A Global Genomics Nursing Alliance (G2NA) to Accelerate Integration of Genomics into Everyday Professional Practice

Meeting Report Executive Summary

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G2NA Retreat Executive Summary

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Key Points

- Nurses are essential to realizing the integration of genomics into healthcare.
- There are significant, shared global challenges to nurses being able to integrate genomics into everyday practice.
- The greatest challenges are around education and awareness about genomics.
- Nurse leaders and experts across nursing, genomics and healthcare from 17 countries and 7 international/ major international organizations met at a 3-day Retreat at the Wellcome Genome Campus, UK, to construct a Roadmap for action to accelerate transformation of practice.
- Participants agreed the establishment of a Global Genomics Nursing Alliance (G2NA) was an appropriate vehicle to increase genomic nursing capacity, guided by the Roadmap.
- The G2NA will provide an international network for all nurses; seek to influence regulation and standards; collaborate with interprofessional communities; facilitate access to education resources.
- A plan of action with recommendations has been drawn up to guide the way forward.

Context

Nurses have a pivotal role in bringing the benefits of genomics to everyday healthcare. However strategic global effort is needed to transform nursing policy, practice, education and research to provide a professional workforce enabled to embrace genomic healthcare.

Aim

We aimed to create and implement a plan of action to guide and accelerate the integration of genomics into nursing professional practice globally, through five complementary activities:

1. Establishing a Global Genomics Nursing Alliance (G2NA) for knowledge mobilisation, ongoing collaboration, consultation, sharing, and research.
2. Creating a G2NA Roadmap that lays out how to integrate genomics into nursing education, practice and research.
3. Establishing a Maturity Matrix to inform strategy to improve care and serve as a benchmark for progress and that recognises real-world constraints.
4. Identifying existing nursing assets in genomics that could be shared throughout the international nursing community.
5. Determining key features needed for a sustainable G2NA platform.

Methods

A two phase approach was used to gather data; prior to (phase 1) and during a 3-day invitational Retreat (phase 2).

Phase 1
Data were gathered from participants through two online surveys:

1. Scoping healthcare systems, nursing and genomics in mainstream and specialist services in each country, and gathering views on challenges and priorities in integrating genomics into nursing;

2. To inform Maturity Matrix development, nominations were sought for up to six core areas for action which could be used to benchmark progress in delivering effective nursing which promotes health outcomes globally through genomics.

Two pre-meeting webinars briefed participants on the initiative and provided broader context.

Phase 2
At the Retreat we utilized Liberating Structures techniques in an innovative participatory approach to a structured programme of activities designed to gather data on the essential components of a Roadmap to accelerate integration of genomics into nursing. Additional data were collected during Retreat utilizing real time voting. A graphic facilitator was employed to capture a visual record of discussions and social media (Twitter: @g2na4health; #g2naretreat) was used to disseminate news and views on the Retreat. Specially constructed video facilities captured participants' views on the issues of the day on camera.

Participants
Twenty-nine participants attended the Retreat, including the six members of the Program Team and a Graphic Facilitator. Participants were selected on the basis of their knowledge, expertise and/or global leadership in genomics, healthcare, nursing, and policy. Seventeen countries and seven international or major national organizations were represented. Participants from two other countries contributed to the surveys but were unable to attend the Retreat.

Outcomes

Context
In the scoping survey, 25 responses were received from 23 individuals, for 17 countries and seven organizations. The responses showed that:

- The majority of the 12 genomic applications[1] listed in the survey are concentrated in specialist centres.
- Prenatal and newborn screening is more widely available, in 10 and 14 countries respectively.
- 11 applications were identified as 'not at all available' by between 1 and 3 countries.
- All countries provided newborn screening.
- There is limited utilisation of nursing skills in genomic applications other than at Advanced Practitioner level, except prenatal/newborn screening.

Challenges to integration of genomics into nursing practice
Three of the top 4 ranked challenges in this category focussed on education:

- Limited access to point of care educational information and clinical decision support
- Need for resources to link genetic variation to clinical implications of phenotypes
- Lack of expertise and training programmes in genetics, genomics informatics and/or statistics
- Lack of consensus on what investment is needed.

