



West Midlands Academic Health Science Network

Genomics Medicine Centre Innovation Audit Report

September 2016

Version 0v5 – FINAL VERSION

Achieving change together

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Section 1: Introduction and Background



Innovation Assurance Audit - Background

West Midlands Academic Health Science Network (WM AHSN) is seeking to demonstrate to NHS England, NHSI and the membership of the WM AHSN that there have been a number of demonstrable examples of significant additional innovation outcomes that have been driven through the work undertaken by WMAHSN. These outcomes in turn will influence and improve patient pathways at a significant level both regionally and nationally. This includes how the introduction of innovation, combined with the transformation of clinical practice, has delivered improved healthcare outcomes and other benefits for patients through adoption and diffusion of ground breaking best practice.

To demonstrate this, the AHSN has undertaken two innovation assurance audits to confirm and challenge the innovation arising from developments in those areas. This report focusses on the innovation arising from the West Midlands Genomics Medicine Centre (WM GMC), with a particular focus on what has been achieved through taking a whole regional patient population approach with the majority of NHS providers and commissioners, academia and industry across this footprint. The output (this report) is a communications pack of key messages and other content for publication on Meridian that can be used with NHS England and AHSN members to:

- Enable national recognition that the West Midlands region is achieving its innovation and transformation targets
- Influence the on-going development of GMCs in other parts of the country.



Genomics Medicine Centre (GMC) Project Summary

Project AIM

To transform NHS service delivery through the introduction of Whole Genome Sequencing (WGS) as part of the range of genetic tests available to clinicians in mainstream service delivery.

Project OBJECTIVES

- To recruit cancer and rare disease patients into the 100K project in line with sample trajectories agreed with NHS England
- To deliver the project through mainstream clinical service delivery wherever possible
- To develop a 'hub and spoke' model that involves all the NHS providers across the West Midlands
- To transform genomics education delivery through widening participation in the wider workforce and supporting the development of specialists
- To use the project as a platform for other regional service developments.

Project INPUTS

Funding of £200 per successfully sequenced sample is provided by NHSE, plus capital funding for set up costs. A programme team and three Genomics Ambassadors have been recruited.

Project ACTIVITIES

- Patient recruitment through clinics
- Patient and public engagement
- Development of an education and training programme to support workforce development
- Development of laboratory services in the Regional Genetics Service at BWH, Molecular Pathology in UHB and the HBRC biobank
- Development of an informatics platform to support end to end sample management with associated patient records
- Communications and engagement in Local Delivery Partner (LDP) sites.

Project OUTPUTS (Planned)

- Rare disease and cancer patients recruited in line with agreed contractual sample trajectories with NHSE
- Genomic testing becomes increasing mainstream across the full range of NHS providers across the West Midlands
- New education and training interventions in place with access arrangements across a wide range of disciplines
- Bespoke patient record and sample management and tracking system that can be utilised by other GMCs
- Local laboratory capacity and capability to undertake genetic testing developed and supported.



