includes the Cignoweb.it logo and a tagline: 'Risorse informative di qualità per pazienti, familiari e cittadini in oncologia e ambito sanitario.' There is also a photo of an elderly woman using a laptop. On the right side, there is a 'Hai bisogno di supporto?' section with links for 'Associazioni', 'Helpline', and 'Cerchi un istituto di cura? Consulta...'. Below this are links for 'Libro bianco AIOM', 'Oncoguida', 'Sportello Cancro', and 'Libro Bianco FAVO sulla riabilitazione oncologica'. The footer contains logos for 'Servizio Nazionale di Accoglienza e Informazione sul Cancro', 'Allianza contro il cancro', and 'FAVO', along with copyright information and a 'Powered by @Cui!' notice.

www.cignoweb.it can help!!!

❖ The librarian's **expertise in quality evaluation of the information for health consumers (HonCode, ETHIC ©)** is highly required as well as his/her attitude to effectively collaborate with other HCW

❖ He can be a powerful driver of the whole Patient Education process.



www.cignoweb.it can help!!!

Actually, our small group of librarians/information specialists working as “catalysers” noticed that:

1. Presentations by HCW/language more and more **scientific & conversational**
2. Doctors started to **enjoy Talking** with Patients in small groups and Patients Talking with Doctors
3. **Controversial** aspects are discussed
4. **Patients priorities** are respected (eg CAM and nutritional counseling, new drugs side effects etc)

Conclusions

So CHI librarian can

- ❖ help patients getting up from their knees
- ❖ **facilitate doctors to reduce the traditional asymmetry**
- ❖ **Empower his/herself being active part of the whole process.**

Thank you for your attention!

itruccolo@cro.it