CROSS PARTY GROUP ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS

Wednesday 25 November 2020

11.30 – 12.30

Virtual Meeting

MINUTES

- **Welcome and Introductions**

  Bob Doris MSP welcomed all in attendance.

- **Minutes of last meeting**

  The minutes of the meeting held on 26 October 2020 were agreed as accurate.

  Actions from the previous meeting are progressing as planned, members will be notified of any updates by email.

- **Overview of CPG Report: 'Improving Care for Rare Conditions in Scotland'**

  Natalie Frankish provided a short presentation on the progress of the CPG's report "Improving Care for Rare Conditions in Scotland". Natalie explained the report had been drafted and shared with a sub group of patient organisations – the draft has not yet been shared widely as it may be subject to further changes following the publication of the UK Framework for Rare Diseases, Rare Disease UK's Patient Experience Survey and today's presentation on the CONCORD Project.

  It was proposed that a draft of the report, taking into account the expected developments above, would be circulated to the CPG in early January for approval and agreement. The report would then be 'launched' at the January meeting of the CPG before being shared with the Scottish Government's Rare Disease Policy Team, and the relevant Ministers.

  ACTION: NF to convene a further sub group meeting to discuss the report draft.

  ACTION: NF to circulate a draft of the report for comment to CPG members by mid-January.

  ACTION: NF to arrange next CPG meeting for January.

- **Overview of the CONCORD project**

  Emma Hudson provided an informative presentation on the CoOrdiNated Care Of Rare Diseases (CONCORD) Project, a project funded by the National Institute for Health Research Health Services and Delivery Research Programme. The project looks at what coordinated care means, what specific components characterise "coordinated care" and in what ways care for people with rare diseases may be similar or different to coordinated care for people

with other conditions. The project includes a survey of people affected by rare diseases (patients, carers and health professionals).

Professor Stephen Morris provided a brief introduction to the next stage of the project. Plans for "CONCORD 2" are focusing on a mixed methods evaluation of the role of care coordinators. Professor Morris noted that there may be scope to see how the work of the CPG could feed into this work.

- **Discussion**
  - Patient satisfaction with care was discussed. It was noted that patients view on their care can often be influenced by their perception of the NHS as a valuable service. There was some indication that patients participating in the CONCORD study had illustrated that there was dissatisfaction within qualitative responses. Patients may report being satisfied with care – but not their care coordination.
  - It was noted that communication between professionals and people about their care plans was lacking – for example some people could be accessing care through a specialist centre and have a care plan in place, but the patient is not aware of it. A care plan must include the involvement of the patient in the development of that care plan – otherwise "it's just notes".
  - For some people with rare conditions, coordination is good and not everyone will need a specific care coordinator. This is something to consider for future funding requests. It was noted that while some people may have their care well-coordinated by different specialisms, having a single point of contact is helpful (although this may not be one, single individual).
  - It is important that where a care coordinator exists – a patient should know about.
  - Clarification on the definition of a care plan was sought. A care plan is a paper or electronic document which describes the health services and support that are needed and should be agreed between patients, carers and professionals. It might be a single document, or part of another record, which may include non-health services such as education, care and health plans.
  - It was noted that patients with rare conditions are often considered 'expert patients' and it is important that this is a feature of a care plan and acknowledged by a care coordinator. A care coordinator has role in ensuring the plan is smoothly implemented.
  - Noted that most people would not want to be overly dependent on a care coordinator – but important to have access to their support and their knowledge.
  - It was noted that the key to a good care plan is implementation – and for that, there needs to be accountability for how a care plan is delivered.
  - Disconnect between paediatric and adult services – may be as a result of paediatric care centring around the family while adult care centres around the person.

- Noted that CONCORD survey comes at the end of the UK Strategy for Rare Diseases – survey shows that not as much achieved in terms of care coordination. The take home message is that there are a sizable portion (around half) of people with a rare disease who have no coordination of their care – this is what needs to be improved upon.
- What should a care coordinator do? Better scheduling of appointments, liaising with health and social care professionals, active involvement in the development of a care plan. Bob Doris notes that this should be achieved regardless of the condition, and a role for health and social care partnerships/health boards – Bob notes that it maybe that another model is right and needed, but asks why existing models might not be working. It was noted that in rare diseases, having professionals who understand/have clinical experience of rare diseases and their challenges is key – the problem is that professionals dealing with a rare condition often do not know what they are dealing with and as such do not know how to appropriately coordinated – this is why models that can work for chronic and more commonly known and understood conditions don't work as well for rare conditions.
- Good next step – to identify exemplars of good coordination and use this as a basis of shaping a service.
- It was noted that there may be an industry interest in this topic – particularly as personalised medicine increases. There would be value in exploring whether there is scope for industry support. Noted that care coordination services should be routed in the NHS services, pharma involvement would have to recognise this rather than a condition or treatment specific approach.
- Health economic and preventative spend arguments were considered to be important in engaging funding support from Government/NHS – there isn't hard evidence in rare conditions as yet, but definitely an economic case to be explored. Cost savings likely, and probably even more likely within rare conditions.

ACTION: NF to ensure CONCORD study is referenced in CPG Report

- **Date of next meeting -** To be confirmed

  ACTION: NF to circulate details of next meeting

Attendance – CPG on Rare, Genetic and Undiagnosed Conditions – 25 November 2020

Bob	**Doris MSP**	**Convener**
Mark	**McDonald MSP**	**Co-Convener**
Natalie	Frankish (Secretariat)	Genetic Alliance UK
Professor Stephen	Morris	CONCORD Study
Emma	Hudson	CONCORD Study
Mike	Cain	HSP Support Group
Kirsten	Patterson	NHS Tayside Genetic Nurse Specialist
Liz	Dougan	Office for Rare Conditions Glasgow
Harriette	Campbell	Sickle Cell Support Group
Amy	Comrie	EDS UK
Andrew	Deans	NHS Lothian
Gill	Dickson	PSP Association
Rae	McNairney	Primary Immunodeficiency UK
Catherine	O'Hara	Behcet's UK
Lynn	Stewart	MyAware
Dan Michelle Amy Marion Jenni	Farthing Erskine Hunter Butchart Hampson	Haemophilia Scotland Aarskog Syndrome Foundation Genetic Alliance UK Novartis Kyowa Kirin