



Long Term Conditions Alliance Northern Ireland

Response to Draft Programme for Government Framework 2016 – 2021

22 July 2016

“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. Fortunately, there are known, effective strategies to curtail their growth and reduce their negative impact. The solution is to embrace a new way of thinking about and managing chronic conditions. Through innovation, health care systems can maximize their returns from scarce and seemingly non-existent resources by shifting from an acute to a chronic care model. Many countries are making the shift and starting with the development of innovative chronic conditions programmes. Small steps are as important as system overhaul. Those who embrace change, large or small, are experiencing benefits today and creating the foundation for success in the future”
(WHO, 2002)

About Long Term Conditions Alliance Northern Ireland

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. Our 25 member organisations represent approximately 500,000 people with long term conditions in Northern Ireland.

The extent of the challenge:

“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)

The impact of long term conditions in Northern Ireland:

- 1 in 3 of the population live with at least one or more long term condition
- People with long term conditions account for 50% of GP appointments and 70% of hospital admissions
- By 2030, the number of people living with cancer and the long term consequences of the condition and treatment is expected to rise to over 100,000.ⁱ
- 225,000 local people are living with cardiovascular disease.ⁱⁱ
- Cardiovascular disease or CVD (heart & circulatory) causes a quarter of all local deaths or 3,700 deaths each year – that’s an average of 10 people each day.ⁱⁱⁱ
- Over 15,100 people 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 significant causes of ill health and disability locally along with CVD, respiratory disease and cancer.^{vi}
- It is estimated that 1 in 5 local people have a mental health problem at any one time.^{vii}
- 20,000 people live with dementia, but only 3 out of 5 have a formal diagnosis.^{viii}
- 37,000 local people live with Chronic Obstructive Pulmonary Disease (COPD).^{ix}
- 84,000 people live with diabetes.^x
- 400,000 local people experience long term chronic pain.^{xi}
- 300,000 local people have been diagnosed with arthritis.^{xii}
- Over 8 years, the prevalence of Lymphoedema has increased by more than 3 times.^[i]
1 in 4 people need palliative care are not accessing it – that’s nearly 3,000 people each year.^{xiii}
- Epilepsy misdiagnosis affects 4,600 people and cost N Ireland £8.9m every year.^{xiv}
- 3 million people in the UK are estimated to have osteoporosis – the fragile bone disease that leads to 300,000 painful and debilitating fractures every year.

- 91% of over 75s take at least one or more items of medication.^{xv}

Prevention and support to live longer, healthier, happier lives

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.

Long term conditions not only wreak havoc on individuals' and families' lives but can also blight the wellbeing of communities and increase deprivation and inequality. These conditions mean that many of us will live shorter lives and live a great proportion of our lives with disability. (The Richmond Group of Charities, 2016)

With an aging population, ¼ of the population living with one or more common long term condition and increasing pressures on health and social care resources; we believe prevention is a moral and practical necessity. We call on the NI Executive to work with the voluntary sector and take bold action to reduce preventable deaths and illnesses. As outlined by the Richmond Group in their *Living Longer, Living Well* report “We can make the biggest positive impact on people’s lives by reducing the preventable health risks which can lead to long term health conditions such as Type 2 diabetes, breast cancer, arthritis and chronic obstructive pulmonary disease (COPD).

However, while prevention is vital, it is equally important to ensure that people living with unavoidable long term conditions such as multiple sclerosis, Type 1 Diabetes and heart failure receive appropriate treatment and support to manage their condition and remain independent.

Voluntary sector is a key partner

As an Alliance we are committed to working in partnership across sectors to ensure everyone living with one or more long term conditions get the right support, at the right time and in the right place. We welcome the ambitious statement of purpose “Improving wellbeing for all – by tackling disadvantage and driving economic growth” and call on all Executive Departments to utilise the experience and expertise of the voluntary sector as partners, at every stage, in achieving this purpose.

The LTCANI welcomes the outcomes based approach outlined in the Draft Programme for Government Framework. The implication that responsibility, delivery of outcomes and accountability will be shared across all Executive departments is extremely welcome. We believe health is everyone’s business. As outlined in 2016 NI Assembly election manifesto, we believe all government departments must work together to ensure a co-ordinated approach is taken to meet the challenges long conditions bring to individuals, their families, the community, health services and Northern Ireland.

