

UK RARE DISEASES POLICY BOARD PAPER ON THE FUTURE OPERATIONAL MODEL FOR THE UK RARE DISEASE FORUM

PURPOSE

1. To inform the Board of the new operating model for the UK Rare Diseases Forum and provide comments.

BACKGROUND

2. The UK Rare Disease Forum was set up to steer development of the UK Strategy for Rare Diseases (the Strategy) and was tasked with the Strategy's governance after its publication in 2013. The Forum's membership included representation from the rare diseases community, industry, academics and researchers. This governance structure is unsustainable under the constraints of a reduced DH structure post-January 2017. Thus a more sustainable governance structure was proposed and agreed mid-2016, to also enable a sharper focus on high-level policy development and implementation to support delivery of the 51 commitments in the Strategy.

NEW MODEL

3. This paper sets out a new operational model for the Forum based on interviews with Forum stakeholders and in line with the Policy Board Terms of Reference and the Forum's aim, objectives and operating principles laid out in Appendix 1. The new model provides mechanisms for supporting meaningful engagement and collaboration between and amongst the Forum and the Policy Board members and for improving Forum membership.
4. The proposal is to expand membership of the existing Forum, to incorporate a wider range of stakeholders, including representation from non-genetic rare disorders and rare cancers. A fully featured online knowledge and collaboration platform will be established to support interaction between the Policy Board and Forum and among Forum members and support small (fewer than 10 members) Task and Finish Groups giving detailed consideration to specific issues. The online platform will enable Forum members to track progress and work towards implementation of the Strategy, support knowledge transfer on best practice and current research and facilitate communication between members.
5. This model would include an annual conference or symposium, chaired by the Deputy Chief Medical Officer, to bring together a range of stakeholders to discuss progress on the Strategy, emerging technologies and policies in rare diseases and to engage directly with UK Government and Health Service decision makers.
6. Further details on the exact operation and practicalities of this model are described in Appendix 2. There is an option for the Department of Health's eXchange platform to be used to support this (Appendix 3) although this would need further clearance.

POTENTIAL MEMBERSHIP

- Rare disease patients and patient groups e.g. Genetic Alliance UK, Specialised Healthcare Alliance, Cancer52

- Patients/patient groups for non-genetic rare diseases e.g. British Society for Rheumatology and the newly established Rare Autoimmune Rheumatic Disease Alliance.
 - Devolved administrations stakeholder groups e.g. Northern Ireland Rare Disease Partnership
 - Clinicians e.g. Birmingham Health Partners
 - General Practitioners e.g. Royal College of General Practitioners
 - Nurses e.g. Royal College of Nursing
 - Researchers e.g. Rare Diseases Translational Research Collaboration and Newcastle Institute of Genetic Medicine
 - Industry e.g. Association of the British Pharmaceutical Industry
 - Thinktanks e.g. PHG Foundation
 - International input e.g. UK ERN coordinators and RD-Action
7. There is scope to invite other patient representative organisations, academics and research bodies, once the Forum is established and **we would welcome any suggestions from Board members.**

NEXT STEPS

8. Following discussion at the Board on 9 January, DH will begin the work on putting the new model in place. It is hoped that the new way of working will be announced as part of UK Government's contribution to Rare Diseases Day 2017.

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APPENDIX 1: FORUM AIMS

The Forum's primary aim is to provide comprehensive stakeholder insight, perspective and advice on challenges, key issues and risks to delivery of the 51 commitments in the Strategy and to encourage and facilitate discussion on future rare diseases policy development.

FORUM OBJECTIVES

The Forum's core objectives are to collaborate with the Policy Board to:

- 1) Monitor implementation of the Strategy
- 2) Provide stakeholder perspective on delivery challenges, issues and risks to implementation of the Strategy
- 3) Develop policy through participation in issue focused task and finish groups.
- 4) Provide stakeholder perspective to the biennial report to UK Ministers, ensuring that it represents the views of patients, industry and other key rare disease stakeholders.

FORUM OPERATING PRINCIPLES AND RELATIONSHIP WITH THE POLICY BOARD

The Forum will

- Champion the work of the Forum members and their role in implementing the Strategy
- Act as a platform for constructive dialogue and exchange between the Policy Board and the wider Rare Diseases community
- Work with the Policy Board in development of policies and plans
- Facilitate balanced representation and participation of stakeholders across the rare diseases community in implementation of the Strategy, raising issues, proposing priorities and identifying areas that may require detailed consideration.
- Work with the Policy Board to raise awareness and enhance understanding of rare diseases as an important healthcare issue and improve communications with the wider Rare Diseases community.

APPENDIX 2: IN DEPTH OPERATING MODEL AND PRACTICALITIES

Online collaboration, discussion and knowledge platform enhanced by participation in Task and Finish Groups and an annual symposium

Online collaboration and knowledge platform

There is precedence for effective engagement with health and care stakeholders through online platforms exemplified by the National Institute for Health and Care Excellence's public engagement programmes¹, NHS England's public board meetings² and the varied initiatives of the Diabetes Online Community³.

Long term, the ambition is for the online platform to become a single, recognised knowledge hub collating reports, best practice and enabling active discussion groups (virtual or in-person, formal or informal) to be convened, drawing on the full diversity of expertise, knowledge and experiences represented in the Forum membership.

In the short term, all finalised, relevant paperwork concerning Rare Diseases policy and the Strategy (including Policy Board papers, agenda, minutes and reports) will be made available in a timely fashion via the online platform for viewing and comment by Forum members. The online platform will be a key mechanism by which Forum members can track progress and work towards implementation of the Strategy.

Task and Finish Groups

Task and Finish groups will be a core part of the collaboration mechanism. The Forum will be able to propose the scope and membership of small (fewer than 10 person) Task and Finish (T&F) groups to take forward specific projects pertinent to implementation of the Strategy. Issues to be taken forward by T&F groups must support either the implementation of one or more of the Strategy commitments in or an issue related to science, research or healthcare in the field of rare diseases national policy development. Final commissioning of the T&F groups will be agreed by the Policy Board.

Annual conference or symposium

An annual conference or symposium chaired by the Deputy Chief Medical Officer should be a commitment. This will be a chance to bring together a range of stakeholders to discuss progress on the Strategy, emerging technologies and policies in rare diseases and to engage directly with UK Government and Health Service decision makers.

¹ <https://www.nice.org.uk/Get-Involved/stakeholder-registration>

² <https://www.england.nhs.uk/about/board-meetings/>

³ <http://www.inputdiabetes.org.uk/doc-diabetes-online-community/>

APPENDIX 3: DH eXchange (DHeX) ONLINE PLATFORM

DHeX has been successfully used to support collaboration with external stakeholders across 300 projects and has a number of useful features:

- Membership control: DHeX is invitation-only requiring users to register for an account.
- DHeX can support upload and storage of all file types and content including video, blogs and documents. Users have control over viewing and editing rights.
- DHeX can support co-editing of documents, discussion groups and private messaging.
- DHeX is optimised for readability, is configured for use over multiple devices and is accessible via any browser.

Longer term, depending on demand, DHeX could additionally provide support for:

- Live chats hosted by members.
- Subject to agreement, Policy Board meetings may be filmed and uploaded onto the platform.
- Members should strive to upload content monthly.
- Compatibility with existing social media platforms