Chronic conditions will not go away; they are the health care challenge of this century. Alteration of their course will require determined effort among decision-makers and leaders in health care in every country in the world.

*World Health Organisation*
By 2030, the number of people in Northern Ireland living with cancer and the long term consequences of the condition and treatment is expected to rise to over 110,000.¹

The Long Term Conditions Alliance Northern Ireland (LTCANI) is an umbrella body for voluntary and not for profit organisations working with and for people with long term conditions. We represent approximately 500,000 people with long term conditions in Northern Ireland.

"By 2020, the number of adults in Northern Ireland living with a long-term condition is expected to increase by 30%.

DHSSPS - Living with Long Term Conditions (A Policy Framework April 2012)

Long term conditions can affect all aspects of people's lives. They can be devastating and can last for years – or for life. People with long term conditions need long term support in minimizing the impact of their conditions and maximizing their independence and quality of life. They need timely and effective health and social care interventions. They need information and support in managing their conditions on an ongoing and daily basis. They need to feel engaged with their own care, to feel responsible for their own health and able to make decisions for themselves.

As an Alliance we are committed to working in partnership across sectors and with all Government Departments because 'Health is everyone's business.'

225,000 local people are living with cardiovascular disease.²

Cardiovascular disease (heart & circulatory) causes a quarter of all deaths in Northern Ireland, or 3,700 deaths each year – that's an average of 10 people each day.³
We want the Northern Ireland Assembly to commit to working with LTCANI to meet the needs of people living with long term conditions. Our priorities are:

1. Provide clear strategic direction to achieve better outcomes and meet the needs of people living with long term conditions.

Northern Ireland has a wide variety of policies, strategies and frameworks in relation to Long Term Conditions, but no overarching implementation plan that coordinates them all. A framework with clearly defined outcomes and measures is fundamental to drive the transformation and change that is needed to meet the needs of the population.

The LTCANI believes Transforming Your Care laid out strong recommendations for improvement in long term conditions and the Donaldson Report highlighted the need for a whole systems reconfiguration across all sectors of health and social care. We look forward to contributing to the future redesign of Health and Social Care across Northern Ireland.

It is estimated that 1 in 5 people in Northern Ireland have a mental health problem at any one time. vi

Over 15,100 people in Northern Ireland are living with heart failure. iv

Over 35,000 local people have survived a stroke. Over half of stroke survivors are under the age of 75.v

Mental health is now regarded as 1 of 4 most significant causes of ill health and disability in Northern Ireland along with cardiovascular disease, respiratory disease and cancer.vi
In the next Assembly we recommend:

- Health is everyone’s business. All Government Departments need to work together to ensure a co-ordinated approach is taken to meet the challenges long term conditions bring to individuals, their families, the community, health services and Northern Ireland.

- Clarity on the overarching policy direction and supporting implementation plan for health and social care and specifically long term conditions.

- The voluntary sector has a seat at the table in the development of any new emerging structures.

- A roadmap is developed to deliver the recommendations in the Donaldson Report. Any reconfigured services should provide a simplified infrastructure and take account of previous and current reviews – including Service Frameworks, pathways and the Hospital Plan for Northern Ireland.

- There should be robust programme management to include effective planning, deliverables, costings, milestones, oversight and quality indicators. Overall accountability and leadership for the policy and implementation plan is key and should be clearly communicated.

- LTCANI input to an agreed definition of patient centred care with associated, measurable outcomes. Evidenced based, best practice should be used to inform commissioning.
2. Deliver Patient Centred Care to people with long term conditions.

Health is everyone's business. People and their carers must be recognised as experts by experience working in partnership with those experts by profession in the planning & delivery of services. Services should be integrated and based on collaborative working across all sectors. The person and their interests should be at the centre of all relationships within Health and Social Care.

In the next Assembly we recommend:

• We recommend all patients diagnosed with a long term condition are informed and supported to be involved in decision making around their treatment and care.

