

Executive Group & Secretariat – Online Meeting

Date: Wednesday, 22 January 2025

Minutes of meeting

Attendees:

Richard Stevens
David Snelson
Samina Begum
Jo Gumbs
Richard Ballerand
Ceri Steele
Yvonne Adebole
John Marsh (lost connection)
Alison Stone
Chris Carrigan
Elizabeth Lloyd-Owen
Gladis Foster

Apologies:

Dave Chuter

Item 1

Where we are heading: use MY data's internal work

Summary of intended output, deadlines (where applicable) and lead(s)

1.1 Charity Commission Update

The Charity Commission contacted Dave, who is leading on our charitable status application. They asked questions about use MY data's set up, if we hold data, how we get our educational output verified and who we work with and how. Dave responded to the queries. He is now awaiting an email to confirm the discussion and to advise us of any possible changes that we may need to make.

1.2 Logo

Elizabeth reiterated the rationale behind the refreshing of the logo. She sent out to the Executive Group Members designs of logos pre-meeting for feedback and hoping to reach an agreement on 22/1/25. She explained through the lens of Byline Comm (the external organisation we have contracted) their perception of the design and colour orientation. An example is the Connectivity logo which looks explicitly as a joined-up partnership with other health agencies. However, this design is being used by more than one organisation presently.

She also explained how the logo should be authentic to use MY data and reflect use MY data's identity which should be inspiring, versatile, timeless, a power tool for communication as well as looking polished and professional. The essence of the logo is to capture attention and signal what we stand for. Another point is that we are living in a highly visualized environment where

first impressions are important and lasting, so the logo needs to capture attention and signal “who we are and what we stand for” in a nutshell.

The Executive Group reviewed the proposed logos with Elizabeth’s information and gave their feedback. There were varied views expressed and several other options suggested to amend some of the options on offer.

Richard Stevens requested Members present to further scrutinize the logo based on colour, shape and digital accessibility within 24 hours of the meeting and to send comments to Elizabeth. She will then discuss them with Byline Comm, so that they can offer us revised designs (two or three). Elizabeth will send these to the Executive Group in week beginning 3rd February.

Item 2

Where we are heading: use My data’s external work

Summary of intended output, deadlines (where applicable) and lead(s)

2.1 NPaDD draft programme

All the Executive Group Members present unanimously agreed that the draft programme prepared by Chris was good to go out.

2.2 Funding information

Alison gave an update on the funding needed for the conference. The original estimate was £30,000 and the current figure is £42,000 or £35,000 if trimmed of some “nice to have” items.

We have two gold sponsors confirmed, providing £6,000 each. The sponsors are Health Data Research UK/Pedri and Dare UK. Richard Stevens specifically expressed concern at the huge potential shortfall and that our budget shows expenditure not income and it is far from balancing.

We have four other sponsorship opportunities pending (two contacted us proactively and two who we have reached out to). Alison and Georgina, Event Manager, are liaising with the potential funders and will provide updates on developments, as soon as received. The potential sponsors are all in the commercial sector.

Alison asked the Executive Group for their help and to suggest potential funders that she can contact. Some suggestions were received, with more to follow via email.

The Executive Group would like the Secretariat to set a deadline for obtaining the funding. So that, if we haven’t reached what we need, we can postpone/cancel, without incurring costs. 31st March was the proposed date, when the EG has a f2f meeting.

2.3 Registration and deposit

With an eye on the funding needed to produce the conference, the Executive

Group agreed that all delegates should pay a fee - with the exception of our Members. The amount is to be decided and Alison will take this work forward, post-meeting.

Our Members will need to pay a deposit, for which the amount of £25.00 was agreed. Alongside this, the deposit text was agreed. The text highlights that:

1. some concessionary places are available, if paying the deposit is a barrier to attending and
2. if notice of not being able to attend is given (within an agreed timeframe), the deposit will be returned.

2.4 Delegate categories & quotas – the categories of delegates were agreed – this is to ensure we have a wide range of stakeholders. Categories are:

Patient, relative or carer

Academic

Campaign group

Charity

Commercial sector (including industry & pharma)

Health Care Professional

Policy or thinktank organisation

Public (member of)

Public Sector (including Gov)

Researcher

Student

The number for each category is to be determined. Alison will work out potential quotas and submit to the Executive Group for their review.

Item 3

Any other business

There was no other business.

Item 4

Date of next meeting: In person

Monday, 31 March, 10:45 – 15:00

NCVO, Society Building, All Saints Street, NI 9RL