Section 2: Project Approach

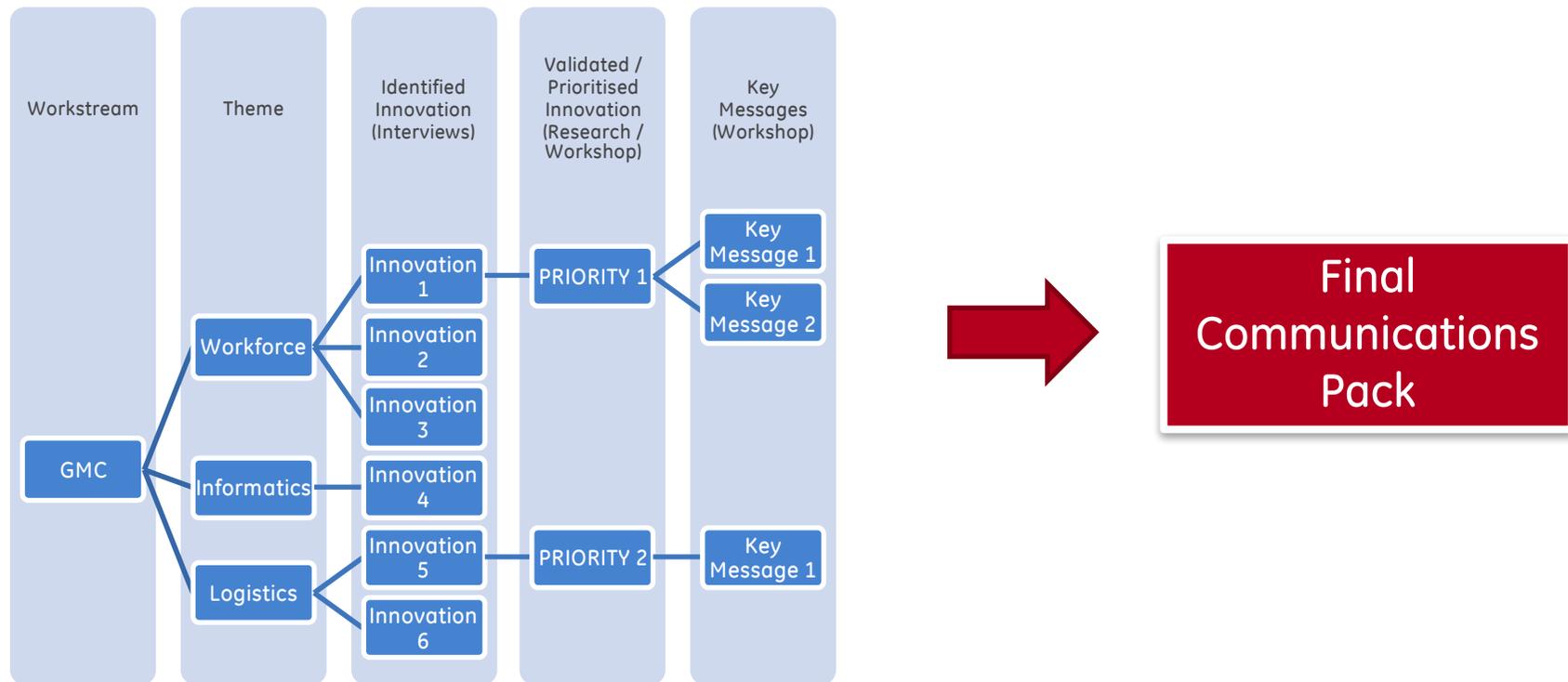


Project Approach

Following an initial project mobilisation meeting with Tony Davis (WM AHSN sponsor) and Dion Morton (Clinical Lead for the project), a number of key themes for the review were agreed and communicated to project stakeholders.

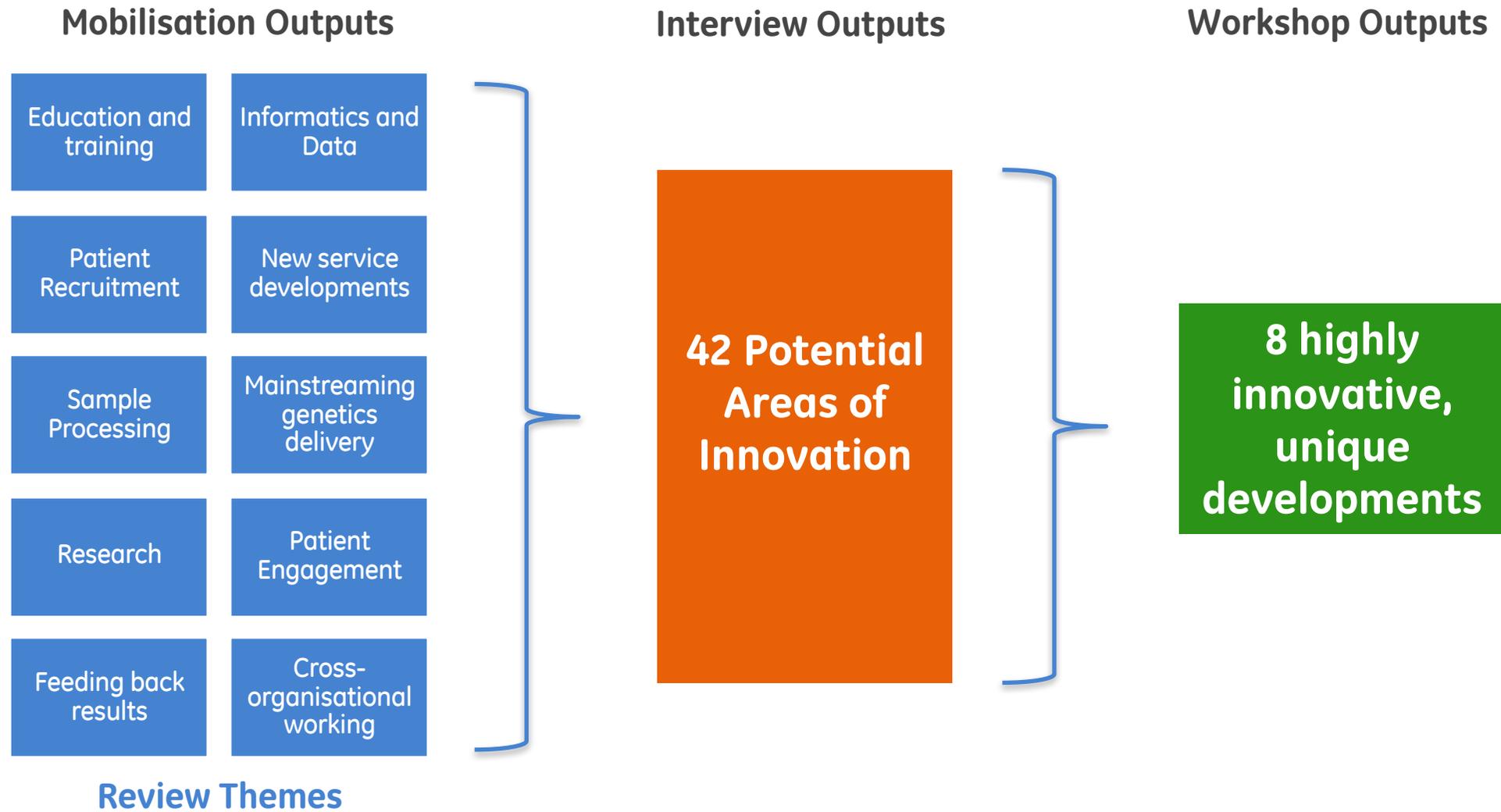
15 semi-structured interviews were undertaken with a variety of people involved with the GMC project to identify a long list of potential innovations that could form part of the final communication pack. These innovations were summarised against the agreed themes and the benefits of each innovation documented. The full Innovation Audit Summary for this project can be found in Appendix 1.

