



Department of  
**Health, Social Services  
and Public Safety**

[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

# **THE DONALDSON REPORT RECOMMENDATIONS**

## **Consultation Response Questionnaire**

## CONSULTATION RESPONSE QUESTIONNAIRE

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

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**Responses must be received no later than 22 May 2015**

I am responding: as an individual   
on behalf of an organisation   
(please tick a box)

<input type="checkbox"/>
<input checked="" type="checkbox"/>

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## Background

On 8 April 2014 former Health Minister Edwin Poots announced his intention to commission former Chief Medical Officer of England, Professor Sir Liam Donaldson, to advise on the improvement on governance arrangements across the HSC.

Sir Liam was subsequently tasked with investigating whether an improvement in the quality of governance arrangements is needed and whether the current arrangements support a culture of openness, learning and making amends.

The Donaldson Report was published by the Health Minister Jim Wells on 27 January 2015. It sets out 10 recommendations which refer to a wide range of areas across the health service in Northern Ireland. The full report can be accessed at:

<http://www.dhsspsni.gov.uk/donaldsonreport270115.pdf>

## **Purpose**

This questionnaire seeks your views on the recommendations arising from the Donaldson Report, and should be read in conjunction with the report which includes the recommendations.

## **The consultation questionnaire**

The questionnaire can be completed by an individual health professional, stakeholder or member of the public, or it can be completed on behalf of a group or organisation.

**Part A:** provides an opportunity to answer questions relating to specific recommendations and/or to provide general comments on the recommendations.

**Part B:** provides an opportunity for respondents to give additional feedback relating to any equality or human rights implications of the recommendations.

When responding to Part A please indicate which recommendation(s) you are providing feedback on:

<b>Please tick which recommendations you are providing feedback on</b>	
Recommendation 1	X
Recommendation 2	X
Recommendation 3	X
Recommendation 4	X
Recommendation 5	X
Recommendation 6	X
Recommendation 7	X
Recommendation 8	X
Recommendation 9	X
Recommendation 10	X
General Comments	X

## INTRODUCTION

Please find attached the response from the Long Term Conditions Alliance NI

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 in Northern Ireland. Collectively LTCANI member organisations ( 25 in total) represent approximately 500,000 people with long term conditions in Northern Ireland. We are a membership organisation which is funded by an annual membership fee. We do not receive any core or statutory funding.

Long term conditions can affect all aspects of people's lives, 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 medical intervention, but they also 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 with partners in the statutory, independent, voluntary and community sectors to improve the health and wellbeing ,treatment and care for those we represent.

We look forward to playing a part in the implementation of the recommendations in this report.

## APPROACH

The level of detail of response to each recommendation is determined by its direct importance to the members of the LTCANI:

1 = of some importance

2 = of moderate importance

3 = of critical importance

### Part A

#### Feedback on Recommendations

##### **Recommendation 1**

**We recommend that all political parties and the public accept in advance the recommendations of an impartial international panel of experts who should be commissioned to deliver to the Northern Ireland population the configuration of health and social care services commensurate with ensuring world-class standards of care.**

The Report states that ‘A proportion of poor quality, unsafe care occurs because local hospital facilities in some parts of Northern Ireland cannot provide the level and standard of care required to meet patients’ needs 24 hours a day, 7 days a week. Proposals to close local hospitals tend to be met with public outrage, but this would be turned on its head if it were properly explained that people were trading a degree of geographical inconvenience against life and death. Finding a solution should be above political self-interest.’

The process of creating these recommendations will entail Personal and Public Involvement (PPI) on behalf of the panel and consultation with all relevant stakeholders.

