



**INTERNATIONAL AGENCY FOR RESEARCH ON CANCER
CENTRE INTERNATIONAL DE RECHERCHE SUR LE CANCER**

**Governing Council
Fifty-first Session**

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Auditorium*

**SUGGESTIONS FOR SPECIAL PROJECTS TO BE FINANCED
FROM THE VOLUNTARY UNDESIGNATED CONTRIBUTIONS ACCOUNT**

1. At its 50th Session in May 2008 the Governing Council requested the Secretariat to prepare suggestions for special projects on which to spend voluntary undesignated contributions.
2. Proposals for special projects in low- and medium-resource countries were presented to the Scientific Council at its 45th Session in January 2009 (Document SC/45/12, see Annex below).
3. The Scientific Council endorsed the Director's proposals after detailed debate on the 'Behavioural Change' component.
4. The Governing Council is requested to approve the use of US\$ 1.0 million from the Voluntary Undesignated Contributions Account to cover the cost of three Special Projects in low- and medium-resource countries: a) improving the coverage and quality of data from cancer registries in Africa, Asia and South and Central America; b) recruitment of skills in behavioural and sociological research initially focused on screening in low-resource countries, to enable the translation from proof-of-principle of the value of low technology cancer screening into implementation at the population level; and c) the Gambia Hepatitis Intervention Study (GHIS), namely to demonstrate the efficacy of HBV vaccination in reducing liver cancer incidence, whilst also building on this platform in order to enable a new generation of studies of cancer etiology and prevention in the region. Strengthening this unique national cancer registry in West Africa will also be a feature of this investment.

Annex
Document SC/45/12, as presented to
the Scientific Council in January 2009

PROPOSAL FOR THE USE OF
VOLUNTARY UNDESIGNATED CONTRIBUTIONS

Request for support for special projects
in low- and medium-resource countries

Background

1. Low and medium-resource countries face an increasing burden of cancer with a more than tripling in incidence projected in the first fifty years of this century. The Agency has a unique opportunity to address itself to this challenge through its research on cancer prevention and by engaging in cooperation with its international partners. However, this general principle needs to translate into action by investment in a number of specific, targeted initiatives. The Governing Council, at its 50th session in May 2008, urged the Agency to make a proposal to the 51st session to use some of the Special Account for Undesignated Contributions currently standing at a value of US\$ 0.7 million. The account is expected to increase to US\$ 1.7 million later in 2009 as the advance facility, which was created in this account in 2008 to pre-finance projects funded from designated contributions, will be closed.
2. The Scientific Council is requested to review and recommend support for these three Special Projects in low- and medium-resource countries, to a total value of US\$ 1.0 million.
3. Cancer registration plays a key role in cancer control/public health and etiological research. Nevertheless, there is a paucity of high quality data from cancer registries in Africa (less than 1% population coverage), Asia and South and Central America (~4%). One of the core roles of the Agency has been to establish close collaboration with cancer registries in these areas thus providing a valuable foundation, both in terms of practical experience and networks of key contacts. However, a step change in effort and resource is needed if significant improved coverage and quality of data is to be achieved.

4. Cancer screening has proven value and is established in many countries. However, people in low- and medium-resource countries often have no access to screening or there are inadequate funds to establish such methods. In addition, the social, cultural and economic barriers to implementation of screening are significant but little studied. The Agency has a strong and successful programme of low technology cancer screening initiatives in low-income countries. However, the translation from proof-of-principle into implementation at the population level requires research into socio-economics, health service provision and culture among other factors. One of the future directions proposed by the new Director (see Document SC/45/10) is to strengthen the Agency by recruitment of skills in these latter areas, initially focused on screening in low-resource countries.

5. The third project represents an area of long-term commitment from IARC, namely the Gambia Hepatitis Intervention Study (GHIS). The GHIS began in 1986 and has a current projected follow up 30 to 35 years in order to assess the protective effect of infant hepatitis B virus (HBV) vaccination against HBV chronic carriage, liver disease and liver cancer. This project, led by IARC, is a joint undertaking with the Medical Research Council of the United Kingdom and the Government of the Republic of The Gambia. As the project is nearing its phase of final evaluation, investment is needed to acquire detailed demographic and clinical data that will ensure the primary aim of the project is realized, namely to demonstrate the efficacy of HBV vaccination in reducing liver cancer incidence, whilst also building on this platform in order to enable a new generation of studies of cancer etiology and prevention in the region. Strengthening this unique national cancer registry in West Africa will also be a feature of this investment.

A. Cancer registration in low- and medium-resource countries

Three components are required in order to make a significant advance in this area.

1. Cancer Registries

6. Last year the Agency provided US\$ 10 000 to each of seven African cancer registries (selected from among 27 applications). The objective was to assist in the production of cancer incidence data over the next three years. However, the initiative was of limited scope and was responsive in nature, rather than strategically identifying high priorities where no cancer registration activity currently exists. For example, Indonesia (population 230 million) has no population-based cancer registry and in rural India cancer registration covers just three million (only Trivandrum, 0.6 million, included in CI5 IX) of the population of 750 million (representing 70% of whole Indian population as of 2005). Clearly much more could be achieved in an area where the Agency should continue to provide world-wide leadership in the future.