The core project team then undertook an initial assessment of each of the longlisted potential innovations to identify a draft shortlist of innovations that were highly innovative and unique to the West Midlands. The impact of the innovation on the GMC project itself or its stakeholders was also assessed as part of this process. The Innovation Summary, and the outputs of the prioritisation exercise, was circulated to project stakeholders for review and comment prior to a project workshop, where the final shortlist of innovations for the communications pack were agreed along with the key messages that needed to be communicated to the key stakeholder audiences for this work.



Innovation Review Outputs

The following diagram summarises the key outputs from each stage of the process outlined on the previous page.



Section 3: Key Innovation Profiles



Key Innovation 1 – Cross-organisational / Partnership working

Innovation Description

Development of a partnership with all hospitals in the West Midlands being a Local Delivery Partner (LDP) site

Key Benefits

- All hospitals in the West Midlands area share the benefit of being part of the 100K genome project and not just the large teaching hospitals
- Drives improved standards for patients through the application of learning in one Trust across the others
- Major enabler of transformational change, as recognised in the local STP plans
- Supports the development of the 'prevention' agenda
- Upskilling in local knowledge on pathology services
- Can provide frontier treatment in local areas through the 'hub and spoke' model
- Reduces travel to Birmingham from distant parts of the West Midlands for patients and their families
- Reduces the 'post code lottery' of service provision
- Enables each hospital to have a capability to deliver genetic diagnostic and treatment services locally with hub support as required
- Improvement in quality of ways of working
- Improves networking across the region.

Key Messages

- Although other GMCs have LDPs, the scale of the partnership and the ambition for developing those relationships and delivering associated services is unique in the West Midlands.
- The West Midlands GMC is built on strong historical relationships that have survived multiple NHS re-configurations. This includes the Regional Genetics Service (RGS) that has been delivering genetics services on this footprint for 20 years, and other clinical networks such as the Strategic Cancer Network (SCN)
- There is now a wider understanding in Trusts of what clinical genetics services can offer in adult care, and any barriers can be addressed on a regional basis (e.g. who is paying for the tests).
- Developments to date have enabled a number of spin-offs, such as the proposed use of triumvirates (Clinical Genetics, Laboratory Genetics, Ambassadors and Clinical Specialists) to provide MDT review before feedback of results to patients
- Working across the whole footprint enables the push towards mainstreaming of clinical genetic testing at pace and scale
- The GMC is attracting high profile external interest as a result of its partnership e.g. the development of pharmaco-genomics services with the Mayo Clinic, with the West Midlands being the lead partner for the UK for the OneOme project
- These developments are driving a new innovative response to the reconfiguration of genetics services by moving towards a model of a regionally owned genomics service
- There is strong leadership and buy-in from all the LDP partners, despite recent changes in senior leadership across a number of these organisations.



Key Innovation 2 - GENIE

Innovation Description

Development of the GENIE patient record and sample tracking system to support GMC operations.

Key Benefits

- Supports workflow management of the end to end process from patient recruitment through to sample collection and processing, and final reporting to the patient. Combines relevant clinical data with genomic data - provides a EPR type system through integration with local systems
- Reduces duplicate data entry requirements
- Links patient records across multiple hospital sites, creating an opportunity for use in other rare disease activities outside the project
- Holds, accesses and reuses data locally which can be used (with consent) for other purposes (e.g. research)
- Has enabled the provision of licences for EMC Documentum for LDP Trusts, which allows these organisations to use these licences to support Paper Free at the Point of Care working in other areas
- Increased opportunities for collaboration with the pharmaceutical industry to potentially commercialise the data
- Provides the ability to capture the phenotype data at the time of the test.