**Q1. Do you agree that a panel of experts should be appointed to make recommendations on the configuration of Health and Care services in Northern Ireland? If so, should this panel be made up of international experts?**

Strongly agree      Agree      **Neither**      Disagree      Strongly disagree

Comments:

This is rated 1 – of some importance to the LTCA

The LTCANI seeks clarification around what this recommendation means by ‘the configuration of health & social care’, for example does this refer to all or certain areas of the health & social care system? LTCA has understood it to mean that a whole systems reconfiguration is needed across all sectors of health & social care which includes primary & secondary care, PHA, HSCB & the Trusts. Any reconfiguration of services should also take account of previous & current reviews of our infrastructures, such as the Hospital Plan for NI. As suggested above, a clear Terms of Reference for the implementation of the recommendations should define the scope & remit of each recommendation, as well clearly state the relevant parties responsible & accountable for its implementation.

There have been many external experts who have reviewed & reported on the NI Health and Social Services system. LTCA believes that the focus of future energy should be on implementing effective change rather than further review which would further delay reform. We also foresee difficulty with the recommendations of an impartial international panel of experts being ‘accepted in advance’.

LTCANI is supportive of system wide reform which delivers the best outcomes for patients. The method of design whether it be a panel of experts (either local or international) or otherwise, should not delay implementation or jeopardise patient safety in any way.

Any reform should be effectively communicated with the public who play a vital role in the reconfiguration of services & its successful implementation. Public engagement, executed correctly can increase awareness of benefits, manage expectations & ultimately gain buy in.

**Q2. If such a panel is appointed, should political representatives have the final say in accepting any recommendations?**

Strongly agree      Agree      **Neither**      Disagree      Strongly disagree

Comments:

Decisions around accepting recommendations should be driven by the needs of & the best available outcomes for the population.

**Q3. Are there alternative ways for Northern Ireland to determine a configuration of health and social care services commensurate with ensuring world-class standards of care?**

If you consider there is, please complete the box below

Comments:

LTCANI believes the best outcomes for patients must be at the core of service design & delivery.



## Recommendation 2

**We recommend that the commissioning system in Northern Ireland should be redesigned to make it simpler and more capable of reshaping services for the future. A choice must be made to adopt a more sophisticated tariff system, or to change the funding flow model altogether.**

The Report states that 'The provision of health and social care in Northern Ireland is planned and funded through a process of commissioning that is currently tightly centrally-controlled and based on a crude method of resource allocation. This seems to have evolved without proper thought as to what would be most effective and efficient for a population as small as Northern Ireland's. Although commissioning may seem like a behind-the-scenes management black box that the public do not need to know about, quality of the commissioning process is a major determinant of the quality of care that people ultimately receive.'

In response to this finding the Minister announced, on 27<sup>th</sup> January 2015, that Departmental officials have been asked to undertake a review of the effectiveness of existing commissioning arrangements. This is due to report in the summer of 2015.

### Q1. Do you agree with this recommendation?

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

This is rated 1 – of some importance to the LTCA

LTCANI supports the recommendation to redesign the current NI commissioning system to make it simpler and more capable of reshaping services for the future. We would also propose that the redesign process includes greater involvement of the community & voluntary sector to access increased carer/user participation. LTCA would welcome participation in the design of future Commissioning.

### Recommendation 3

**We recommend that a new costed, timetabled implementation plan for Transforming Your Care should be produced quickly. We further recommend that two projects with the potential to reduce the demand on hospital beds should be launched immediately: the first, to create a greatly expanded role for pharmacists; the second, to expand the role of paramedics in pre-hospital care. Good work has already taken place in these areas and more is planned, but both offer substantial untapped potential, particularly if front-line creativity can be harnessed. We hope that the initiatives would have high-level leadership to ensure that all elements of the system play their part.**

The Report states that ‘The demands on hospital services in Northern Ireland are excessive and not sustainable. This is a phenomenon that is occurring in other parts of the United Kingdom. Although triggered by multiple factors, much of it has to do with the increasing levels of frailty and multiple chronic diseases amongst older people together with too many people using the hospital emergency department as their first port of call for minor illness. High-pressure hospital environments are dangerous to patients and highly stressful for staff. The policy document Transforming Your Care contains many of the right ideas for developing high quality alternatives to hospital care but few believe it will ever be implemented or that the necessary funding will flow to it. Damaging cynicism is becoming widespread.’

