Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Tuesday 20th March 2018

Committee Room 3 – 1pm to 2.00pm

Minute of Meeting

- **Welcome and introductions**

Apologies were received from: Liz Dougan, Arlene Smyth, Rebecca Pender, Sandra Thoms, Sue Rees, Lynn Stewart, Rebecca Stewart, Lynn Laidlaw, Margaretha Sweeney Baird

- **Review of minutes from last meeting and matters arising**

The minutes of the last meeting were agreed by email.

The key action from the last meeting was to write to the Cabinet Secretary regarding progress of the Montgomery Review (specifically the New Medicines Fund), specialist nursing provision and the discussion about a centre for rare diseases that took place at the last meeting.

The CPG received a written response on 28th February 2018 which had been circulated to members prior to the meeting.

- **Scottish Plan for Rare Diseases**

Victoria Milne (National Planning Team Leader, Scottish Government) and Angela Simpson (Senior Policy Manager for Rare Diseases, Scottish Government) attended the meeting to provide an overview of the Scottish Plan for Rare Disease, the policy context in which it exists and a summary of the Scottish Government's biennial report which was published on 28th February 2018. The report can be accessed here.

In summary, the Scottish Government published "It's not rare to have a rare disease: The Scottish Plan for Rare Diseases" in 2014. The plan describes how Scotland is currently contributing to the delivery of the UK Rare Disease Strategy. A Rare Disease Implementation Oversight Group has been tasked with monitoring the implementation of the Scottish Plan's recommendations.

The biennial report, whilst acknowledging that policies may seem removed from patients and that the pace of change can appear slow, affirms the Scottish Government's commitment to implement the Plan's recommendations throughout the NHS in Scotland. Examples of progress include:

- Improving data collection through a short life working group established to consider how information on rare diseases be captured in Scotland. A Congenital Anomalies Register for Scotland is currently being developed.

- The SHARE register provides opportunities for patients with rare conditions to register their interest in participating in health research. Patients can have access to live trials and the SHARE register will be useful when it comes to developing new treatments.
- National Services Division is leading on work to improve co-ordination of care through Scotland's National Managed Clinical Networks and through the development of pathways for rare diseases (for example, vasculitis).
- Care Opinion provides patients with an opportunity to provide real time feedback and share their care experiences, allowing for patient involvement in shaping of services.
- Initiatives such as the Scottish Genomes Partnership, which provides 1000 Scottish patients with access to the 100k Genomes Project, are steps to improving the journey to diagnosis.

There was acknowledgement that more could be done to involve patients and patient groups in implementation, and to communicate the progress that has been made. Patient groups in attendance acknowledged that the Biennial Report had been valuable in demonstrating how much progress has been made, and that the content was encouraging.

A specific issue relating to p32 and the short life working group report on Vasculitis was made – specifically that some patient representatives/groups that had been involved in this work had not been aware of the report. It was agreed that this would be looked in to.

A further issue, relating to the communication of patient pathways and information on how to access services out with Scotland was raised. There was consensus that more needs to be done to publicise patient pathways and to communicate new services and developments. How care pathways are identified and used in times of crisis (A&E admissions for example) was also identified as an area that requires further work.

With regards the proposed Congenital Anomalies Register, it was confirmed that there are plans to ensure that this corresponds with similar work being undertaken by Public Health England.

Bob Doris, in summary of the discussion, highlighted that the discussion had reflected that the themes of the recent Rare Disease Day event. There is much to be celebrated and progress is being made, but challenges remain.

- **Cabinet Secretary Response to CPG**

The Cabinet Secretary responded to the CPG's letter on the 28th February 2018.

Specialist Nursing: The Cabinet Secretary's response included an update that the Chief Nursing Officer, under the auspices of the Transforming Nursing, Midwifery and Health Profession Roles Programme, will commence a specialist nurse practice sub group. The sub group will be asked to consider the need for a specialist nursing service for rare, genetic and undiagnosed conditions.

Natalie Frankish updated that a meeting will also take place between the CNO's office, the Scottish Government's Rare Disease policy team and Genetic Alliance UK to discuss this matter. CPG members are invited to share their views with Natalie in advance of this meeting.

Montgomery Review: The Cabinet Secretary provided clarification on the New Medicines Fund. The future of the NMF appears to rest on the success of the negotiations on the PPRS scheme. Members raised concerns about the absence of contingency plans should the PPRS fail to deliver adequate funds. It was noted that the Health and Sport Committee may consider this during it's budget considerations.

The importance of patients being able to present directly to SMC was raised. Members noted the success of having patient representatives at the SMC table, a new initiative which allows patients the right to clarify points and answer questions.

It was noted that there is still no official announcement on the new framework for ultra orphan medicines. This is expected in Spring. It was agreed that the next meeting (June) would look at this wider issue, with invitations extended to SMC and Scottish Government.

- **AOB**

Lobbying Register: It was noted that the Lobbying Act was now in action and that the lobbying register was now live. Cross Party Groups are exempt from the requirement to register provided that they are quorate. In the event a meeting is conducted without a quorum, the lobbying register rules must be complied with. Natalie will send details on the lobbying register to members. Bob Doris MSP and John Scott MSP were present at this meeting.

- **Date of Next Meeting**
  - AGM meeting will be held on 17th April 2018 at 1pm.
  - The next formal meeting of the CPG will be held on June 2018 at 1pm.

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Attendees

Amy Caffrey	British Liver Trust	Attendee
Harriette Campbell	Representing Sickle Cell	Attendee
Michelle Conway	Alexion	Attendee
Bob Doris (Chair)	MSP	Attendee
Hannah Van Hove	Office of Rare Conditions, Glasgow	Attendee
Jane Ferguson	Ettrickburn	Attendee
Natalie Frankish (Secretariat)	Genetic Alliance UK	Attendee
Simon Flynn	Genzyme	Attendee
Lesley Loeliger	PNH Scotland	Attendee
John Miller	Action Duchenne	Attendee
John Scott MSP	MSP	Attendee
Lynn Shields	TSA	Apologies
Karen Ferguson	Funny Lumps	Attendee
Hazel McLachlan	Bechets Syndrome Society	Attendee
Wendy Inglis Humphrey	Scottish Genomes Partnership	Attendee
Victoria Milne	Scottish Government	Guest
Angela Simpson	Scottish Government	Guest