• New commissioning arrangements should be designed around the needs of patients and carers and incorporate all aspects of living with long term conditions – including clinical, social, wellbeing and welfare.

• There are mechanisms developed to capture patient reported outcomes which shape service delivery and feed into the improvement cycle.

• Healthcare should remain free at the point of access, especially to people with long term conditions who can be disproportionately disadvantaged by small incremental changes to the wider healthcare system.

• High quality, safe and effective services should be delivered close to home where possible and centralised where appropriate in order to deliver the best patient outcomes.

• Carers assessments are comprehensively and equitably offered to carers across Northern Ireland and gaps in services to carers systemically identified and met.
We want the Northern Ireland Assembly to commit to working with LTCANI to meet the needs of people living with long term conditions. Our priorities are:

Northern Ireland has a wide variety of policies, strategies and frameworks in relation to Long Term Conditions, but no overarching implementation plan that coordinates them all. A framework with clearly defined outcomes and measures is fundamental to drive the transformation and change that is needed to meet the needs of the population.

The LTCANI believes Transforming Your Care laid out strong recommendations for improvement in long term conditions and the Donaldson Report highlighted the need for a whole systems reconfiguration across all sectors of health and social care. We look forward to contributing to the future redesign of Health and Social Care across Northern Ireland.

It is estimated that 1 in 5 people in Northern Ireland have a mental health problem at any one time. Over 7 years, the prevalence of Lymphoedema has increased by more than 2.6 times. In Northern Ireland 1 in 4 people who need palliative care are not accessing it - that’s nearly 3000 people each year. Epilepsy misdiagnosis affects 4,600 people and costs N Ireland £8.9m every year.

In the next Assembly we recommend:

- The existing commitments in the current Programme for Government remain a priority & are resourced as a matter of urgency.
- Statutory Health & Social Care organisations must work closely across all sectors in the development and delivery of quality assured education and training programmes.

3. Supported Self Management for people with long term conditions.

Self management should provide people with long term conditions with the knowledge and skills they need to manage their own condition more confidently and to make daily decisions which can maintain or enhance their health and well being as well as their clinical, emotional and social outcomes.

There is a growing body of evidence in Northern Ireland demonstrating the efficacy of self care and self management programmes, including those delivered by LTCANI members.

Self management has been proven to be an enabling tool which helps people manage their condition at home at critical times which can help reduce the impact on emergency admissions.
Long term conditions account for half of all GP appointments and 70% of hospital bed days.

91% of over 75s take at least one or more items of medication.

To summarise, long term conditions will not go away; they are the health care challenge of this century. LTCANI is committed to working in partnership to help meet this challenge. To help make this achievable we recommend the Northern Ireland Executive:

- Provide clear strategic direction to achieve better outcomes and meet the needs of people with long term conditions.
- Deliver patient centred care to people with long term conditions.
- Supported self management for people with long term conditions.

LTCANI and its members are committed to working with key stakeholders to support the delivery of the Donaldson Report. An appropriate framework and structure link with statutory bodies will be required, together with a mandate for the sector, to ensure effective oversight of the delivery of self management as per the Long Term Conditions Framework.

For more information about our election calls contact Heather Monteverde, Chairperson of LTCANI at hmonteverde@macmillan.org.uk
For more information about the LTCANI and our work visit: www.ltcani.org.uk #LTCANI

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ii BHF NI estimate based on GP patient data.
iii NISRA, Deaths by sex, age and cause, 2014 (http://www.nisra.gov.uk/demography/default.asp100.htm)
iv DHSSPSNI, Quality & Outcomes Framework, 2014-15
vi DHSSPS (2011) Service Framework for Mental Health & Wellbeing, Belfast: DHSSPS.
viii ‘20,000 reasons to take action on dementia.’ Alzheimer’s Society Northern Ireland Manifesto 2016
x Prevalence data in QOF Disease Prevalence (2014/15) data
xiv Joint Epilepsy Council of the UK and Ireland; Epilepsy prevalence, incidence and other statistics December 2011.
300,000 local people have been diagnosed with arthritis.