In his presentation to the Health Committee on 28 January 2015 Sir Liam stated that he had highlighted paramedics and pharmacists as examples of areas where innovations could take place to improve the quality of care whilst potentially releasing some of the pressure on hospitals.

Existing Transforming Your Care documents, including the Vision to Action Consultation and the Strategic Implementation Plan, can be found at <http://www.dhsspsni.gov.uk/index/tyc.htm>

#### **Q1. Do you agree with the recommendation for a new Transforming Your Care implementation plan?**

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

This is rated 2 – of moderate importance to the LTCA.

LTCANI calls for an honest update on the status of Transforming Your Care in terms of progress against achievement of its recommendations. We would reinforce the importance of its implementation & support renewed action plans to make this happen.

**Q2. Do you agree that alternative models of working for healthcare professionals, including pharmacists and paramedics, should be examined to help address the pressure on hospital services? If so, which staff groups do you feel could have an expanded role?**

Strongly agree

Agree

**Neither**

Disagree

Strongly disagree

Comments:

All available options which could relieve pressure on acute services should be investigated. Analysis of system wide services could also highlight potential sources of knock on pressures to hospital services, which could be alleviated through reconfiguration. Promotion & support of better self-management and patient education could also an also help reduce acute pressures.

#### Recommendation 4

**We recommend that a programme should be established to give people with long-term illnesses the skills to manage their own conditions. The programme should be properly organised with a small full-time coordinating staff. It should develop metrics to ensure that quality, outcomes and experience are properly monitored. It should be piloted in one disease area to begin with. It should be overseen by the Long Term Conditions Alliance.**

The Report states that ‘Many people in Northern Ireland are spending years of their lives with one or more chronic diseases. How these are managed determines how long they will live, whether they will continue to work, what disabling complications they will develop, and the quality of their life. Too many such people are passive recipients of care. They are defined by their illness and not as people. Priority tends to go to some diseases, like cancer and diabetes, and not to others where provision remains inadequate and fragmented. Quality of care, outcome and patient experience vary greatly. Initiatives elsewhere show that if people are given the skills to manage their own condition they are empowered, feel in control and make much more effective use of services.’

The Department launched a policy framework for long term conditions – *Living With Long Term Conditions* – in April 2012. The Public Health Agency chairs a Regional Implementation Group, which includes representatives from the Long Term Conditions Alliance and other key stakeholders, which is overseeing the development of an action plan on long term conditions. This will include consideration of key metrics.

The Living with Long Term Conditions document can be accessed at:  
<http://www.dhsspsni.gov.uk/long-term-condition.htm>

This supports the delivery of the Programme for Government which makes a commitment to enrol people who have a long-term (chronic) condition, and who want to be enrolled, in a dedicated chronic condition management programme. Between 2011/12 – 2012/13 there was a 13% increase in the number of people enrolled in such programmes and a 25% increase in the frequency of such programmes.

**Q1. Do you agree with the proposed focus on enabling people with long term conditions with the skills to manage their conditions?**

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

Self-management techniques can improve the patient experience and have been found to improve clinical outcomes and reduce unplanned hospital admissions. The LTCANI are currently not structured or resourced to oversee the type of programme suggested in the Report but would welcome an expansion of relevant quality programmes and wider involvement in decision-making in the commissioning of programmes.