Challenges to education
There was broad consensus on the key challenges to successful integration of genomics into nursing education, the top 5 ranked being:

- Insufficient curriculum time to cover genomics
- Insufficient numbers of educators able to teach genomics
- No requirement for nurses to demonstrate competence in genomics in order to qualify
- No/limited leadership
- Reluctance to consider different approaches to nurse training that facilitate integration of new knowledge and clinical advances.

Top priorities
There was strong consensus on the importance of addressing education and awareness raising. Other top priorities were around addressing resources to support genomics in nursing; the status and visibility of nurses and nursing, generally and in relation to role in genomics; the organisation and delivery of healthcare that incorporates genetics and genomics.

Maturity Matrix
The core areas for action (domains) to deliver effective family- and community-focussed nursing care which results in improved health outcomes and which could be used to benchmark progress in genomics integration were agreed as:

A. Enhanced education and workforce development;
B. Effective nursing practice that builds on an evidence base, with clear delineation of nursing roles and interventions in delivering genomic healthcare;

[1] Systematic family history taking; risk assessment/ genetic testing for disease susceptibility; preconception testing; prenatal screening; newborn screening; disease screening based on genomic technology; disease prognosis; tumour sequencing; targeted therapies; pharmacogenomics; sequencing for infectious agents

C. Infrastructure and resources to support incorporation of genomics in education, practice and services;
D. Collaboration and communication on a shared vision of genomic healthcare across borders and professional groups;
E. Person, family and community-focussed care, with accessible services and an informed public;
F. Leadership in transforming healthcare through policy development.

These domains were refined through an iterative process and were complementary to the prioritized needs identified. Each domain theme is underpinned by sub-themes, indicators, benchmarks and measures.

Establishing a G2NA
Participants were invited to identify their 'Big Idea' for G2NA. Ideas rated most highly by participants focused on the formal establishment of G2NA to develop and maintain a community of practice, influencing policy at strategic level, influencing practice through raising awareness and through emphasising the nursing role in genomics.

There was consensus that the Global Genomics Nursing Alliance, guided by the Roadmap, should perform the following functions:

- Provide an international network for all nurses
- Seek to influence regulation and standards
- Collaborate with the interprofessional community
- Facilitate access to education resources
- Establish a policy-focussed strand
- Seek a role in public awareness activities
- Establish a research-focussed strand.

Action Plan

The Action Plan to finalise the Roadmap and establish the G2NA is being formulated. Short-term plans focus on two strands:

G2NA operations and expansion

- Establish a G2NA Strategic Plan
- Devise a Funding Strategy
- Explore collaborative opportunities with the Global Genomics Medicine Collaborative (G2MC)

Dissemination

- Outcomes are being disseminated through conferences, meetings, reports to funders and a series of peer reviewed manuscripts.
- A video summarizing the Retreat is available at https://www.youtube.com/watch?v=8keUQFAJtFw&feature=youtu.be
- G2NA leads will provide ongoing feedback to the Policy lead for Genomics in Health Education England to share strategic direction.
- G2NA participants agreed to disseminate news of G2NA through their networks and relevant websites.
- The G2NA website will be developed further as a resource for members and others.
- Posters prepared by participants will be collated and uploaded to the G2NA website.
- A G2NA moderated listserv to facilitate communication between members has been implemented (contact Kathleen Calzone at calzonek@mail.nih.gov to join).

- During the Retreat, an estimated 51,274 Twitter accounts were reached by #g2naretreat and 34,801 by @g2na4health (30 contributors). Social media will continue to be used to maintain interest via the G2NA Twitter account (@g2na4health).

Recommendations

In developing a G2NA Strategic Plan, the following should be considered:

Leadership and engagement

1. Nurses must be involved at strategic and operational levels in planning to address global and national challenges around the implementation of genomic medicine across the healthcare continuum. The G2NA leadership team should be expanded.
2. Strategic alliances with international nursing organizations should be established and/or strengthened to facilitate awareness raising, resource mobilization and dissemination.
3. Representatives from other countries should be sought and engaged.
4. G2NA should seek interprofessional collaboration with other health disciplines.

