

Genetic and environmental determinants of melanoma: translation into behavioural change

A network of excellence project

Funded by the European Commission
sixth framework programme



PRIORITY 1

Life sciences, genomics and biotechnology for health

**Plan for Using and Disseminating
the Knowledge**

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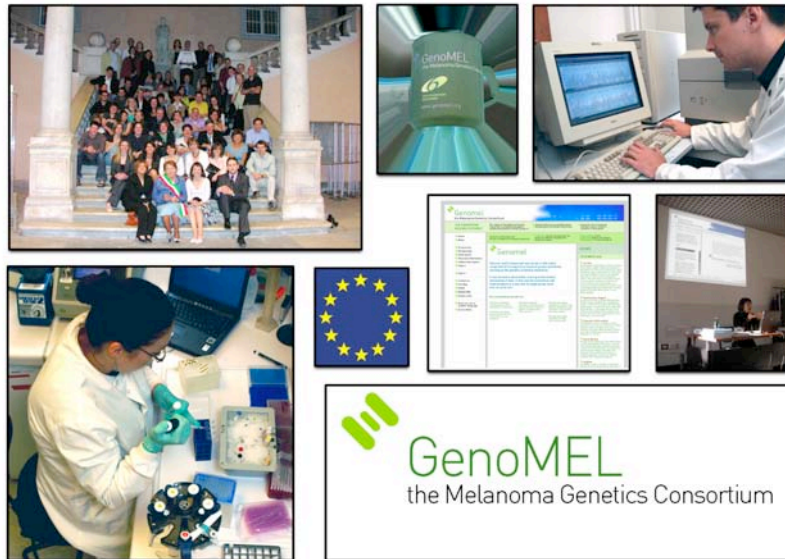
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Introduction



GenoMEL is an international research consortium working on the genetics of melanoma. It is a network of excellence (NoE) with most of the world's leading melanoma genetics research centres at its core. Our NoE has a joint program of activities (JPA) consisting of the four themes of management, integration, research, and the spreading of excellence. These activities will generate new knowledge and this plan has been written and updated to fully exploit that knowledge.

As part of the NoE programme, the consortium has been expanded to include many complementary centres and disciplines. For example, new members have been found in the diverse fields of psycho-oncology, multi-media design and medical ethics. A partnership has also been formed with a commercial molecular genetics company to assist in the identification of new melanoma genes.

The GenoMEL steering committee is responsible for liaising with the work package leaders with regard to new knowledge. The project management team (PMT) shall

facilitate knowledge transfers in conjunction with the steering committee in five different ways.

- By contributing to the design and effective implementation of the GenoMEL plan for using and disseminating the knowledge (PUDK).
- By identifying GenoMEL knowledge that could beneficially influence melanoma research in general.
- By overseeing training programmes, workshops and dissemination of results and innovations.
- By interacting with external advisors, with other relevant European organisations such as the EORTC¹ melanoma group, the IARC², the WHO³ melanoma group and with other European Commission funded programmes in related research fields.
- By actively engaging with other framework programme (FP) project managers to share best practice.

Genetic research, genetic testing and possible patenting

In 2007 considerable work was undertaken to identify new ‘melanoma genes’. This work, particularly WP 2.2, has the potential to generate patentable results in 2008. Discussions are well advanced as to how such discoveries can be protected and about how any proceeds will be divided. A memorandum of understanding (MOU) has already been circulated and agreed. Work has also begun on a consortium wide material transfer agreement (MTA). The MTA will simplify the process of sharing samples and encourage further research integration. The aim is to have this consensus document in place by the summer of 2008.

The data that GenoMEL is likely to generate on the psychological impact of genetic testing will also be of relevance to the pharmaceutical/biotechnology industry and

¹ European Organisation for Research and Treatment of Cancer

² International Agency for Research on Cancer

³ World Health Organisation

health care agencies developing genetic testing. The sharing of such knowledge will be under the oversight of the steering committee. GenoMEL also has an active internal ethics committee in the form of the GenoMEL joint advisory group (JAG). The JAG is composed of lay people, melanoma patients and relevant ethical/healthcare professionals. In 2007 it reviewed the ethics of offering genetic research test results to participants and produced a list of recommendations. These were subsequently considered by the steering committee and it was agreed to improve the collective feedback of the consortium to its research participants. The visible evidence of this is the recent expansion of the website with new lay summaries of GenoMEL papers.

