

Genetic and environmental determinants of melanoma: translation into behavioural change

A network of excellence project

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sixth framework programme



PRIORITY 1

Life sciences, genomics and biotechnology for health

**Final Plan for Using and Disseminating
the Knowledge (PUDK)**

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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. 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.

Over the past five and a half years GenoMEL has undertaken an ambitious joint programme of activities (JPA) consisting of the four themes of management, integration, research, and the spreading of excellence. These activities have generated new knowledge and this plan has been written and updated to fully exploit that knowledge.

The GenoMEL Steering Group is responsible for liaising with the work package leaders with regard to new knowledge. The project management team (PMT) facilitate knowledge transfers in conjunction with the Steering Group 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 EORTC¹ melanoma group), with the IARC², the WHO³ 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)

As part of the NoE, GenoMEL has identified 10 loci associated with melanoma susceptibility. These results have been disseminated in the form of several *Nature Genetics* papers and various press releases. Patenting or other protections are not considered appropriate for such results at this time but discussions have taken place to allow for this eventuality. A memorandum of understanding (MOU) is in place and specifies the consortium partners' intentions regarding the ownership and commercialisation of IP resulting from joint research. Several further papers are currently under review by *Nature Genetics* and we hope to publish additional results in the next six months. GenoMEL is also exploiting its genetic findings by collaborating with other consortia in the US and Australia. All resulting publications will fully acknowledge framework programme funding.

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 the results have been published in the *European Journal of Cancer*

¹ European Organisation for Research and Treatment of Cancer

² International Agency for Research on Cancer

³ World Health Organisation

Prevention and in *Cancer Epidemiology, Biomarkers and Prevention*. A third paper is currently under review with the journal *Archives of Dermatology*. The sharing of such knowledge in other forms will be under the oversight of the Steering Group. Enquiries have already been received from the pharmaceutical industry regarding the questionnaire results.

Following publication, numerous requests from other researchers have been received for the questionnaire items and/or the questionnaire images. GenoMEL has therefore shared these materials with researchers in the UK, Switzerland, Australia, Croatia, Canada, New Zealand, Germany and the USA. GenoMEL will continue to share these resources with a view to advancing this field of research.

Educational meetings for GenoMEL members, local researchers and clinicians

Over the last five and a half 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 will take place as appropriate.

As part of its NoE commitments GenoMEL arranged educational meetings in parallel with its summer meetings. Successful parallel meetings were held in Genoa (Italy), Lund (Sweden), Ljubljana (Slovenia), Leeds (UK) and Tel Aviv (Israel). GenoMEL members have also participated in numerous national, European and international meetings. Indeed, members have been invited to present their GenoMEL findings at numerous international meetings. GenoMEL is already planning scientific meetings for 2012 and 2013 and will consider opportunities for associated educational events.

Researcher mobility and integration

As part of the NoE GenoMEL undertook an exchange programme that resulted in 28 successful applications. These applications were for a wide range of activities and projects. They included everything from laboratory exchanges to devising health promotion literature. Unfortunately, GenoMEL no longer has funding to support a formal exchange programme.

However, GenoMEL groups will continue to collaborate closely with exchanges of personnel, data and samples.

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>).

During the NoE period GenoMEL published 80 scientific articles, including papers in *Nature Genetics*, the *International Journal of Cancer*, the *European Journal of Cancer*, the *International Journal of Epidemiology*, the *Journal of Investigative Dermatology*, the *Journal of the National Cancer Institute*, the *Journal of the American Academy of Dermatology*, the *American Journal of Human Genetics*, *Cancer Research*, and the *Journal of Medical Ethics*. However, we also have numerous papers currently under review by journals and expect to submit still more. GenoMEL is likely to continue publishing results obtained during the NoE period for the next two years.

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. As part of this work GenoMEL has used the Internet to reach as many people as possible. Since the website went live in 2005 we have received over 120,000 visitors.

Two further 'podcasts' were added to the GenoMEL website in 2010. No further podcasts are planned but the seven existing podcasts will remain available on the website and in iTunes. GenoMEL also explored other 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.

In 2010-2011 GenoMEL investigated the use of mobile phone application (or ‘apps’) to communicate with the general public. Prototype dermoscopy tutorial apps were created for both the Android platform and Apple’s iOS. The iOS version was made available on iTunes and has been downloaded several thousand times. NKD and GenoMEL’s Spanish group are in discussion about updating the dermoscopy app. Part of this discussion concerns the possibility of charging users to download the app or seeking commercial sponsorship.

The GenoMEL website carries a content management system (CMS) that allows users to explore the implications of a diagnosis of malignant melanoma⁴. In 2009 this was extensively revised and expanded. Two CMS productions aimed at clinicians were also added to the website in 2009, one promoting the early diagnosis of melanoma⁵, the other encouraging the use of dermoscopy⁶. In 2010 the early diagnosis CMS was reviewed and revised. A further CMS, concerning genetic counselling for familial melanoma was also added to the website.

Currently there are no funds available to develop these packages further. However, NKD and the University of Leeds have undertaken to support the website and to make these packages available for the foreseeable future. They will also seek funding to continue their development.

Collaborative research and data sharing

GenoMEL now has a central online database containing information on 16,251 individuals from 2,146 families. The GenoMEL team at the University of Pennsylvania has agreed to support the database for the foreseeable future and is leading the analysis of this dataset.

GenoMEL also 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.

⁴ <http://www.genomel.org/diagnosis/>

⁵ http://www.genomel.org/WP_3.3/wp3.3.html

⁶ <http://www.genomel.org/dermoscopy/>

- Where the proposed use of data is of potential benefit to the scientific and health care communities.

GenoMEL has formulated a data sharing policy⁷, with exchanges subject to a formal approval procedure that considers any relevant ethical issues and cost concerns. For example, an application was received from Dr Eduardo Nagore's group at the Fundacion Instituto Valenciano de Oncologia. This resulted in an exciting collaboration combining GenoMEL's extensive SNP-array data and the expertise of Dr Nagore's Bioinformatics group.

Networking

GenoMEL has sustained its participation in international groups such as HuGENet⁸ and the Melanoma Research Foundation. More formal and active links were established with the EORTC, the Society for Melanoma Research, the European Cancer Patient Coalition, 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.

Networking has also taken place within the field of FP project management. The Leeds project manager is a member of the European Community Project Managers' Association (ECPMA)⁹ and the Leiden project manager is a member of the EU Project Managers Association in the Netherlands (EUPMAN)¹⁰ steering group. These groups have a combined membership of several hundred with members in the UK, the Netherlands, France, Sweden, Greece, Germany, Macedonia, Italy, Spain, Belgium, Sweden, Cyprus, Finland, Slovenia and Switzerland. The prime purpose of these two groups is to exchange FP project management skills and experience. A combined ECPMA/EUPMAN meeting took place in early 2010. The ECPMA and EUPMAN are currently discussing the possibility of combining their efforts and establishing a common website.

⁷ http://www.genomel.org/consortium_information.php#js_data_sharing

⁸ The **H**uman **G**enome **E**pidemiology **N**etwork

⁹ www.ecpma.eu

¹⁰ www.eupman.eu

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 with other emerging Project Manager networks across Europe.