Key Messages

- GENIE is significantly supporting the development of the overall digital maturity of the region and underpins the delivery of local Sustainability and Transformation Plans (STPs). Such developments facilitate access to capital monies to further develop GENIE to become a class leading product (e.g. the NHS Global Digital Excellence Fund)
- The project is a national trailblazer for integrating care records with genomic data to support clinical decision making
- The West Midlands have highly advanced levels of interoperability and system agnostic integration at a regional level, which are underpinned by robust data sharing agreements. This includes links to the Somerset Cancer Registry (to improve COSD completion rates and overall cancer data quality) and a mini-spine (for supporting patients out of region)
- GENIE influences the choice of other systems in use across the Local Delivery Partners to ensure full system interoperability across the region
- Through functionality that allows the inclusion of a list of potential patients for recruitment, the use of GENIE has improved the overall consenting process and provides intelligence on the overall conversion rate.
- Other GMCs have licenced and now use the system to underpin their GMC operations
- GENIE was built on an existing platform developed for the Cancer Research UK Stratified Medicine project, and is continually being developed in line with the emerging GMC requirements (including the provision of advanced search capabilities).
- The system allows further data collections to be made and integrated with GENIE (e.g. stereotactic ablation data with associated DICOM images), which act as a 'proof point' that GENIE can be expanded to capture other clinical data.



Key Innovation 3 – Development and adoption of bioinformatics tools

Innovation Description

Development and adoption of bioinformatics tools to support variant identification, prioritisation and interpretation in routine services as well as the 100K Genome Project (e.g. Phenocap, Sapientia, GenomeOncology)

Key Benefits

- Single source of information for phenotype data and test requesting
- Deep analysis of complex data sets leading to quicker identification and ranking of relevant variants for likely cause
- Better phenotype information accompanies requests for routine tests, which if return negative, can be used as a source of phenotype information for GENIE
- Provides improved interpretation support, which for each variant lists diagnostic associations, prognostic significance, available therapies, and relevant trials, and provides this information to the referring clinician.

Key Messages

- Although still in development, Phenocap captures deep phenotype information for a genetics test during routine testing. If the routine test result is negative, then deep phenotype information is already available when a patient is recruited into the 100k Genome project. This is a unique development across GMCs
- The information captured in Phenocap is imported into Sapientia to prioritise the variants found in the routine test through the use of bioinformatics algorithms to find, filter and prioritise the variants in relation to the specific test taken or the condition being investigated
- GenomeOncology provides a dynamically curated database to support the interpretation of genetic variants in cancer, which is accessed once test results have been received and a report produced which highlights the significance of the identified variants. The way in which this tool is applied is unique in the UK
- The tools are used in conjunction with each other (where appropriate) to support mainstream care delivery in a unique way. The tools are constantly in development to support care delivery models of today and the future, which are rapidly changing in line with advances in personalised medicine.



Key Innovation 4 – Core partnership with the local Biobank for sample management

Innovation Description

Three way partnership between the Regional Genetics Service at Birmingham Women's Hospital, Molecular Pathology labs at University Hospitals Birmingham and the local biobank (HBRC) based on existing projects and sample management pathways.

Key Benefits

- Single agreed process and way of working means a more efficient and effective operation that leads to improved service quality
- Quality check of sample and relevant data by HBRC prior to submission to GEL leads to an increased likelihood of being able to get WGS results returned to the patient first time and reduces the number of rejected samples, which has a cost implication for GMC (20% failure rate from LDP transfer to BioBank converted to 100% success rate when transferred from BioBank to GEL biorepository).

Key Messages

- This development builds local capability in cancer sample extraction at LDP sites (e.g. HEFT, UHCW) which allows the expansion of local provision of clinically relevant genetic laboratory services
- The partnership supports the development of a network of sites for cancer sample laboratory work which can provide expertise and mutual support as required
- Retained samples in the biorepository can be matched with phenotypic data and aligned with specific research and development requirements, which is attracting industry at regional level
- Local funding (from Advantage West Midlands) has been invested for outward facing benefit across the whole region rather than for the benefit of a single organisation, which underpins the development of local capability and a mature network on local laboratory sites (as outlined previously).



Key Innovation 5 – Genomic Ambassadors

Innovation Description

Appointment of three Genomic Ambassadors to support development of the LDPs in the North, Central and South parts of the region, which are funded by the AHSN.

Key Benefits

- Locality based expertise in clinical genetics to provide first line support to clinicians seeking to recruit patients
- Dedicated support to getting LDP sites live, recruiting and consenting patients, meeting clinicians and discussing with management
- Improved support for communications activity (both to communicate to staffing groups and the public) to increase the profile of the 100,000 Genomes Project and genomics in general. This includes linking staff up with educational opportunities associated with genomics, fostering closer collaboration with regional genetics services, and training staff specific to their job role and help to establish local SOPs for various staffing groups.