In our manifesto we made the following recommendations:

- 1. Provide clear strategic direction to achieve better outcomes and meet the needs of people living with long term conditions**
- 2. Deliver patient centered care to people with long term conditions**

3. Support self-management for people with long term conditions

We remain convinced that focusing on these key areas is central to supporting people to live longer, healthier and happier lives and call on the NI Executive to adopt ambitious, clear and measurable targets with an appropriately resourced implementation plan.

Collectively, our Alliance has significant experience and expertise in the development of various strategies and frameworks to tackle the challenge of long term conditions. However, the failure has always been in the implementation and resourcing of these plans. For example, below is a list of relevant strategies and frameworks, containing much needed opportunities to improve the diagnosis, treatment and care of long term conditions, which have either not been fully implemented locally or implementation has been slow.

- Living with Long Term Conditions – A Policy Framework (2012)
- Making it Better
- Cardiovascular Health & Well-Being Framework
- Stroke Strategy
- Community Resuscitation Strategy

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 and urge the NI Executive to ensure that existing frameworks and strategies are implemented as they are the foundations on which the Programme for Government outcomes are based on.

Clear road map for implementation

It is essential that there is a clear implementation plan to achieve outcomes outlined in the Draft Programme for Government. This plan must include clear targets, involve all relevant partners including the voluntary sector and be fully resourced. We feel that the indicators outlined in the Draft Framework are not adequate.

The LTCANI strongly believes that the Programme for Government will be most successful when it is aspirational about the changes in outcomes that it wants to deliver. To achieve this, the indicators have to be SMART based. For example, indicator 4 relates to the reduction of preventable death but does not refer to how and when this will be achieved.

The LTCANI strongly recommends the adoption of the World Health Organisation's target which calls on Governments to take action and reduce premature deaths by 25% by 2025.

Non-communicable diseases (NCDs) include heart disease, stroke, cancer diabetes and chronic lung disease. They are collectively responsible for 86% of deaths in Northern Ireland before the age of 75. That equates to 4,600 lives each year. Successfully achieving this target would enable over 1,000 local lives saved each year.

The LTCANI believes this target is achievable through full implementation of existing Frameworks and strategies as these have a strong focus on primary and secondary prevention and tend to place the patient at the centre of care. The implementation of these strategies is only achievable with adequate resources and funding via a reform and modernisation roadmap.

Concern around uncertainty - Funding

LTCANI welcomes the Government's manifesto commitment to allocate an additional £1 billion to health to deliver the much needed reform and modernisation over the next five years, but we require clarification on the current status of these political pledges given the cost of corporation tax, the prospect of new spending commitments and a British exit from the European Union.

Accessibility of this document

Please note that the Draft Programme for Government Framework document and consultation survey was not accessible to all. There was no easy read/aphasia friendly version available. This precludes many people from participating in this important consultation process and raises serious concerns about the NI Executive's ability to achieve the indicators outlined in the document – to improve cultural participation and increase the quality of life for people with disabilities. This is not acceptable and the Executive has not met its duties under the DDO or its own Disability Strategy. The Executive should have made provision for the development of accessible formats before publication given the shorter timescales.

In the following section we will respond to the relevant outcomes:

Outcome 1 – We proposer through a strong, competitive, regionally balanced economy

We welcome this outcome and would like to concentrate our comments in relation to outcome 1 in two areas – firstly the role of the charities on the high street and secondly, the role of research and development in supporting the local economy.

By providing 100% rate relief, the Northern Ireland Executive has been a critical partners in helping ensure that as much as possible of the funds raised through the

sale of donated good via a charity shop goes towards public benefit – via good causes.

LTCANI supports the ‘More Than A Shop’ campaign which aims to promote the charity shop sector generally, and protect the 100% rates exemption for charity shops in light of the vast public benefit the sector delivers in Northern Ireland.

