

## **LONG TERM CONDITIONS ALLIANCE NI ANNUAL REPORT 3 June 2016**

As Chair of the Long Term Conditions Alliance NI it gives me great pleasure to present the Annual Report.

The past year has been busy and challenging. As reported previously the Alliance has an increasing high profile often resulting in expectations beyond what we can deliver.

As usual we have had a presence at all the political party conferences where there has been considerable support and interest from our elected representatives. I would like to thank colleagues from the Committee who willingly volunteered to give up their weekends to attend and staff the stall.

The development of the LTCA Manifesto for the 2016 Assembly election began a year ago. Many of you attended workshops over the summer to debate and agree our Manifesto asks and also attended our event in the autumn to launch our document. Thank you to all who contributed and in particular Jayne Murray, (British Heart Foundation) for coordinating content and working with the designer and printer to get the job done in time for party conference season. Very big thanks also to Fiona Greene (NI Chest Heart & Stroke) and Joan McEwan (Marie Curie) for actually writing the content, re-writing and editing several times. I think we can all agree that the end product was both excellent in content and professional in appearance. Going forward, over the next Assembly, this document will guide the working of the Alliance.

Over the past year we have deepened our relationship with NICON, the NHS Federation for Northern Ireland. Members on behalf of both the LTCA and their respective organisations contributed to the development of their Manifesto and its launch at Stormont, which was very well received. As Chair, I contributed at NICON's fringe events at several

political party conferences and have also recently contributed a blog on behalf of LTCA. Kate Fleck and I, as Secretary and Chair, also had the opportunity to participate in a small select event organised by NICON with Sir Stephen Dorrell which was very productive and informative.

Representatives from the Committee continue to participate in the Long Term Conditions Strategy Implementation Group which is both informative and frustrating! We are encouraged to see the focus on self management but would like to see more clarity and vision around the definition, education and ambition of this approach.

As Chair of the LTCA and a nurse by profession, I continue to participate in the Central Nursing & Midwifery Advisory Committee chaired by the Chief Nursing Officer. More recently CNO has asked that I chair a regional group, facilitated by NIPEC, to develop a framework for specialist practice nursing. This group has now met twice and agreed to focus on cancer and diabetes in the first instance. The working group comprises representatives from the Department of Health, Public Health Agency, Workforce Leads from all Trusts, representatives from the four Hospices and the Universities. Competencies for specialist nurses have been developed. The group should report its findings to CNO in spring 2017.

Members have worked collaboratively as part of the prescriptions coalition, led by Crohn's & Colitis Association, and supported a very successful social media campaign. I would like to commend this and also the "Keep us well" campaign managed by British Heart Foundation and Multiple Sclerosis Society. As an Alliance we are delighted that prescription charges will not be reintroduced for people living with long term conditions in Northern Ireland – in essence taxing the sick.

We continue to respond to consultations and requests for information and to participate in events and conferences – Kate most recently at Collaboration NI. Members from many of our organisations are involved in Integrated Care Partnerships and Local Commissioning Groups. Going forward we will be interested in the development of new commissioning

structures and also on the emerging GP Federations and indeed Programme for Government – always with our service users' best interests at the heart of all we do.

Also of note in the past year is our revamped website. I would like to personally thank Sophie Mullan from Digital Coach for all her efforts and would encourage all member organisations to use it and forward content.

2016 has been a year of change for the Committee. One of the founding members, previous Chair and Vice Chair, Steve McBride, retired in December. The Alliance owes Steve a huge debt and we thank him for his contribution and wish him good health and happiness for his retirement. Marina Clarke from Epilepsy Action also retired in September past and we wish her well in her retirement.

Several people are owed special thanks

- Arlene from Macmillan
- Alyson and Debbie from Arthritis Care who in addition to their own busy jobs have supported Kate and me in our roles as Secretary and Chair.
- I would particularly like to thank Kate for all her work as Secretary to LTCA. Behind the scenes her efficiency keeps the show on the road. I could not have functioned without her gentle reminders and advice.
- Thanks also to Patricia Gordon in her role as Treasurer.

Kate has decided to step down as Secretary. I have decided to step down as Chair. But both of us will remain on the Committee.

Thanks to all for your contribution.

I commend this Report to you.

Thank you.

A handwritten signature in black ink that reads "Heather Monteverde". The signature is written in a cursive, flowing style.