Key Messages

- The Ambassadors facilitate getting the best out of what local hospitals can offer to their patients regarding genetic testing, and support the mainstreaming of genetic testing into routine clinical practice
- The Ambassadors act as an independent advocate for genomic service development for the sub-regional patch rather than as a representative of the genomics hub, which supports the development of relationships at various levels with a wide range of organisations
- The three genomics ambassadors have different skills and strengths, and as a result form an effective team to work with the central hub to influence its future direction and as a result, can challenge any centralised developments that are best delivered locally
- The appointment of the ambassadors has enabled local pathology departments across the West Midlands to be linked into being a core part of the GMC and subsequently work together as a network
- AHSN funding for the posts aligns with drive for the GMC to take a regional approach to genetic service development.
- As a result of the Genomic Ambassadors being in post, there has been an increased awareness and interest in AHSN activities from clinicians in local Trusts.



Key Innovation 6 – Utilisation of Medical Students

Innovation Description

Allocation of 40 4th year Medical Students to the GMC programme to work on a 12 month attachment with a specialist in UHB, BCH or BWH to aid with searches for appropriate patients for recruitment, consenting and other elements of patient recruitment process itself, and entering information into GENIE.

Key Benefits

- Innovative approach significantly enhances and broadens genetic education and awareness across non-geneticists.
- Provides capacity and capability for the recruitment of patients, leading to higher number of samples being taken and an increased likelihood of achieving the GMC target trajectory
- Clinical genetics workforce is released to undertake training and awareness raising around mainstreaming genetic testing.

Key Messages

- This integrated scheme with clinicians and scientists across the GMC offers a wide range of placement opportunities for medical students
- The medical student scheme supports curriculum development and genomics education in the clinical workforce which is one of the GMC's key priorities
- The scheme helps future medics work with a wider group of clinical and scientific professionals which helps them develop their skills in the use of MDTs to support patient care delivery.
- Awareness of genetics and its application across a wide range of specialisms is spreading to students not on the programme through discussion and word-of-mouth.



Key Innovation 7 – Widening participation in specialist genomics education

Innovation Description

There are two distinct but related developments:

- Development and provision of a Genomics Masters Access course
- Proposed development of an Advanced Clinical Practitioner qualification in genomics (MSc equivalent)

Key Benefits

Genomics Access Course

- Enables nurses and AHPs to access basic genetics / genomics and related basic science study material to underpin further study in Genomics, including the Masters in Genomics provided by University of Birmingham.

Advanced Clinical Practitioner in Genomics

- Aims to provide a more clinically focussed qualification than a MSc in Genomics, which is has very detailed science content.
- Available in a modular fashion to support CPD, including a focus on supporting genetics service delivery support in primary care.

Key Messages

- The Genomics Access Course was developed in the West Midlands and is now being adopted across the country as the 'gold standard' for pre-masters genomics education
- The Advanced Clinical Practitioner course was proposed by the West Midlands GMC and is being developed by the national team in conjunction with a number of GMCs. It is built on a ten year history of genetics training for AHPs and nurses by pioneering the clinical nurse specialist role.
- The West Midlands pioneered clinical genetics education into specialties and the original cohort of four specialist nurses are still in the health and care system in the West Midlands and contributing to the development of this curriculum.
- Mainstreaming genetics and educational support is developing a wide base to support genetics skills and application across all fields.



Key Innovation 8 – Patient and Public Engagement Group participation

Innovation Description

Including patients in PPI Groups who have refused to be part of the programme (not just those that have been through it)

Key Benefits

- Enables rich learning to be gained from the consent and recruitment process that can be applied into future recruitment activity, which should lead to increased numbers going through the project in future.

Key Messages

- The work demonstrates the GMC's commitment and focus on quality improvement of its core processes, in particular patient recruitment and consent, which are at the heart of the delivery of the project
- This activity supports the overall GMC objective of widening participation and inclusion
- Patient and public concerns will be taken on board and acted on where possible through the formal inclusion of those who do not want to be part of the project.



Section 4: Summary



Summary of the Overall Key Messages (Page 1 of 2)

Innovation	Benefits/Impact	Key Messages
Cross-organisational / Partnership working	All West Midlands hospitals share the benefits of the GMC providing local genetic diagnostic treatment with central hub support.	Scale and ambition of the regional partnership is unique and mainstreams genetics across the West Midlands. Spinoffs such as Triumvirates, Mayo relationship, expansion of GENIE data set all possible as a result.
GENIE	Reduction in data re-entry and support for end-to-end workflow from recruitment to patient feedback. Holds, accesses and reuses data locally for use across sites for research in rare diseases and other areas.	Digital maturity in the region is enhanced, building on existing CRUK Stratified Medicine platform, advancing interoperability and agnostic integration, influencing system choice and now licensed to other GMCs.
Development and adoption of bioinformatics tools	Quicker identification and ranking of variants, improved interpretation support, improvement in phenotype information capture into GENIE.	Phenocap will capture deep phenotype information, which can be imported into Sapia to prioritise variants. Unique use of GenomeOncology, a dynamically curated database), supports interpretation of genetic variants in cancer.
Core partnership with the local Biobank for sample management	Efficiency and effectiveness improvement leading to improvements in service quality, including reduction in sample rejection rate by Genomics England.	Building local clinically relevant genetic laboratory capability in cancer sample extraction across LDP sites in the West Midlands region. Matching of retained samples and phenotypic data aligned with research is attracting industry at a regional level.