Charity shops in N Ireland:

- Raise money for much needed causes – £10.5M raised by sector last year (All for charitable Purposes). 100% business rates would cost the sector £5.5m. Even a 20% rates imposition would mean a £1.1M loss to the good work of charities in N Ireland.
- Support high streets – NI high street vacancy rate is 16.3% – UK Average 9.1%. Charity shops are a vibrant part of a local economy, not the cause of high vacancy rates. Charity shops help drive footfall to town centres.
- Provide jobs – the Charity Retail Association estimate (CRA) that if charity shops in NI paid 100% rates = 400 job losses to sector, 20% rates = 130 job losses to sector.
- Provide volunteering opportunities - combats social isolation and loneliness amongst older volunteers and equips young people and the long term unemployed with skills for employment- it is clear that people in Northern Ireland value these opportunities with over 5,400 people getting involved.
- Support the environment – in 2015, the CRA estimated that Northern Ireland based charities diverted over 21,000 tonnes of textile from landfill - a saving to local councils of £1,777,000.

As outlined above, a change in the current rates exemption for the charity retail sector would substantially damage the charity’s ability to raise much needed funds within Northern Ireland which would have far reaching consequences for the social fabric of the local community and would compromise the fundamental principle of public benefit not private gain which underpins the long standing rationale for charitable exemption from business rates in Northern Ireland.

Secondly, LTCANI highlights the important role of the charity sector in strengthening the local economy through research. For example, for every £1 that is invested in medical research, £4.14 is returned to the local economy.

Research is one the UK’s biggest assets. It underpins improvements in health and wellbeing and importantly, drives economic growth and productivity. Charities such as British Heart Foundation N Ireland (BHFNI) play an important role in funding life-saving and life-enhancing research.

Across different conditions and diseases, people are now living longer, healthier lives thanks to investment in science. For example, due to the advancements in treatment and diagnosis, seven out of ten people surviving a heart attack.

UK research relies on stable, long-term investment from a range of funders – from UK Government and industry, to charitable funders such as the British Heart Foundation, Cancer Research UK, Diabetes UK, etc. Together, these funders support research in all its forms, from basic laboratory research to large clinical trials. The same is true for Northern Ireland – the money invested in research has a tangible economic benefit and is helping to fund the next major breakthroughs in treatment.

LTCANI recommends that the Northern Ireland Executive provides continued long term investment, maintained in line with inflation, to build on the research base in Northern Ireland.

The research environment needs long-term investment to continually thrive and grow in Northern Ireland. Whilst new, state-of-the-art facilities and equipment, requiring capital spend, provide an exciting opportunity for research, they will be unable to deliver world-leading science without resource budget for the work that is already being carried out by talented researchers both in Northern Ireland and across the UK.

LTCANI believes that all areas of research should be supported including clinical research and we would highlight the long standing partnership approach between our local universities, health & social care and the voluntary sector. It is essential to recognise the role the voluntary sector has in innovation, research and development and creativity.

Outcome 3 We have a more equal society

- We welcome this outcome.
- We note that the NI Executive plans to make its contribution by ensuring compliance with legislation and yet the Programme for Government document itself is not available in accessible formats, as required by law. We would urge that this is immediately addressed.
- We welcome the commitment to work with the voluntary sector to achieve this outcome.
- We believe the indicator focus more on promoting diversity rather than addressing issues of equality and equitability and believe further indicators should be added to address the social determinants of health inequality
- We believe 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.
- The measures don't measure issues of health inequality. It's not just about years in life, it's about quality of life
- We believe the NI Executive should tackle the social determinants of poor health

Outcome 4 We enjoy long, healthy active lives

- We feel this is an extremely important outcome and welcome the emphasis on prevention and secondary prevention to ensure that everyone has the opportunity to live longer, healthier lives.
- It should be noted that almost a 1 in 4 people in Northern Ireland live with one or more long term condition and to enable to live longer, healthier lives it is essential make self-management available to all.
- 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 wellbeing 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 as well as achieving greater self-efficacy.
- We believe it would be appropriate to add a specific indicator in relation to supporting people with long term conditions, who want to be enrolled, to attend a specialist chronic condition management programme. For example, this indicator could be *“Increase people’s ability to take control of their own health”*. This would connect with Indicator 9 and Indicator 28 *“Increase the confidence and capability of people and communities”* to support greater self-efficacy by enabling people living with long term conditions to play a proactive role in managing their own condition.
- As outlined above we believe the voluntary sector has an important role in supporting this outcome and call for the statutory sector to recognise and utilize the voluntary sector as partners to achieve this goal.
- We feel that the impact and legacy of the conflict and its link to the high levels of mental health conditions in Northern Ireland should be reflected in the indicators and specific indicators put in place to tackle this.
- In order for people to enjoy longer, healthier lives we believe people with long term conditions 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.
- Evidence based services which ensure prompt diagnosis and support patients to self-manage (such as the Fracture Liaison Service for reducing broken bones) are essential to minimizing the harm of long term conditions. This practice should be systematically implemented in Northern Ireland so that everyone can benefit.
- We welcome the emphasis on prevention but believe it is essential that adequate investment is provided for secondary prevention and self-management to support people who are already living with long term condition to maintain their health and independence.

