Gen-Equip: Equipping European Primary Care Health Professionals to Deal with Genetics

www.primarycaregenetics.org

Report following the Primary Care Genetics Workshop

Sharing Best Practice: Equipping European Primary Care Health Professionals to Deal with Genetics

Date	**Friday 5th May, 2017** **0930hrs – 1630hrs**
Venue	**30 Euston Square, London** **(headquarters of the Royal College of General Practitioners).**

The Gen-Equip Project is Co-funded by the EU: 2014-1-UK01-KA204-000065

Table of Contents

Tables

Introduction

The Gen-Equip project [www.primarycare genetics.org] is co-funded by the EU Erasmus+ programme and is the work of partners from six European countries. We have developed a programme of online learning modules and tools to support daily practice in primary care. This workshop was organised to disseminate the project, obtain feedback, and create a network of interested persons to ensure ongoing support and sustainability of the educational programme.

Aims and learning outcomes

The aims of this workshop were to:

- Share best practice on facilitating good standards of genetic healthcare in primary care practice
- Introduce the series of online educational material available to primary care professionals and discuss how they can be used.

The stated learning outcomes were as follows.

After completing this workshop, attendees will:

1. Understand the need for primary care professionals to engage with genetics and genomics to directly influence patient care
2. Be able to utilise a range of educational tools to support learning in their peers, students and colleagues
3. Be familiar with a range of strategies to engage primary care professionals in genetics education.

Financial arrangements

As funding for this event was provided via the Erasmus+ grant, we were able to offer free registration, which included lunch and refreshments. However, we were aware from the outset that the costs of travel to London would pose a barrier to some potential attendees, therefore we sought some additional funding to provide travel fellowships to those who needed them. Funding support was obtained from the Galton Institute (£1000) and the University of Plymouth School of Nursing and Midwifery (£5000). This enabled us to offer travel fellowships of 200€ to 28 participants from 11 countries. In addition, the Health Education England Genomics Education Programme provided travel funding for a proportion of attendees from with the United Kingdom.

Invitations to the Workshop

Invitations to the workshop were issued via the partners to:

- Primary care colleagues in each partner country
- Institutions and associations focussed on primary care (e.g General practitioner associations in each country)
- Educators focussed on genetics (e.g Health Education England Genomics Education Unit)
- Genetic specialists with a known interest in health professional education (via partner networks and the European Society of Human Genetics)
- Representatives of patient and support groups (e.g. via Genetic Alliance UK).

Participants

This workshop was planned to provide a forum for sharing experiences regarding genetics education in primary care across a wide range of stakeholders. Invited participants included primary care professionals (general practitioners, community paediatricians, midwives, primary care nurses), genetics professionals (medical geneticists, genetic counsellors), relevant patient group representatives and those involved in provision of education for primary care professionals.

There were 64 participants who booked a place at the workshop and 61actually attended. These 61 participants were from 14 European countries (Table 1). The additional seventeen people who attended were from the partner institutions involved in the project (Appendix I), making a total of 78 people at the Workshop.

Table 1. Workshop participants by country

Country	Number
Belgium	2
Czech Republic	3
Finland	1
Iceland	1
Israel	1
Italy	3
Netherlands	10
Portugal	13
Republic of Ireland	2
Spain	4
Sweden	1
Switzerland	2
Turkey	1
UK	17
Total	**61**

Programme

The programme was designed to enable participants to:

1. Learn more about genetics education in primary care
2. Share their own challenges and successes in providing genetic education for primary care professionals
3. Share a range of different educational tools
4. Provide feedback and direction for the Gen-Equip project.

Thus, the programme was divided into presentations and guided group work sessions (Table 2). Time was also allowed for informal networking and discussion. All formal presentations were made available to all participants after the Workshop and a participant contact list was circulated to encourage post-Workshop networking.

All participants were asked ten days before the workshop if they wished to present a resource that they had used. Six participants responded and were included in the programme in an afternoon session.