Summary of the Overall Key Messages (Page 2 of 2)

Innovation	Benefits/Impact	Key Messages
Genomic Ambassadors	Provides local first line support for LDPs with recruitment, clinician engagement and management. Communications support to promote 100K project and genomics education.	Provides an independent regional voice. Local pathology departments form a region-wide network. Combine different skills and experience and work as a team. Value being driven through AHSN funding.
Utilisation of Medical Students	Provides capacity and capability for the recruitment of patients, leading to higher number of samples being taken and an increased likelihood of achieving the GMC target trajectory. Supports genetic education in the future medical workforce.	Integrated placement scheme with clinicians and scientists across the GMC, offering a wide range of opportunities. Supports workforce development, which is one of the GMC's key priorities.
Widening participation in specialist genomics education	Supports a wide range of clinical professionals, with varying degrees of basic science and genetics training, to undertake more advanced studies in genomics	The Genomics Access Course developed in the West Midlands and is now being adopted across the country as the 'gold standard' for pre-masters genomics education.
Patient and Public Engagement Group participation	Enables rich learning to be gained from the consent and recruitment process that can be applied into future recruitment activity to increase numbers going through the project	Demonstrates the GMC's focus on quality improvement of its core processes, in particular patient recruitment and consent, and supports the overall GMC objective of widening participation and inclusion.



Appendix 1: Innovation Audit Summary Longlist



Informatics and Data

Innovation Description	Benefits
Development of a cardiology registry from across the region which brings together genetic and clinical data	<ul style="list-style-type: none">• Supports the identification of a potential cohort of patients and families for testing, which increases the relevant testing pool• Can be repeated across other specialties
Biobank have dealt with a lot of issues regarding consent and information sharing when bringing together data for clinical and academic purposes (i.e. aligning biobank and GMC consenting processes where possible)	<ul style="list-style-type: none">• Enables the West Midlands to rapidly utilise data arising from the GMC for research and translational medicine purposes, allowing it to be an 'early publisher' of research findings• Supports the local research community with a wider range of data and samples for additional research work



Sample Processing

Innovation Description	Benefits
Quality check of sample and relevant data by HBRC prior to submission to GEL / Illumina (delivered through data validation rules built into GENIE)	<ul style="list-style-type: none"> • Increased likelihood of being able to get WGS results returned to the patient first time and reduces the number of rejected samples, which has a cost implication for GMC (20% failure rate from LDP transfer to BioBank converted to 100% success rate when transferred from BioBank to GEL biorepository) • Pathways in place across 18 hospitals to support service integration.
Sample collection from LDPs uses normal NHS sample collection pathways (where possible) , and implementation of a single collection point (HBRC) for all samples to be sent to GEL / Illumina	<ul style="list-style-type: none"> • Reduces costs of sample collection and transportation through using existing channels • Reduces transport costs to Illumina through single collection point for NHS BT
Centralised UKAS accreditation at a whole organisational level for UHB (rather than individual physiological service level). Used existing CQC and Monitor returns for core information and appointed lead person for Trust wide accreditation	<ul style="list-style-type: none"> • Costs for UKAS accreditation for UHB team dropped from £130k to £27k as a result of having a single accreditation team. • Packaged up learning from this work for use by other West Midlands Trusts and beyond (UHB are already supporting Imperial implement this) • Helps attract skilled clinical workforce to an accredited service • improved working across the various 'ologies'
Liquid handling sample robot in place	<ul style="list-style-type: none"> • Sample processing capacity grown from 3000 to 9000 samples per month
Accelerated development of new sequencing panels and bioinformatics tools to support identification of cancer variants	<ul style="list-style-type: none"> • Quicker and more reliable identification of cancer variants on exomes and clinical exomes, and ultimately WGS data once received.



Mainstream genetics service delivery (Page 1 of 2)

Innovation Description	Benefits
<p>Being able to refer tests from mainstream clinics rather than having to refer to a clinical geneticist (using lead nurses)</p>	<ul style="list-style-type: none"> • Shorter waiting time for the patient to receive care • Shorter waiting time for the results for patients • Specialty consultant keeps the direct patient relationship • Increased numbers of patients captured and monitored • Snowball effect on number of consultants and other clinicians wanting to deliver testing as part of their mainstream service delivery model • Opportunity to offer personalised medicine approach which reduces chemo/radiotherapy use and increases more targeted interventions • Improved engagement with LDP partners • Better links between RGS and local departments through increased awareness • Clinicians see genetic testing as a viable clinical diagnostic option, which increases the use of genetic services overall • Genetics is embedded into every hospital, supported by a specialist team • Reduced rate of referrals to clinical genetics • Reduced travel time and patient inconvenience associated with seeing a genetic specialist
<p>Introduction of an MDT to review potential genetic test patients</p>	<ul style="list-style-type: none"> • Provide assurance that only the most relevant patients are referred for testing, increasing the clinical value, for one of the four potential genetics pathways: <ul style="list-style-type: none"> • Existing main genetics pathway - referral of patient to clinical genetics • Highly specialised clinics - supported by clinical genetics • Expert specialty based mainstream core MDTs/clinics - supported by clinical genetics - MDT or relevant clinical team advises LDPs. • 100K triage - direct advice/support from relevant clinical geneticist on appropriate referral route.