- We believe that reform of the health care system should run hand in hand with prevention programmes to ensure that high quality, safe and effective services are delivered close to home where possible and centralized where appropriate in order to deliver the best patient outcomes.
- We would strongly recommend that the £1billion additional health and social care funding, proposed by the parties in government, is ring fenced for the implementation of the recommendations outlined in the Donaldson report rather than short term solutions such as investment in waiting lists.

Outcome 5: We are an innovative, creative society, where people can fulfil their potential

Building on our response to outcome 1 regarding research, LTCANI would highlight that innovation within the healthcare sector has historically improved the quality of care that a patient receives then they fall ill. Representing over 24 charities and organisations, LTCANI would ask the Northern Ireland Executive to recognise the voluntary sector as an important partner in the future reform and modernisation of Health & Social Care in Northern Ireland.

Through their research and innovation, charities have been at the forefront in bringing innovative healthcare treatments to health systems. This is extremely evident in areas such as cardiovascular disease (CVD) where charities such as the BHF has helped pave the way for new methods of treatment and better prognosis for those suffering from CVD. For example, science funded by the BHF has led to treatments for heart attacks, advance in pacemakers, transplant surgery, defibrillators and development of statins.

With Bengoa’s recommendations combined with the Programme for Government, the LTCANI wants to work closely with the Northern Ireland Executive to promote research and innovation in the reform and modernisation agenda.

The voluntary sector can bring so much to reform and modernisation. Not only can we help shape the conversation but we can bring some of the solutions.

Please see appendix for information on the following innovations:

British Heart Foundation - Intravenous Diuretics at home and in the community

Macmillan - Sustainable Cancer Service Redesign: Transforming Cancer Follow up Programme

Cancer Focus – Keeping Well and Well Aware

LTCANI members have individually and collectively invested £millions in research, development and innovation and would welcome playing a key role going forward.

Outcome 6 We have more people working in better jobs

- We are keen to work with the NI Executive to address how they will address helping people with disabilities and long term conditions to gain and retain employment
- We note that people with long term conditions are not listed among the people the NI Executive intend to collaborate with and we would urge this to be amended.
- People with long term conditions want to and are able to work and should be helped to gain employment, keep their jobs or return to work with the support of employers, health care professionals and appropriate public policies which support inclusion.
- The employment of family members who act as carers for people with long term conditions is also impacted upon and strategies need to be in place to support carers to stay in or return to work.
- Employers should be supported to be able to fully facilitate people with long term conditions, through the development of training and best practice.
- Volunteering has in key role in supporting people with long term conditions to learn new skills, build confidence, and tackle economic inactivity and social isolation. For e.g. More than 50 stroke survivors volunteer with the Stroke Association in a variety of roles in Northern Ireland. For many people this is an important bridge back into the or paid employment following the trauma of a stroke

Outcome 8 We care for others and we help those in need

- We welcome this outcome and the emphasis on meeting the needs of the most vulnerable in society and giving people the opportunity and means to help themselves.
- We would welcome further clarification on the definition of “essential needs” and urge the Executive to consider all aspects of need – including support to maintain good mental health and wellbeing, tackle social isolation and ensure good quality of life for all.
- We welcome the commitment to put in place services to provide excellent levels of care for those who need it. However, we would like to see a greater acknowledgement of the need for a continuum of care – especially for those with life long, incurable long term conditions, for whom their care needs will evolve over time.
- We believe the voluntary sector has a vital role to play and should be a key partner in building the confidence and abilities of individuals and communities. As noted above, voluntary sector organisations including members of the Long Term Conditions Alliance NI, have vast experience and expertise in supporting people to develop the skills and confidence to self-manage their conditions, and therefore reduce the demand on limited health and social care resources.