Educational meetings for GenoMEL members, local researchers and clinicians

During 2005, 2006 and 2007, GenoMEL organised training meetings for research nurses, research assistants and clinicians undertaking data collection and the phenotyping of research participants. These sessions also covered the vital topics of accurate data collection and online data entry. Such activities are a key indicator of GenoMEL's integration as a research consortium. Refresher sessions and the training of new members will take place when appropriate.

As part of its NoE commitments GenoMEL arranged an educational meeting in parallel with its 2007 summer meeting in Sweden. This parallel meeting attracted over 90 delegates and provided Nordic clinicians and researchers with the opportunity to hear eminent speakers on 'cutting edge' topics. It was a multilingual event with the morning session conducted in Swedish whilst the afternoon session was in English. The intention is to build on this experience with similar parallel meetings in 2008, 2009 and 2010.

Researcher exchange programme

GenoMEL is committed to a researcher mobility scheme (the GenoMEL exchange programme or GEP) to encourage the exchange of ideas, laboratory techniques and

other research skills. In 2007 GenoMEL funded three more three-month exchanges to facilitate research projects in melanoma genetics. These were in the specific areas of molecular studies, epidemiological work and clinical research.

Following a review it was concluded that only a small proportion of consortium members could actually spare three months to participate in such exchanges. It has therefore been proposed that exchanges under the GEP should last between four and twelve weeks, depending on the project. A companion GenoMEL exchange fund (GEF) will be established to support shorter exchanges of up to one month. The GEF will also support a wider range of activities aimed at fulfilling GenoMEL's commitments to disseminating its knowledge (in all its forms) and integrating its researchers. Further public details of the revised GEP and the new GEF will be posted on the GenoMEL web site in early 2008. These exchange activities will continue for at least the five years of the grant, and will hopefully continue beyond that time in some form.

Publications and peer presentations

The activities of GenoMEL are primarily disseminated to other scientists by publication, by the GenoMEL and eMelanobase websites, and by a strong representation at international meetings (see Networking). GenoMEL is actually in the process of adopting the eMelanobase website and one of our Dutch participants, Leiden University Medical Centre (LUMC), will be hosting it from Leiden. The plan is for the site to be available by the summer of 2007 at <http://www.LOVD.nl/CDKN2A>.

In 2007 GenoMEL members were also involved in a range of international meetings including the first world meeting of interdisciplinary melanoma/skin cancer centres. This inaugural meeting was organised by GenoMEL's Spanish group, and attended by over 350 people from 22 different countries. It is hoped that the proposed GEF will provide extra support for peer presentation activities and for communication with the European public.

Communication with relevant professionals and the public

GenoMEL is committed to the goal of spreading knowledge to stakeholders such as melanoma families, the general public and health care professionals. To further this aim GenoMEL is using developing technologies to reach as many people as possible. In 2007 usage of our web site greatly increased and it is now receiving over two thousand visitors a month. Many of the 'core' pages are available in Dutch, Spanish, Russian, Swedish and Latvian, however, much work remains to be done in the area of translation.

A further 'podcast' has been mounted on the GenoMEL web site as a way of communicating with both GenoMEL members and the wider public⁴. It was also hoped to produce some video podcasts in 2007 but due to other workload demands this was put on hold. The PMT hope to revisit this proposal in 2008.

GenoMEL is also exploring other emerging web technologies to reach a wider audience. During 2008 and 2009 GenoMEL intends to investigate the use of professional networking websites, such as LinkedIn (www.linkedin.com) and Plaxo (www.plaxo.com), and social networking sites, such as Facebook (www.facebook.com) and Bebo (www.bebo.com), to engage with a wider circle of the world's population.

The GenoMEL web site already carries a content management system (CMS) that allows users to explore the implications of a diagnosis of malignant melanoma⁵. Several more CMSs are being developed, targeted at different groups including patients and clinicians.

The intention of GenoMEL is to fully exploit its results by educating the European public about the consequences of their lifestyles and behaviours (both in terms of sun

⁴ <http://www.genomel.org/english/podcastPages/podcasts.htm>

⁵ <http://www.genomel.org/english/patientInformation>

protection and the checking of their moles and so forth.) As part of this aim a health psychology questionnaire was added to the website. This extensive questionnaire concerns behaviour in the sun and will inform the eventual GenoMEL risk estimation tool. So far this questionnaire has garnered over 6,000 respondents and it should provide invaluable experience for the creation of the later questionnaires. During 2007 the GenoMEL web site clearly demonstrated GenoMEL's commitment to communication and innovation.