Mainstream genetics service delivery (Page 2 of 2)

Innovation Description	Benefits
Clinical geneticists become a more effective networked service with published contact numbers for advice, support and referrals	<ul style="list-style-type: none"> • Access to clinical geneticists for a wider range of clinicians across a broader range of Trusts and specialties • More appropriate use of clinical geneticist specialist skills
Involvement of Rare Disease UK	<ul style="list-style-type: none"> • Ability to provide information on undiagnosed conditions to patients and support as necessary
Raised profile of genetics and GMC	<ul style="list-style-type: none"> • Teams are seeing the success and wanting to get patients involved. E.g. Liver. Clinicians seeing these as clinical diagnostic tests and not purely academic research and therefore the upside for their patients. • Clinicians become increasingly aware of referral pathways that they did not know were options available to them • Clinicians are also starting to realise the benefits of genomic sequencing around a primary diagnosis (drug reactions, other conditions/susceptibilities etc.)
Enabling certain tests ordered by mainstream clinicians to be paid for by specialist commissioning budgets (only normally accessible to clinical geneticists)	<ul style="list-style-type: none"> • Reduces a main barrier to mainstreaming, i.e. the fact that tests done in mainstream have to be funded locally and are not in tariff
Revised local guidelines for genetics testing, developed in conjunction with speciality clinicians	<ul style="list-style-type: none"> • Improved 'gatekeeping' for genetic testing



Research

Innovation Description	Benefits
<p>West Midlands is leading at least 3 GECIP research domains and is a team member in at least 2 others</p>	<ul style="list-style-type: none">• Local universities will be at the forefront of being able to maximise the research and translational medicine opportunities that arise from GMC, including partnerships with local universities• Allows the scaling up of research across the country for very rare diseases through the GECIP programme• As one of the more predominant recruiters and with having the largest population of any GMC catchment area, West Midlands has a ready made cohorts of patients for stratified treatment trials once the results starts to emerge from the 100,000 Genomes Project.



Education and Training

Innovation Description	Benefits
Masters in Genomics programme (UoB)	<ul style="list-style-type: none"> • Provision of specialised, dedicated training to a multi-disciplinary cohort of staff
Design and provision of a taught one day consent training course	<ul style="list-style-type: none"> • Course is aimed at supporting staff within the LDPs to actively recruit and consent patients and incorporates patient case and scenario based work to build confidence for staff not usually directly involved in genetic counselling
Development of a blended learning package designed to equip health professionals with the skills and knowledge required to consent patients	<ul style="list-style-type: none"> • Incorporates the Genomics England Education Programme 'Preparing for the consent conversation' and 'A face-to-face conversation element' which is based on a train the trainer model to enable local delivery of consent training to staff.
School level engagement re. careers in genomics (16-19 yr. olds)	<ul style="list-style-type: none"> • Increased likelihood of young people wanting to make a career in laboratory or genetics related roles, which is required to support overall future specialist workforce needs
Use of personalised medicine masterclasses with real life examples through 'case based approach'	<ul style="list-style-type: none"> • More accessible and 'real' for clinical staff, and easier to then lead into conversations about whether patients are on the right pathway, or to change the existing pathways (or both)
Internship of clinical academics in genomics	<ul style="list-style-type: none"> • Support clinical academic development from MSc. to MRes. to PhD where appropriate
Development of the clinical geneticist role	<ul style="list-style-type: none"> • Increased sub-specialisation, increased amount of clinical geneticist time to support mainstreaming through education at LDP level, more specialist advisory input to help develop therapeutic and treatment options



Patient Engagement

Innovation Description	Benefits
Setting up individual PPI Groups for Rare Diseases and Cancer	<ul style="list-style-type: none"> • Enables wider engagement with patients who are part of the 100k programme, and not just PPI reps
National lead on getting patients viewpoint on current consent material	<ul style="list-style-type: none"> • West Midlands patients are leading the reform of the current, centrally provided and approved consent materials
Engagement of young people through the Roald Dahl Disease Transition Coordinator post at BCH	<ul style="list-style-type: none"> • Improved support for children with a syndrome without a name (SWAN) • Improved recruitment rates due to specialist children's coordinator