## Recommendation 5

**We recommend that the regulatory function is more fully developed on the healthcare side of services in Northern Ireland. Routine inspections, some unannounced, should take place focusing on the areas of patient safety, clinical effectiveness, patient experience, clinical governance arrangements, and leadership. We suggest that extending the role of the Regulation and Quality Improvement Authority is tested against the option of outsourcing this function (for example, to Healthcare Improvement Scotland, the Scottish regulator). The latter option would take account of the relatively small size of Northern Ireland and bring in good opportunities for benchmarking. We further recommend that the Regulation and Quality Improvement Authority should review the current policy on whistleblowing and provide advice to the Minister.**

The Report states that 'The regulation of care is a very important part of assuring standards, quality and safety in many other jurisdictions. The Review Team was puzzled that the regulator in Northern Ireland, the Regulation and Quality Improvement Authority, was not mentioned spontaneously in most of the discussions with other groups and organisations. The Authority has a greater role in social care than in health care. It does not register, or really regulate, the Trusts that provide the majority of healthcare and a lot of social care. This light touch role seems very out of keeping with the positioning of health regulators elsewhere that play a much wider role and help support public accountability. The Minister for Health, Social Services and Patient Safety has already asked that the regulator start unannounced inspections of acute hospitals from 2015, but these plans are relatively limited in extent.'

In response to this recommendation the Minister announced, on 27<sup>th</sup> January, that he was seeking to speed up the roll out of unannounced inspections in acute hospitals, and that the 2003 Quality, Improvement and Regulation Order would be reviewed with a view to introducing a stronger system of regulation of acute health care providers. That announcement also advised that proposals would be submitted to the Executive for changes to the existing system of regulation of non-acute services.

More information on the role of RQIA and regulation can be found at [www.rqia.org.uk](http://www.rqia.org.uk)

He also announced that a review of the operation of whistleblowing in health and social care bodies would be undertaken with recommendations on how to improve its effectiveness.

**Q1. Do you agree that the regulatory role of RQIA should be expanded to focus more upon the services delivered by acute hospitals in Northern Ireland?**

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

LTCANI see an increased role for RQIA in the areas outlined with regard to the delivery of Trust services. This should be taken on Board within the Strategic Leadership Group announced by the Minister and take up the recommendation on whistleblowing to strengthen and protect those in the service and patients, service users and carers to improve practice and outcomes.

**Q2. Do you agree that the functions of RQIA should be tested against the option of outsourcing this function?**

Strongly agree

Agree

Neither

Disagree

Strongly disagree

Comments:

As above.

**Q3. Do you agree that the current policy on whistleblowing needs to be examined? If yes, are there any comments you wish to make on how the review is conducted or its scope?**

Strongly agree

Agree

Neither

Disagree

Strongly disagree

Comments:

As above.

:

### **Recommendation 6**

**We recommend that the system of Serious Adverse Incident and Adverse Incident reporting should be retained with the following modifications:**

- **deaths of children from natural causes should not be classified as Serious Adverse Incidents;**

- **there should be consultation with those working in the mental health field to make sensible changes to the rules and timescales for investigating incidents involving the care of mental health patients;**
- **a clear policy and some re-shaping of the system of Adverse Incident reporting should be introduced so that the lessons emanating from cases of less serious harm can be used for systemic strengthening (the Review Team strongly warns against uncritical adoption of the National Reporting and Learning System for England and Wales that has serious weaknesses);**
- **a duty of candour should be introduced in Northern Ireland consistent with similar action in other parts of the United Kingdom;**
- **a limited list of Never Events should be created**
- **a portal for patients to make incident reports should be created and publicised**
- **other proposed modifications and developments should be considered in the context of Recommendation 7.**

The Report states that ‘The system of incident reporting within health and social care in Northern Ireland is an important element of the framework for assuring and improving the safety of care of patients and clients. The way in which it works is falling well below its potential for the many reasons explained in this report. Most importantly, the scale of successful reduction of risk flowing from analysis and investigation of incidents is too small.’

The Minister has announced that he will be instructing the HSCB and PHA to prioritise changes to the Serious Adverse Incident (SAI) system. He has also announced that a Never Events list will be developed for Northern Ireland and that he is beginning the process for creating a statutory duty of candour Northern Ireland.

