GenoMEL
the Melanoma Genetics Consortium

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 (PUDK)

Updated December 2008

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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 programme 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:

i. By contributing to the design and effective implementation of the GenoMEL plan for using and disseminating the knowledge (PUDK).

ii. By identifying GenoMEL knowledge that could beneficially influence melanoma research in general.

iii. By overseeing training programmes, workshops and dissemination of results and innovations.

iv. By interacting with external advisors, with other relevant European organisations (such as the EORTC[1] melanoma group), with the IARC[2], the WHO[3] melanoma group and with other European Commission funded programmes in related research fields.

v. By actively engaging with other framework programme (FP) project managers to share best practice.

Genetic research, genetic testing and protection of intellectual property (IP)

In 2008, further work was undertaken to identify new ‘melanoma genes’. Currently no special protections are considered appropriate and a series of papers are being drafted for publication. However, discussions are well advanced as to what provisions need to be made for protection of IP from future discoveries, and about how any potential proceeds from such discoveries might be divided amongst contributing parties. A memorandum of understanding (MOU) is already in place and specifies the consortium partners’ intentions regarding the ownership and commercialisation of IP resulting from joint research.

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[1] European Organisation for Research and Treatment of Cancer
[2] International Agency for Research on Cancer
[3] World Health Organisation

Further to the MOU, a consortium-wide material transfer agreement (MTA) has been drafted. The MTA is aimed at simplifying the process of sharing samples across the consortium and encouraging further research integration. It was hoped to have this consensus document in place during 2008 but obtaining the agreement of every relevant group is likely to take a further 6-12 months.

The data that GenoMEL is generating on the psychological impact of genetic testing will be of relevance to the pharmaceutical/biotechnology industry and health care agencies developing genetic testing. The first online questionnaire generated a tremendous response from the public, and scientific papers are currently being drafted based on the results. The sharing of such knowledge in other forms will be under the oversight of the steering committee. Enquiries have already been received from the pharmaceutical industry regarding the questionnaire results.

Educational meetings for GenoMEL members, local researchers and clinicians

Over the last three years GenoMEL has organised training meetings for its research nurses, research assistants and clinicians undertaking data collection and the phenotyping of research participants. These sessions have 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. Further refresher sessions and the training of new members will take place as appropriate.

As part of its NoE commitments GenoMEL endeavours to arrange educational meeting in parallel with its summer meetings. Unfortunately this was not possible in 2008. However, GenoMEL played an active role in promoting the Perspectives in Melanoma XII meeting and participated in a number of other national, European and international meetings. Parallel meetings are already being planned for the 2009 and 2010 GenoMEL meetings in Slovenia and Leeds respectively.

Researcher mobility and integration

GenoMEL is committed to a researcher mobility scheme to encourage the exchange of ideas, laboratory techniques and other research skills. To enhance this scheme GenoMEL has created two strands – a GenoMEL Exchange Programme (GEP) and a GenoMEL Exchange Fund (GEF). The GEP enables researchers to undertake exchanges of up to three months to work collaboratively with a host group on their research project. The GEF supports shorter exchanges and a wider range of activities aimed at fulfilling GenoMEL's commitments to disseminating its knowledge (in all its forms) and integrating its researchers. 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 web, and by a strong representation at international meetings (see Networking). GenoMEL has adopted the eMelanobase database of CDKN2A variants and it is now part of the LOVD (Leiden Open Variation Database). One of our Dutch participants, Leiden University Medical Centre (LUMC), hosts and maintains this web accessible database (available at http://www.LOVD.nl/CDKN2A).

In 2008, a number of high profile articles were published involving the journals Nature Genetics, the International Journal of Cancer, the European Journal of Cancer, and the Journal of Investigative Dermatology.

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 2008, our website continued to receive an average of over two thousand visitors a month. Apart from English, 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.

Two further 'podcasts' have been mounted on the GenoMEL web site as a way of communicating with both GenoMEL members and the wider public[4]. One of the podcasts features an excellent documentary on sunbed use created by a University of Leeds broadcast journalist student.

GenoMEL is also exploring other emerging web technologies to reach a wider audience. During 2008, GenoMEL investigated the use of professional networking websites (such as LinkedIn and Plaxo), and social networking sites (such as Facebook, MySpace and Bebo), to engage with a wider circle of the world's population. These activities produced mixed results, however, GenoMEL's Latvian group successfully used a social networking site to boost the number of people completing the GenoMEL online questionnaire aimed at the public. They sent invitations via the www.draugiem.lv website ('draugiem' means 'friends' in Latvian).

The GenoMEL web site carries a content management system (CMS) that allows users to explore the implications of a diagnosis of malignant melanoma[5]. A second CMS is nearing completion that acts as a tutorial to encourage clinicians in the early diagnosis of melanoma. Several more CMSs are being developed, and will go 'live' in 2009.

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 protection and the checking of their moles and so forth). As part of this aim a health psychology questionnaire was hosted on the website. This extensive questionnaire concerned behaviour in the sun and is assisting with the development of a GenoMEL

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[4] http://www.genomel.org/english/podcastPages/podcasts.htm
[5] http://www.genomel.org/english/patientInformation

risk estimation tool. Recruitment to this questionnaire has now ended with over 11,000 people accessing the questionnaire.

Further online questionnaires were launched in 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. During 2008, the GenoMEL web site clearly demonstrated GenoMEL's commitment to communication and innovation.

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. Following the JAG's advice, in 2008 the consortium improved its collective feedback to its research participants and the public at large. Partly as a result of this, GenoMEL received a commendation for its patient information web page in the 2008 BMA[6] Medical Book Competition Awards.

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.

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[6] British Medical Association

GenoMEL has formulated a data sharing policy[7], with exchanges subject to a formal approval procedure that considers any relevant ethical issues and cost concerns. Several expressions of interest from external researchers were received in 2008 and one of the GenoMEL funded postdoctoral fellows, Dr. Ruby Chang, is leading an international research collaboration with the pooling of data sets from Australian, American and European centres. The first paper from this work has already been published in the International Journal of Cancer[8].

Networking

GenoMEL has sustained its participation in international groups such as HuGENet[9] and the Melanoma Research Foundation. More formal and active links were established with the EORTC, the Society for Melanoma Research and 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 June GenoMEL held a very successful scientific meeting in Paris, France with attendees from across Europe. 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. It is expected that the 2009 meeting in Slovenia will continue in the same vein.

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. In

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[7] Information about the GenoMEL data sharing policy is available at http://www.genomel.org/english/dataSharing.htm

[8] Paper entitled 'A pooled analysis of melanocytic nevus phenotype and the risk of cutaneous melanoma at different latitudes' available at http://www3.interscience.wiley.com/cgi-bin/fulltext/121409172/HTMLSTART

[9] The **Hu**man **G**enome **E**pidemiology **Net**work

particular, GenoMEL members gave presentations at Commission events on gender issues and biobanking. The consortium also participated in the 'Network of Networks' (http://www.supportresearchnoes.eu/) initiative to secure the long-term future of networks of excellence.

Members of GenoMEL 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 2008, the number of registered members was sustained at approximately 150. The facility for downloading documents has continued to be popular.

Networking has also taken place within the field of FP project management. The Leeds project manager has become the secretary of the European Community Project Managers' Association (ECPMA)[10]. Within the space of three years this association has expanded to include over eighty 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 Netherlands[11] 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. Links are also being formed between the emerging Project Manager networks across Europe.

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[10] Further information about the ECPMA can be found at www.ecpma.eu

[11] Please see http://www.eupman.eu for further details