Table 2. Workshop Programme

Time	Topic	Leader/speaker
0930 hrs	Registration and refreshments	
1000-1020 hrs	Welcome and introduction to the Gen-Equip project Setting objectives for the day	Professor Heather Skirton (Gen-Equip Project Leader)
1020-1040 hrs	Why is it important that primary care professionals engage with genetics?	Dr Mariana Campos Genetic Alliance (UK)
1040-1100 hrs	Opportunities and challenges engaging primary care professionals with genetics	Dr Isa Houwink (Netherlands)
1100 - 1215 hrs	What has been the experience in your country/setting? Sharing challenges and opportunities in practice.	Professor Heather Skirton Participants working In small groups
1215 hrs	**Networking lunch (provided)**	
1315-1345 hrs	Gen-Equip: Resources for primary care education in genetics	Dr Leigh Jackson (UK)
1345-1415 hrs	Strategies for engaging primary care in genetics education	Dr Jude Hayward General practitioner with special interest in genetics (UK)
1415-1500 hrs	Sharing of resources used by workshop participants (5-6 minutes per speaker) 1. Edward Miller – UK 2. Anju Kulkarni – UK 3. Marco Crimi – Italy 4. Stefania Boccia - Italy 5. Alana Ward – Ireland 6. Paula Silva – Portugal	Participants, facilitated by Dr Milena Paneque (Portugal) and Ms Vigdis Stefansdottir (Iceland)
1500 – 1530 hrs	Afternoon break with fruit, tea, coffee	
1530 – 1610 hrs	Sharing experiences - How can you use the resources in your own setting? Where are the gaps? Suggestions for disseminating the resources?	Participants in small groups, led by Dr Daniela Turchetti (Italy) and Dr Vaclava Curtisova) (Czech Republic).
1610-1630 hrs	Summary and final feedback	Prof Heather Skirton

Results of the group work

During the first group work session, participants were asked to work in groups with colleagues from different countries: each group included representatives of both primary care and genetics. The task was to determine the opportunities and challenges involved in providing genetics education for primary care from the perspective of primary care, and opportunities and challenges from the perspective of the genetics specialist.

The results were discussed in the main group and were organised as indicated in Table 3.

Table 3. Opportunities and challenges to providing genetics education for primary care

Opportunities from primary care perspective	Opportunities from genetic specialist perspective
Unique position as a family practitioner	Develop simple guidelines for GPs regarding referral of patients
Position as gatekeeper to other care	Develop simple, straightforward local guidance
PCP knows family well	Integration of resources into existing tools that are accessible to primary care
There are many PCPs	More knowledge in primary care will help rapid and safer diagnosis of patients with genetic conditions
Able to help co-ordinate care with links to specialists	Make genetics part of formal practice guidelines
Collaboration with new research and projects is educational	Teach genetics using daily practice scenarios
Uniformity and consensus on simple guidelines	Empower patients
Opportunity to co-ordinate care	Insertion of more genetics into pre and post graduate training
Special groups on genetics in primary care associations	
Public support and engagement	Primary care can contribute to genetics research
Access available tools and resources	Create simple resources
Learning through patient information	Define ways simple communication , offering different levels of assistance to PCP
More genetics in PCP curricula	Put genetics in context of individualised care, preventive medicine and individualised guidelines
Integrate existing resources in to tools that can easily be used in clinic	Genetics can result in earlier diagnosis
Use clinical decision support	Provide mechanisms of support beyond referral
Clarify areas of responsibility (for patient care)	Be a link between primary and secondary care D
Participate in available training	
Develop courses specifically for PCP linking with schools and other educational initiatives	
Lack of time	
Information overload	