Further online questionnaires will be launched in early 2008 aimed at existing GenoMEL study participants. These questionnaires have greatly benefited from the technical knowledge generated by the first questionnaire. GenoMEL's participant design company, the SME New Knowledge Directorate, are also exploring how they can capitalise on the insights they have gained into such interactive tools with potential clients.

Collaborative research and data sharing

GenoMEL welcomes applications for data access from researchers outside the consortium in the following circumstances.

- Where the proposed use of data is in the best interests of the patients/families from whom these data were derived.
- Where the proposed use of data is of potential benefit to the scientific and health care communities.

To formalize this position GenoMEL has formulated a data sharing policy⁶, with exchanges subject to a formal approval procedure that considers any relevant ethical issues and cost concerns. To date no exchange applications have been received but one of the GenoMEL funded postdoctoral fellows, Dr. Ruby Chang, is leading a

⁶ Information about the GenoMEL data sharing policy is available at <http://www.genomel.org/english/dataSharing.htm>

major international research collaboration with the pooling of data sets from Australian, American and European centres.

Networking

During 2007 GenoMEL sustained its participation in international groups such as HuGENet⁷ and the Melanoma Research Foundation. More formal and active links were established with the EORTC, the Society for Melanoma Research and the IARC via the GenoMEL scientific advisory board (SAB) and various collaborative projects. For example GenoMEL's coordinator, the University of Leeds, is conducting a collaborative research project with the EORTC on aspects of sentinel node biopsies (SNB) in melanoma patients. In addition, the EORTC and members of GenoMEL collaborated on a FP7 project submission entitled PharmacoGenoMEL.

A subset of the GenoMEL participants has also collaborated on a FP7 application coordinated by LUMC called VitaRISK. This ambitious proposal includes a number of research groups outside GenoMEL and is aimed at understanding the relationship between vitamin D levels and cancer risk, including melanoma.

In June GenoMEL held its own, very successful scientific meeting in Lund, Sweden with attendees from across Europe. There was an increased attendance on the previous year with the continued participation of our new groups in Germany, Slovenia and Poland. Researchers from GenoMEL's international groups in South America, Australia, Israel and the USA also attended. This meeting was a key opportunity for networking and the sharing of professional knowledge, and it is expected that the 2008 meeting in Paris will attract an even greater attendance.

GenoMEL members have also participated in a wide range of meetings, conferences and other activities to either publicise GenoMEL or to share knowledge and experience generated by the NoE. Further details can be found in Section 2.

⁷ The **H**uman **G**enome **E**pidemiology **N**etwork

During 2007 GenoMEL continued using web conferencing software⁸ as an alternative to more expensive, traditional physical meetings. Partly due to technical difficulties, the web conferencing was supplemented by highly cost effective teleconferences. It is still hoped to expand the use of the web conferencing software to the wider GenoMEL community to foster greater interaction and engagement.

Members of GenoMEL also have access to the fully featured Members' Section of the web site, with the opportunity to download relevant documents, contribute to discussion 'threads' and to send internal messages to one another. In 2007 the number of registered members increased to over 140. The facility for downloading documents has continued to be particularly popular.

Networking has also taken place within the field of FP project management. The Leeds project manager has become a steering group member of the European Community Project Managers' Association (ECPMA)⁹. Within the space of two years this association has expanded to include over sixty members, predominantly based in the UK but also in the Netherlands, France, Sweden and Germany. The prime purpose of this group is to exchange FP project management skills and experience.

The LUMC project manager is participating in a similar, nascent network in the Netherlands¹⁰ with many of the same aims. Both of these networks hope to eventually provide feedback on FP project management to national information points and to the European Commission itself.

The utility of websites specifically designed for professional networking are also being explored - please see the 'communication with relevant professionals and the public' section on pages seven to eight.

⁸ Marratech software, further information is available at <http://www.marratech.com/>

⁹ Further information about the ECPMA can be found at www.ecpma.eu

¹⁰ Please see <http://www.eupman.eu> for further details