- Caring for others should also include a specific indicator around caring for unpaid and family carers.

Outcome 11 We have high quality public services

- We welcome this important outcome. It is important that a baseline measure is established and clear indicators for quality.
- People affected by long term conditions in Northern Ireland have told us that their healthcare experience varies according to where they live. We believe that everyone should have access to the high quality treatment, care and support they need, when they need it, regardless of where they live in Northern Ireland.
- 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.
- LTCANI has a very specific interest in this outcome. As we have previously outlined LTCANI needs to have a central and partnership role in the reform agenda to design, deliver and implement high quality services. LTCANI members have provided examples of innovations and opportunities to improve the quality of services as part of the Bengoa Report and would urge that these are considered in the action plans.

Outcome 13 We connect people and opportunities through our infrastructure

- This outcome is key for people with disabilities.
- In order to address health inequalities it is vital for people with long term conditions to have good, affordable and accessible housing and access to public transport, employment opportunities, leisure and arts and healthcare facilities to tackle isolation, exclusion and economic inactivity.

Outcome 14 We give our children and young people the best start in life

- As outlined above we believe that health is everyone's business and therefore a joined up and coordinated approach to maintaining good health and wellbeing is essential.
- We believe that focusing on prevention would have the greatest impact on reducing health inequality. It is essential that adequate investment is provided for primary & secondary prevention and self-management to support people are at risk of developing or already living with a long condition.
- The voluntary sector has a key role to play in reducing health inequalities. There are many innovative programmes and initiatives which, with adequate resourcing, could support people to live longer, healthier lives. For example – the Stroke Association runs a *Lessons for Life* Programme which supports children and young people to understand the risk factors for stroke and take steps to reduce their risk.
- It is vital that the voluntary sector's evidence based interventions for behavior

change are adequately funded and recognised as a key of the prevention pathway.

- As outlined above we believe an additional indicator should be included which could support this outcome. The indicator could be “*Increase people’s ability to take control of their own health*”. This would connect with Indicator 9 and Indicator 28 “*Increase the confidence and capability of people and communities*” to support greater self-efficacy by enabling people to take action to reduce their risk of preventable conditions.

Closing remarks

The Long Term Conditions Alliance Northern Ireland welcomes the opportunity to respond to this important consultation on behalf of the 500,000 people living with one or more long term condition.

As outlined in this response we welcome the overarching focus on an outcomes based Programme for Government but feel that more clarification is needed on the policy direction, funding available and implementation plan to achieve these ambitious outcomes. It is vital that the voluntary sector, which represents the voice of thousands of people in Northern Ireland, has a meaningful role in the process. The Long Term Conditions Alliance Northern Ireland is committed to working with all key stakeholders to support the delivery of outcomes which improve wellbeing for all.

For more information or to discuss this response please contact The Long Term Conditions Alliance via LTCANI Chairperson Fiona Greene (Northern Ireland Chest Heart and Stroke) by emailing FGreene@NICHHS.org.uk

ⁱ Cured – but at what cost? Macmillan Cancer Support (2013).

ⁱⁱ BHF NI estimated 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

^v DHSSPSNI, Quality & Outcomes Framework, 2014-15. BHF calculation based on 2013 CPRD prevalence data and ONS population estimates.

^{vi} DHSSPSNI (2011) Service Framework for Mental Health & Wellbeing, Belfast: DHSSPS.

^{vii} CMO (2010) Your Health Matters. The Annual Report of the CMO for N Ireland 2010. Belfast: DHSSPS

^{viii} ‘20,000 reasons to take action on dementia.’ Alzheimer’s Society N Ireland Manifesto 2016

^{ix} [Prevalence data in QOF Disease Prevalence \(2014-15\) data.](#)

^x [Prevalence data in QOF Disease Prevalence \(2014-15\) data.](#)

^{xi} Painful Truth, Patient Client Council Report.

^{xii} Arthritis Care N Ireland, estimates.

^[1] CREST Lymphoedema Guidelines. June 2015 Figures

^{xiii} Source: Hughes-Hallet T, Craft A, Davies C (2011). Palliative care funding review: funding for the right care for everyone, DoH, London. Dixon J, Kind D, Matosevic T et al (2015). Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie. Office for National Statistics (ONS) (2014). 2012 – based National Population Projections.