Challenges from primary care perspective	Challenges from genetics specialist perspective
Identify patients who might benefit from genetic services	To capture the primary care audience
Discrepancies between and within countries re genetic referrals and testing	Gaining access to primary care professionals and services
Difficult to recognise the importance of genetics in their practice	To access PCP and services
Proper application of existing professional knowledge	'Selling' genetics as an important topic for PC
Recognition that they (the PCP) has an educational need in genetics	Helping PCP recognise the importance of genetics in primary care
Translation of theoretical knowledge into clinical application	To make genetics a priority in clinical primary care practice
Identifying the 'needle in the haystack' (those with rare genetic conditions)	Raise awareness of rare genetic conditions
Time to explore family history	Obtaining official recognition for genetic specialists in primary care (in some countries)
Difficulty finding resources	Ensure clear communication to and from primary care
Difficulty accessing expert opinion	Lack of resources
Lack of basic genetics knowledge makes it difficult to explain conditions to patients without assistance of genetics	Create awareness about the frequency of genetic conditions in primary care
Genetics is perceived as a very complex issue	Commitment of time of both PCP and health educators to support education
Obtain ore knowledge in clinical genetics in easy and non-time consuming way	

In the afternoon, the Gen-Equip and a range of other resources for primary care education in genetics were presented. Participants were then asked to form groups according to country or region, and were asked to address the following questions:

1. How can you use the resources in your own setting
2. Are there gaps to be filled? Where are the gaps?
3. Can you give suggestions for improvement of the resources
4. Can you provide suggestions for dissemination of the resources.

After working in groups, the questions were discussed generally. The summary of the discussion points is presented in Table 4.

As organisers, we had a sense that participants were very engaged in the topic. There were numerous questions asked, and in the group work sessions there was a high level of discussion, debate and contribution from participants. In the refreshment breaks, the level of animated conversation continued between participants from different countries and disciplines.

Table 4. Summary of discussion of use of resources and gaps.

Suggestions for use of resources	Gaps identified	Ideas for dissemination
Make accessible for professionals in other professions or healthcare settings	Simplified summaries of patient pathways and referral guidelines	Use professional organisations, support groups and charities to publicise
Implement a common plan regarding genetics education for all specialties	'Just in time' resources using apps and easy technology	Embed into websites and newsletters
Use patients to support need for education of providers	Clinical decision support tools embedded in primary care ICT systems	Advertise in scientific journals
Bi-directional communication between PCP and genetics	Prompts on PCP It systems to consider possible genetic diagnosis	Replicate this workshop in other countries
Use diverse contacts with wide range of stakeholder groups with special interest in genetics	Clinical decision tools	Resources linked to GP trainee portfolios so can be used to meet curriculum objectives
	Simplified summaries for use in clinic	Link resources to CPD portfolio
	Links to CPD portfolio	Link with universities for use in pre and postgraduate education.
	More communication between PCP and genetics to determine PCP needs.	

Evaluation by participants

All participants were asked to complete an evaluation form, in which they were asked to rate the Workshop and also the Gen-Equip resources.

Feedback on the Workshop

Participants were asked to rate each of the sessions offered in the programme individually, using a scale of 1-5, where 5 was extremely useful and 1 was not at all useful. Forty-four completed evaluation forms were returned. The mean scores ranged from 4.1 to 4.7, indicating that all sessions were rated overall as very useful to extremely useful.

While the lectures were all rated well, the participants seemed to particularly appreciate the group work sessions, we here they were able to exchanges ideas in discussion with peers.

Some comments were:

- Brought real experiences of challenges and opportunities. Very useful and practical. Thank you
- Good creative time exploring challenge and opportunities
- Interesting to know how they work abroad, different systems of health insurance doesn't make it easy to come with a common solution.
- Good to see the challenges and differences between professions and countries
- Very interactive! Is nice to have opinions of different professionals
- Good idea to engage into group discussions useful insights…
- Useful to hear similar challenges to different countries.
- Enjoyed the group work/interaction
- Very helpful. Great to hear different opinions and getting to know the people better.
- Really good to chat in small groups - great idea.

Feedback on the Gen-Equip resources

Overall, workshop attendees felt that the GenEquip resources are excellent, useful, interactive, free resources, easy to access/use and applicable to practice. They were considered an important tool in health education and their use could be extended. One participant commented "these resources will facilitate not only the referral but also a taster diagnosis of the patients." However some queried whether lack of time might prevent their use by GPs, with feedback that some of the modules are quite long. It was suggested that the website was re-designed outside of the Gen-Equip framework so that it becomes a stand-alone resource. Another suggested that subtitles were added to the videos.