Results Feedback

Innovation Description	Benefits
<p>Use of triumvirates – (Clinical geneticists, Ambassadors and Clinical specialists) to provide MDT review before results feedback.</p>	<ul style="list-style-type: none">• Additional quality review and check of the implications of the outcomes of the WGS (currently doing this for phenotype and exome results)• Improved quality of communication to patients of the impact of the WGS results• Shared agreement of treatment and management plans• Clinicians feel more confident about feeding back complex and difficult results, especially if results were not 'looked for'• Builds extended support network at 'hub and spoke' level



New Service Development

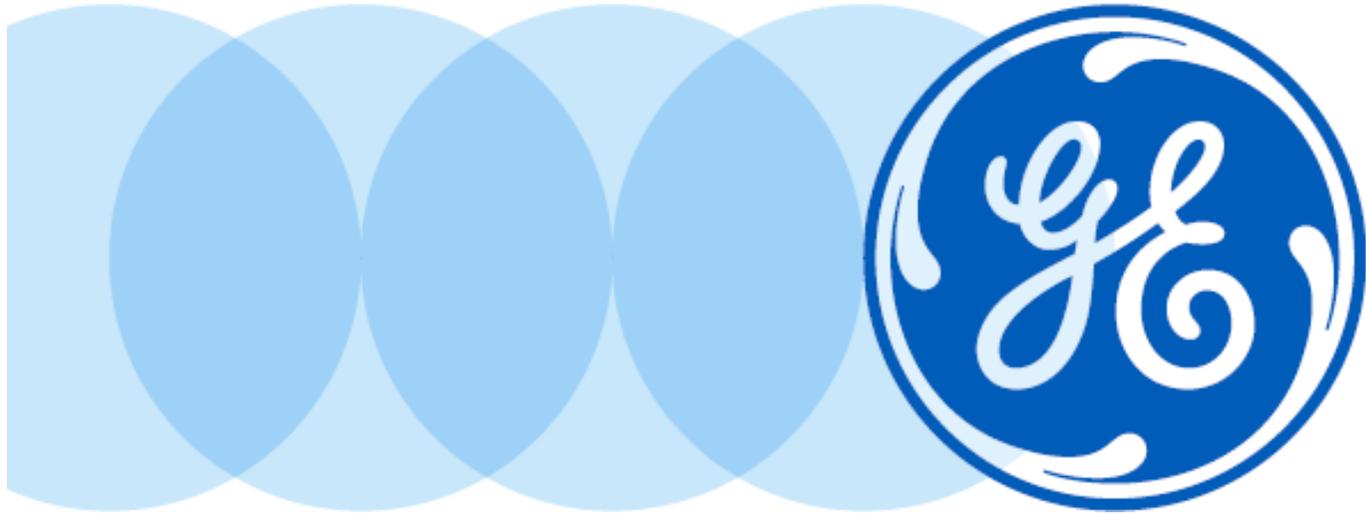
Innovation Description	Benefits
Familial hypercholesterolemia (FH) service developed	<ul style="list-style-type: none">• Improved support to patients and their families where FH has been diagnosed (50% genetic component)• Improved quality of life• Improved life expectancy
Mental Health Services - Early-onset Dementia and Familial Anorexia	<ul style="list-style-type: none">• Improved links with mental health trusts and the potential genetic implications of certain conditions, leading to improved support offerings
Phlebotomy service for children and babies at BWH	<ul style="list-style-type: none">• Removes a significant barrier to recruitment of patients at BWH by making blood taking more accessible



Patient Recruitment

Innovation Description	Benefits
Recruitment undertaken by a central team, supported by local resource where appropriate	<ul style="list-style-type: none"> • Centralised set of skills that can be deployed flexibly across the patch where need is greatest • Reduces reliance on a large number of staff doing recruitment as part of other job roles • Improves cover for sickness, annual leave etc.
Provision of central admin support, supported by local admin resources where appropriate	<ul style="list-style-type: none"> • Efficient method of finding the appropriate patients to approach and then getting the letters out to patients and their families. • Supports follow through on getting patients to appropriate clinics for testing
Using specialist nurses to train other nurses to recruit as part of the day job (cascade training)	<ul style="list-style-type: none"> • Wider nursing workforce empowered to recruit for the 100k project, rather than a limited number of specialist. As a result, the GMC are currently over-recruiting against target
Scheduling 100K GMC appointments on the back of existing appointments	<ul style="list-style-type: none"> • Improved attendance rate • Reduced impact on patients having to travel / take time off • Service transformation is aligned with existing processes
Employing additional dedicated people in theatres to process cancer samples (fresh / fresh frozen). Also seeking to split samples for molecular pathology and RGS testing at source	<ul style="list-style-type: none"> • Reduced reliance on existing workforce (recruitment nurse, CNS etc.) to obtain sample, leading to higher take up rates • Improve quality of sample for RGS testing as not going through molecular pathology tests first





Achieving change together