^{xiv} Department of Health (2012). Long Term Conditions compendium of Information: 3rd
^{xv} DHSSPS Health Survey N Ireland: First results 2014/15 Report. Published Nov. 2015.

Appendices

Appendix 1

British Heart Foundation – Intravenous Diuretics at home and in the community

For example, in CVD management, despite the great success for many people surviving heart attacks, this does not mean the job is done as many people still are having heart attacks, but they are surviving and are now living with CVD and many developing heart failure. Heart failure is one of the main reasons for A&E admission and has a huge impact in the area of unscheduled care. It is in modernising heart failure services that can improve waiting times at A&E and waiting lists times.

Outlined below is an example of a BHFNI innovation within one area of heart failure. It is one of many evidence based innovations that the sector can bring to reform and modernisation

Intravenous Diuretics at home and in the community

Heart failure (HF) is a common progressive life-limiting condition which can have a major effect on the quality of life of patients and their families. Around half a million people in the UK are diagnosed with HF, including over 15,000 local people with many more undiagnosed cases. People living with HF can have periods of relative stability and periods of worsening of the symptoms and signs of HF which require hospital admission and treatment with intravenous (IV) diuretics.

Traditionally it has been usual practice to admit patients to hospital for IV administration if they fail to respond to an increase in oral diuretics. Mean length of stay for a HF admission is estimated to be 12 days. The BHF funded and externally evaluated a 2 year project, across Ten NHS sites (of which 8 were in England) to determine if delivering IV diuretics in the patient's home or in a community setting is safe, clinically effective, cost effective and well received by patients and carers. Total funding awarded by the BHF was £571,980.00.

126 interventions were administered to 96 patients, age range 51-93 (mean age 75). 76% were male, 70% lived with a spouse or other family member, all but one were reported as having a wide range of co-morbidities and 56% had a previous HF related admission in the year prior to the IV diuretic intervention.

Models of delivery were dependent on local infrastructures; although the majority used delivery via HF nurses. 100% patients and 93% carers preferred treatment at home than in the hospital. 79% of people avoided hospital admission, 63% achieved

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target reduction in oedema and weight loss. The project demonstrated safety and efficacy and the IVD at home and community model has been adopted as a proven NICE QIPP case study. The model has been adopted and sustained at the end of the BHF funding period, in Leeds, Ayrshire and Arran, Aneurin Bevan, Darlington and Stoke.

Economic Results:

The average cost per intervention at home was £793 compared to an episode of treatment at a hospital for £3796.

For every £1 invested in the service there is a saving of almost £4.

Investment needed in Northern Ireland to provide the service over 2 years: £275,000

Net savings opportunities across Northern Ireland in first 2 years: £675,000

Appendix 2

Sustainable Cancer Service Redesign: Transforming Cancer Follow up Programme

Background

There are currently 63,000 people living with cancer in Northern Ireland. By 2030, numbers are expected to rise to over 110,000. Our existing healthcare system will not be able to cope with growing patient rehabilitation and secondary prevention needs.

Although cancer is increasingly becoming a chronic condition, aftercare is framed around acute illness with the focus on monitoring and review. However, evidence shows that up to 70% of recurrence is picked up outside clinics.

The Transforming Cancer Follow up programme (2011 – 2014) was the result of a strategic partnership between Macmillan and Northern Ireland's Cancer Network (NICaN), Public Health Agency and Health and Social Care Board.

The overall aim of Transforming Cancer Follow up (TCFU) was to introduce and test new models of breast and prostate cancer follow up across Northern Ireland which would:

- Improve the quality of patients' aftercare experience and promote their health & wellbeing through self-management and holistic needs assessment (HNA)
- Reduce inefficiencies in hospital follow up
- Enhance service coordination and integration
- Guarantee sustainability

What has been achieved so far?

The TCFU team was made up of Macmillan Project Managers based in Northern Ireland's five health trusts. They began by redesigning breast cancer aftercare and replacing a "one size fits all" approach with a more person-centred service. A risk stratified approach places breast cancer patients into one of three pathways: self-directed aftercare (SDA), shared care or complex care.

