In order to offer a service for cancer patients, their families and friends, and for the interested public, the Cancer Information Service (Krebsinformationsdienst) was established at the German Cancer Research Center (Deutsches Krebsforschungszentrum) in 1986. It was based on the model of the U.S. National Cancer Institute’s Cancer Information Service CIS.

The service was set up as a pilot project of the German Federal Ministry of Health. Since 2011, it has been expanded to become the National Reference Center for Cancer Information in order to meet the growing demand for quality assured information on cancer in Germany, and to make it increasingly available for inquiries from professionals, too.
Mission

The Cancer Information Service offers up-to-date, quality assured information that is easy to understand, in all areas of cancer research. The service reaches out to patients and their families as well as to the interested public who have questions about the development, prevention and early detection of cancer. It also reaches out to all professionals involved in the care and support of cancer patients.

The information provided by the Cancer Information Service is independent and comprehensive. It is evidence-based, readily understandable and tailored to individual needs.

The service facilitates orientation in the health care system, supports physician-patient communication, contributes to patient empowerment and supports an active part of patients in medical decisions.

Balanced and scientifically founded information on questions regarding cancer prevention and early cancer diagnosis contribute to a matter-of-fact discussion about these topics.

In pursuing these goals, the service takes on the function of a national reference center for cancer information.
It is important that new findings and advances in oncology swiftly reach the patients. As a link between research and clinical practice, the Cancer Information Service strives to contribute to the rapid distribution of clinically relevant research findings.

By offering information for professionals as well, the service will contribute to accomplishing this goal.

Documentation and evaluation of all inquiries as well as regular user surveys allow continuous quality improvement and customizing services to the demand.

From the data collected and evaluated, the Cancer Information Service can derive recommendations on the provision of cancer information, and obtains evidence about specific needs of individual user groups.

The service makes these findings available to health professionals and to decision-makers in the health care system, thus contributing to health services research.
The Cancer Information Service answers individual questions about cancer: causes and risk factors, prevention, diagnosis, treatment and follow-up care. In addition, the Cancer Information Service supplies contact details and addresses of institutions and organizations involved in medical and psychosocial care and support of cancer patients.

The Cancer Information Service provides information via telephone, e-mail and the internet. The service also issues various brochures and continuously updated fact sheets on relevant topics.

At the National Center for Tumor Diseases (NCT) Heidelberg and at the University Cancer Center (UCC) Dresden, the Cancer Information Service offers face-to-face counseling.
The telephone service is available at the German Cancer Research Center and at a branch office at the University Cancer Center in Dresden daily from 8 a.m. to 8 p.m. at 0 800 420 30 40. Calls within Germany are toll-free. If all lines are busy, callers can leave a call return request.

The confidential conversation on the telephone makes it possible to respond to individual information needs.

All e-mail inquiries to krebsinformationsdienst@dkfz.de or via the secured e-mail form on the Cancer Information Service website are being answered within two workdays.

On its website www.krebsinformationsdienst.de, the Cancer Information Service provides information on a multitude of topics, such as: new research findings, up-to-date scientific knowledge in oncology presented in a comprehensible way, useful tips for cancer patients, contact information, and links to further quality assured information resources.
Quality as a Priority

Primary source of the information provided by the Cancer Information Service is its own knowledge and address database which is continuously being updated and enhanced. The content is based on thorough research and processing of scientific publications and on other reliable sources. These also include information on methods of complementary and alternative medicine.

The Cancer Information Service is independent and free of any conflict of interest. This is also guaranteed by the scientific excellence of the German Cancer Research Center as the provider institution.

Quality management of information provision includes staff qualification and continuing education, communication training, call evaluation, coaching and group supervision.

Based on anonymized documentation of usage along with regular user surveys the Cancer Information Service continuously customizes services to the demand and promptly takes up new topics and content.
A central idea of the Cancer Information Service is networking with national and international providers of quality assured health and cancer information.

Thus, the service is partner in the German National Cancer Plan, lead-managed by the Federal Ministry of Health, where it collaborates with other health organizations and associations to accomplish the common goals of this initiative. In addition, the Cancer Information Service is engaged in various projects dealing with quality assurance of patient information.

Currently, the Cancer Information Service collaborates, among others, with the Institute for Quality and Efficiency in Health Care (IQWiG), with the Independent Patient Counseling Service Germany (UPD), as well as with patient organizations and support groups.