When asked if Gen-Equip would help in their own work environment, participants responded positively. They felt it would help health professionals increase their own knowledge, provide education/resources for primary care professionals and be a tool for dealing with genetic questions in daily practice. Improvement of genetic education was felt to be important by many, for the overall improvement and quality of patient care. Gen-quip was seen as an educational tool that could be used in GP training education, as it would help in daily practice and for raising awareness of genetics.

Some of the comments were:

- Very useful - possibly summaries of key information may work well in addition, given time constraints in primary care
- Excellent resources.
- Need to fully evaluate
- The resources are well developed and are based on the best evidence available.
- The resources are scientific accurate and are easy to access. These resources will facilitate not only the referral but also a taster diagnosis of the

patients. It will be also helpful for PCP patients follow-up in primary care units, specifically on how PCP can manage genetic diseases.

- Very useful, only technical problems [using the] open learning platform. Webinars are a bit 'boring'. I wonder if GP's would take time to follow them.
- Good resources, simple, concise and precise
- These were excellent resources - applicable to practice.
- I find them really interactive and useful
- Perhaps update the platform into a more professional web resource. An idea would be to re-design the website outside the Gen-Equip framework as a stand alone resource.
- Good resources and free - some are quite long and involved. Developmental delay 71 slides- a little threatening?
- Very useful
- Very interesting! Keep up the good work.

How could participants contribute beyond the Workshop?

Many of the participants felt that they would be able to assist in further developing GenEquip and would be able to share GenEquip resources and experiences of primary care education with colleagues. Suggestions included collaboration between training and education leads at medical centres, encouraging genetics education in specific primary health care training programmes, with translation/teaching/contributing to online learning modules and by sign posting health professionals to the Gen-Equip resources.

Participants also felt they could contribute through translation (including additional languages), data collection from other countries currently not included in the GenEquip consortium and by sharing their own experiences in the genetic field and GP area. Other suggestions included reviewing and contributing to content, through publication and presentation, with communication strategies (in advertising), by sharing experiences from their own country with GenEquip at future workshops, contributing at GP lectures and in the development of case studies.

Points for action

As a result of the Workshop, we have taken several actions in response to the suggestions made by participants.

1. We have contacted the Heads of Schools of Nursing, Midwifery and Medicine in universities in the UK by personal email to explain the resources and suggest that they might be used to support education on genetics in their schools.
2. A similar workshop is being planned in Porto, Portugal.
3. We are negotiating use of existing simple summaries for PCP to embed in the website.

Conclusions

We consider that the aims of the Workshop were achieved.

The Gen-Equip resources were publicised and since the Workshop we have noted increased numbers accessing the modules. We also obtained feedback and ideas about the use of the resources and further dissemination. However, one of the major outcomes was that a group of professionals who were interested in this topic were able to discuss it and form new professional networks. It was notable that even with this common interest, participants from different countries were not known to each other before the Workshop. We therefore hope that new professional alliances will result from the event, to further genetics education in primary care in Europe.

Appendix I. List of partners attending the multiplier event

Name	Partner	Country
Heather Skirton	Plymouth	UK
Leigh Jackson	Plymouth	UK
Anita O'Connor	Plymouth	UK
Judith Hayward	Plymouth	UK
Nadeem Qureshi	Plymouth	UK
Peter Lunt	Plymouth	UK
Amanda Young	Plymouth	UK
Mariana Campos	GA UK	UK
Vaclava Curtisova	Charles University	Czech Republic
Radka Pourova	Charles University	Czech Republic
Martina Cornel	VUMC	Netherlands
Daniela Turchetti	University of Bologna	Italy
Milena Paneque	IBMC	Portugal
Anabela Nunes	IBMC	Portugal
Vigdis Stefansdottir	Landspitali Hospital	Iceland
Thordis Jonsdottir	Landspitali hospital	Iceland
Jon Johannes Jonsson	Landspitali Hospital	Iceland