Responsive working

5. A global strategic approach is needed to transform education, evidence-based practice, and infrastructure has begun with the formation of G2NA. One logical next step to inform planning and help identify local needs, barriers and enablers is to conduct regional and national benchmarking based on the Maturity Matrix.
6. G2NA should consider mechanisms by which countries further along the Maturity Matrix can support those at earlier stages of progress.

Resource mobilization

7. A comprehensive work package on resources should be developed and implemented, building on the resources collated for the G2NA Retreat. This should incorporate a gap analysis, identification of resources which might be repurposed, and improving accessibility of existing resources across diverse cultures and audiences.

Dissemination

8. G2NA should continue to utilize social media to raise awareness about G2NA and its activities and consider other approaches, such as regular webinars and newsletters.

Sustainable working

9. Funding is needed to support the G2NA infrastructure and additional activities. Annual face to face meetings will be important to maintain momentum.

Conclusion

As the largest healthcare profession, nurses are essential to realizing the integration of genomics into healthcare. However, nurses globally face many shared and significant challenges. The Retreat generated considerable social capital to accelerate change across global nursing communities, providing the impetus to improve nursing genomics health literacy. It is vital that this capital is harnessed and efforts are coordinated to reduce duplication of effort and burden on any one country. International, interdisciplinary collaboration and support is critical to success in building nursing capacity and capability in genomic healthcare.

G2NA Project Team

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Funding
The Wellcome Genome Campus Advanced Courses and Scientific Conferences programme hosted the Retreat, providing venue, accommodation, logistics support and some contribution towards international travel costs. Health Education England Genomics Education Programme further supplemented these costs. The project was also supported by the Intramural Research Programs of the National Institutes of Health, National Cancer Institute and National Human Genome Research Institute.

G2NA participants	Designation
Naoko Arimori	Professor of Nursing, Niigata University Japan; Board member, Japanese Society of Genetic Nursing
Sivia Barnoy	Associate Professor, Tel-Aviv University, Israel
Inga Bjørnevoll	Head of Medical Genetics, St Olavs, Trondheim, Norway
Cathy Catrambone	President, Sigma Theta Tau International
Sek Ying Chair	Director and Professor, Nethersole School of Nursing, Chinese University of Hong Kong, China
Andrew Dwyer	Assistant Professor, Lausanne Institute of Higher Education and Research in Healthcare, Switzerland
Mary Jane Esplen	Professor and Vice-Chair, Department of Psychiatry, University of Toronto, Canada
Sue Hatton	Senior Nursing Policy Manager, Health Education England
Lian-Hua Huang	Professor of Nursing, Taiwan University, Taiwan
Hussain Jafri	Deputy Project Director Punjab Thalassaemia Prevention Programme, Pakistan
Alastair Kent	Director, Genetic Alliance UK & European Genetic Network
Hester Klopper	Deputy Vice Chancellor, Stellenbosch University, South Africa
Sascha Köpke	Professor of Nursing Research, University of Lübeck, Germany
Chris Patch	Clinical Lead for Genetic Counselling, Genomics England & President-elect, European Society of Human Genetics
Elizabeth Pestka	President, International Society of Nurses in Genetics
Anja van Rens	Genetic Counsellor, Antoni van Leeuwenhoek Hospital; Secretary, Dutch Association of Genetic Counsellors, Netherlands
Pilar Amaya Rey	Professor, Universidad Nacional de Colombia, Columbia
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Memnun Seven	Assistant Professor, School of Nursing Koç University, Turkey
Judith Shamian	President, International Council of Nurses
Juana Mercedes Gutierrez Valverde	Professor, School of Nursing, Universidad Autonoma de Nuevo Leon, Mexico

Other participants unable to attend in person

John Daly	Dean of Faculty, University of Technology/Head of WHO Collaborating Centre, Sydney, Australia
Funmilayo Ikeoluwa	Assistant Chief Nursing Officer, University Hospital Sokoto, Nigeria