In a close collaboration, the Cancer Information Service is partnering with the University Cancer Center (UCC) in Dresden, which hosts a branch office of the telephone information service.

Beyond national borders, the Cancer Information Service collaborates with the Swiss Cancer League, promotes the collaboration of cancer information services in Europe and is actively involved in the International Cancer Information Service Group (ICISG).
The service offered by the Cancer Information Service is unique in Germany:

**Independent**
Quality assured and unbiased information about a complex medical topic that will affect more and more people in an aging population

**Tailored to the needs**
Customized information by telephone and via e-mail, communicated in a comprehensible way, free of charge

**Up-to-date**
Information on the latest developments in oncology, continuously updated knowledge database

**Experienced**
Over 25 years of experience in health communication

**Networking**
Integrated into the oncology research and health services landscape, in close contact with professional associations and patient organizations
The Cancer Information Service is operated by a committed, qualified team working in the areas of telephone service, e-mail service, research of scientific evidence, database and internet editing, and documentation.

Telephone and e-mail inquiries are answered by physicians who have received special training in health communication. Science journalists and scientific staff from the areas of medicine, biosciences and psychology are responsible for information research and editing.
Prospects – National Reference Center for Cancer Information

The high demand for quality assured cancer information could not sufficiently be met to this day, and will continue to grow due to demographic trends.

In order to provide access to such information throughout Germany, the Cancer Information Service strengthens its team and expands its services.
The strong integration of the service into the German Cancer Research Center and the oncology research and services landscape as well as its commitment to quality assurance in cancer information are prerequisites for its being expanded to make it the National Reference Center for Cancer Information by the Federal Ministry of Education and Research (BMBF).
Expanding Services
As a reference center, the Cancer Information Service will expand its information services provided on the Internet and continue tailoring it to the specific needs of different target groups.

As the rapidly increasing body of knowledge in oncology is hardly manageable today, even for experts, the service will directly target health professionals such as physicians, nurses, psycho-oncologists, and psychosocial counselors in the future.

Quality Standards and Networking
As the National Reference Center for Cancer Information, the service will define quality standards for information content and its communication.

It strives to advance networking of reliable information services.
The Cancer Information Service is a service of the German Cancer Research Center (DKFZ).

It is funded by the Federal Ministry of Education and Research (BMBF) and the state of Baden-Württemberg.

Additional project funding is provided by the Federal Ministry of Health and other partners.
The Cancer Information Service
Performance Figures 2011

32,724 individually answered inquiries
and 74 million hits of its website

Users of telephone and e-mail services

<table>
<thead>
<tr>
<th>Women</th>
<th>61%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>37%</td>
</tr>
</tbody>
</table>

(No information in 2%)

Cancer sites inquired

- Breast
- Others
- Uterus, ovaries
- Lung
- Malignant lymphoma, leukemia
- Colon
- Other digestive organs
- Prostate
- Health professionals
- Relatives, friends
- No information
- General public
Subjects of inquiries

Risk factors, prevention, early detection
Diagnostics
Guidance, addresses
Basic, general information
Treatment
Validation of information from other sources
Living with cancer
Customized information and counseling

Needs and concerns of users

User survey

Support in decision making and reassurance
Validation of information from other sources
Customized information and counseling
Need to talk
General information
Guidance and Orientation

www.krebsinformationsdienst.de
The number of hits increased to 74 million in 2011

hits in millions

2007 2008 2009 2010 2011
The Cancer Information Service
Performance Figures 2011

Inquiries answered 32,724
· Telephone service 26,758
· E-mail service 5,325
· Letters 489
· Face-to-face counseling 146

Website accessed 74,038,328

Results of user surveys

Survey among users of the telephone service
· The telephone information specialist was very responsive to my concerns 87%
· The amount of information was just right 86%
· Everything was presented in a comprehensible way 86%
· There was enough time for questions 92%
· The information was very helpful 86%
· I will definitely use the service again when needed 85%

Survey among users of the e-mail service
· Overall satisfaction:
  Very satisfied/satisfied 72%/24%
· Information comprehensible:
  Always/mostly 68%/32%
· Amount of information:
  Just right 88%
Cancer Information Service
Cancer – we answer your questions

Phone 0 800-420 30 40
Daily from 8 a.m. to 8 p.m.
Toll-free within Germany
krebsinformationsdienst@dkfz.de
www.krebsinformationsdienst.de
www.facebook.com/krebsinformationsdienst

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