It was initially agreed that 30% of newly diagnosed breast cancer patients should be placed on the SDA pathway with the support of the Macmillan Recovery Package. This ensures that every patient has access to a Clinical Nurse Specialist (CNS), who carries out a holistic needs assessment and produces a written "care plan". An additional treatment summary helps both patients and GPs understand their treatment and possible longer term consequences. Finally, people are invited to go along to a "health & wellbeing" event, where they hear about all the practical things they can do to keep well.

Patients on the SDA pathway are offered a safer, more responsive service. They have rapid access back into the system via their CNS. Clinical teams now have more time to focus on complex cases.

By December 2014, when the final PwC evaluation was carried out, 58% of newly diagnosed patients were on the self-directed aftercare pathway. As a result, waiting lists for routine follow up appointments had been reduced over the two year evaluation period, showing a:

- 28% reduction in surgical breast review waiting lists
- 39% reduction of patients in duplication between oncology and surgery review waiting lists
- 4% reduction in oncology breast review waiting list

Patient experience has improved as a direct result of these changes. The final evaluation highlighted the following increases in satisfaction rates amongst patients on the new breast programme, compared to the baseline survey:

- The proportion of patients who said they were aware of the importance of lifestyle changes increased by 34% (45% - 79%)
- The proportion of patients who strongly agreed/agreed that they had been supported to manage the practical impact of their cancer increased by 25% (40% - 65%)
- The proportion of patients who strongly agreed/agreed that they had been supported to manage the emotional impact of their cancer increased by 23% (44% to 67%)
- The proportion of patients who strongly agreed/agreed that they had been supported to manage the physical impact of their cancer increased by 16% (59% to 75%)

Progress to date

In 2015, the breast cancer programme showed further exceptional progress (relative to figures from the final evaluation report) on the key deliverables of TCFU across Northern Ireland, including:

- Proportionally more new patients allocated to the 'Self Directed Aftercare' pathway (An average of 64% - ranging from 51% to 78% across the five Health Trusts)
- Proportionally more patients offered post-surgery HNA
- Reduced surgical review waiting lists
- Reduced duplication between oncology and surgery appointments

Under the Cancer Reform banner, TCFU principles are being implemented in cancer services across Northern Ireland. Key priority areas for roll-out include prostate, gynaecological, colorectal and haematological cancers.

Conclusions

The TCFU breast programme represents a welcome demonstration that cancer service redesign can be embedded and sustained after an initial project comes to an end. However, the prostate programme has been more challenging. With a regional commitment to the roll-out of TCFU, including steps towards implementing electronic HNA and the Health and Social Care Board's planned expansion of the Clinical Nurse Specialist workforce, the TCFU programme will be adapted for different cancer types and services.

Appendix 3

Cancer Focus

Community Outreach Programmes – Keeping Well and Well Aware

Cancer Focus NI Community Outreach programmes work with communities and individuals to promote healthy lifestyles and so prevent cancer. The projects prioritise areas of social disadvantage, hard to reach groups and those at great cancer risk, including older people, travelling community, homeless, LGBT, rural communities, manual/outdoor workers, ethnic minorities, long-term unemployed and within prison services. Qualified nursing and health promotion personnel staff our 4 mobile health check vehicles. Interventions address general health and well-being before moving on to discussions of individual's specific health concerns including: smoking cessation support with the option for CO monitoring, skin cancer awareness, skin scanner, body composition, blood pressure, pulse, blood glucose, mental health and wellbeing, body awareness, including use of breast and testicular Long Term Conditions Alliance NI – response to draft Programme for Government
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models. Uptake of screening opportunities is promoted. Participants are encouraged to set individual goals to reduce cancer risk. Information and advice provision is reinforced by the distribution of a range of leaflets and other guidance materials. Where appropriate, service users are referred to other local services.

In 2014/15 the community services carried out 7,458 health checks and reached a further 6,124 people through health talks and community health fairs. 34% of people receiving a health check were referred to other services. 65% of Keeping Well van service users were men – often seen as hard to reach through traditional services. Of these 78% were overweight or obese: 19% had high blood pressure. 97% of Well Aware participants reported and increased awareness of cancer prevention: 98% reported improved knowledge of their awareness of cancer signs and symptoms.