2. Training and technical support

7. Successful, high-quality cancer registration requires training and technical support. This comprises a number of specific activities: maintenance and dissemination of the Cancer Registration software (CanReg5) with development of a web-based platform; dissemination of a standardized cancer registration manual in additional languages, with updated information on classification and coding systems; provision of the updated version of the textbook on "Cancer Registration Principles and Methods"; practical guidelines for health professionals, cytologists, and pathologists, based on local requirements and international standards; quality assurance curriculum for cancer registry staff, in consultation with the International Association of Cancer Registries (IACR); training courses, both distance-learning and local and regional courses; improvement of quality of data production through logistic/technical support and periodical follow-up.

3. Partnerships

8. The context of continuing support to cancer registries is vital to their success. Therefore a third component of this project will involve the Agency creating a more effective network of support between cancer registries in low- and medium-resource countries, including the African Association of Cancer Registries, with links to WHO Regional Offices and governments; between cancer registries in the high-resource countries and those in low and medium-resource countries; and establishment of regional reference centres to work with IARC and IACR to organize training courses and provide other technical support specific to particular needs of individual registries.

9. This Agency initiative in cancer registration will be informed and supported by an international working group to advise the Director on specific elements of the project; to periodically report to the Director on progress and to help in planning for the sustainability of this initiative.

B. Cancer prevention through screening and behavioural change

10. The Agency conducts research to inform cancer prevention policy but does not itself develop or advocate policy. Rather it cooperates with WHO and other international and national organizations towards these goals. However, the Agency proposes to extend its research to investigate how prevention strategies, demonstrated as effective in principle, may be best implemented at a population level. Through this mechanism the Agency will strengthen its contribution to the evidence-base needed to inform public health policy. This involves consideration of socio-economics, health service provision, communication and culture among other factors. This type of research is well-suited to the Agency in that it has a strong international dimension (e.g. in relation to marked inter-cultural differences), is not currently dealt with by other research organizations,

and improvement in the implementation of screening and prevention policies in general would be particularly valuable in low and medium-resource countries, the countries least likely to perform this type of research.

11. Recent research has begun to evaluate the effectiveness of implementing population-based cancer screening, particularly breast and cervix, in routine health care settings. Experience shows that the public health benefits of relevant research findings can be realized only when the resulting mass screening programmes ensure successful participation of individuals in the whole process from high quality testing, diagnosis, treatment through to follow-up care.

12. Current IARC cancer screening research focuses also on the evaluation of the efficacy and cost effectiveness of low technology techniques in reducing the burden of breast, cervical and oral cancers in low-resource settings as well as with European quality assurance issues in breast, cervical and large bowel screening. There have been some sporadic attempts to define the determinants of participation in relation to IARC cancer screening trials in India. It is in this context that it is proposed to initiate and establish more focused behavioural and sociological research activities through the recruitment of a staff member (Grade P3; two-year fixed-term) to enable the improved implementation of cancer screening research findings in the wider realm of health care settings in the low- and medium-resource settings.

C. The Gambia Hepatitis Intervention Study (GHIS)

13. The GHIS is reaching a critical point where investment is needed to ensure that the primary purpose of the project is achieved. In addition, the proposed initiatives will permit added-value through associated research on cancer etiology and prevention in the West African region. The Special Project has a number of specific aims.

1. Clinical diagnosis of liver disease and cancer

14. Clinical diagnosis is essential for evaluation of GHIS. The top priority therefore is to recruit a physician (WHO, P3 – initial three year fixed-term) specialized in hepatology to be based in The Gambia. This individual will have primary responsibility for ensuring the identification of liver cancer cases in the GHIS through the major tertiary health centres. This will involve refining the current diagnostic criteria and ensuring the quality of diagnosis. This appointment will also provide overall leadership to the GHIS in other critical aspects (see point 2 below).

2. Strengthening cancer registration and record linkage

15. GHIS subjects are now reaching age groups in which incidence of liver diseases and liver cancer are rapidly increasing and so documenting these cases in the national cancer registry is vital. Key steps include: reformatting the GHIS database; evaluating methods for database linkage (e.g. using RecLink 2 or other software) and testing linkage parameters; evaluating the suitability of BCG and palm prints as identifiers in adults; developing methods for taking and assessing prints (digital pictures); translating these points into a field Standard Operating Procedure.

3. Improving GHIS infrastructure

16. The GHIS depends upon infrastructure that needs to be replaced or renovated, including (1) vehicles and computers; (2) processing systems for the National Pathology Laboratory; (3) processing systems for HBV/HCV and alpha-fetoprotein testing; and (4) provision of ultrasonography in the main clinical centres.

17. The requested investment in the GHIS is urgent and will ensure that the main hypothesis of the study can be tested. In addition, however, the strengthening of the infrastructure at this stage will offer many opportunities. For example, the Agency has a broader commitment to the study of liver cancer, through its International Liver Cancer Study (ILCS) and a regional base in The Gambia, in cooperation with the Medical Research Council of the United Kingdom, offers an extraordinary opportunity for research on the mechanisms of liver diseases that develop in subjects vaccinated at birth. In addition, research into prevention of other cancers common in the region e.g. cervical cancer and human papillomaviruses, will be facilitated by a renewed commitment to the Agency's presence in The Gambia.

18. In summary, support is requested to (1) appoint a clinical lead for GHIS; (2) improve and control the quality of data collection for record linkage; (3) renovate and replace equipment and infrastructure. The Agency will make use of senior consultancy reporting to the Director where appropriate in achieving these aims.