An Adverse Incident is defined as ‘Any event or circumstances that could have or did lead to harm, loss or damage to people, property, environment or reputation.’ Particular criteria will then be used to determine whether an adverse incident constitutes a Serious Adverse Incident (SAI). More information on the background and procedure for the management of SAIs can be found at: <http://www.dhsspsni.gov.uk/saibackground>

Never Events are a sub-set of Serious Incidents and are defined as ‘serious, largely preventable patient safety incidents that should not occur if the available preventative measures have been implemented by healthcare providers. For more information about the system of Never Events in England, please see: <http://www.england.nhs.uk/ourwork/patientsafety/never-events/>

**Q1. Do you agree with the proposed changes to the Serious Adverse System (SAI) in Northern Ireland?**

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

LTCANI agree that death of children from natural causes should not be classified as Serious Adverse Incidents. We also recognise the value of consultation with those working in the mental health field regarding rules and timetables for investigating incidents involving the care of mental health patients. We would welcome the creation of a patient portal for incident reports drawing on the positive response in other UK systems.

**Q2. Do you agree with the creation of a list of Never Events for Northern Ireland? If so, what do you consider as Never Events?**

Strongly agree

Agree

Neither

Disagree

Strongly disagree

Comments:

**Q3. Do you agree with the introduction of a Duty of Candour in Northern Ireland?**

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

LTCANI supports the proposal to introduce a Duty of Candour in NI.

**Recommendation 7**



**We recommend the establishment of a Northern Ireland Institute for Patient Safety, whose functions would include:**

- **carrying out analyses of reported incidents, in aggregate, to identify systemic weaknesses and scope for improvement;**
- **improving the reporting process to address under-reporting and introducing modern technology to make it easier for staff to report, and to facilitate analysis;**
- **instigating periodic audits of Serious Adverse Incidents to ensure that all appropriate cases are being referred to the Coroner;**
- **facilitating the investigation of Serious Adverse Incidents to enhance understanding of their causation;**
- **bringing wider scientific disciplines such as human factors, design and technology into the formulation of solutions to problems identified through analysis of incidents;**
- **developing valid metrics to monitor progress and compare performance in patient safety;**
- **analysing adverse incidents on a sampling basis to enhance learning from less severe events;**
- **giving front-line staff skills in recognising sources of unsafe care and the improvement tools to reduce risks;**
- **fully engaging with patients and families to involve them as champions in the Northern Ireland patient safety program, including curating a library of patient stories for use in educational and staff induction programmes;**
- **creating a cadre of leaders in patient safety across the whole health and social care system;**
- **initiating a major programme to build safety resilience into the health and social care system.**

The Report states that 'There is currently a complex interweaving of responsibilities for patient safety amongst the central bodies responsible for the health and social care system in Northern Ireland. The Department of Health, Social Services and Public Safety, the Health and Social Care Board, and the Regulation and Quality Improvement Authority all play a part in: receiving Serious Adverse Incident Reports, analysing them, over-riding local judgments on designation of incidents, requiring and overseeing investigation, auditing action, summarising learning, monitoring progress, issuing alerts, summoning-in outside experts, establishing inquiries, checking-up on implementation of inquiry reports, declaring priorities for action, and various other functions. The respective roles of the Health and Social Care Board and the Public Health Agency are clearly specified in legal regulations but seem very odd to the outsider. The Department of Health, Social Services and Public Safety's role on paper is limited to policy-making but, in practice, steps in regularly on various aspects of quality and safety. We believe action is imperative for two reasons: firstly, the present central arrangements are byzantine and confusing; secondly, the overwhelming need is for development of the present system to make it much more successful in bringing about improvement. Currently, almost all the activities (including those listed above) are orientated to performance management not development. There is a big space for a creative, positive and enhancing role.'

**Q1. Do you agree that a National Institute for Patient Safety should be introduced in Northern Ireland?**

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

The LTCANI would welcome the introduction of a Northern Ireland Institute of Patient Safety, and would welcome publication and transparency around it's findings.

There are some current weaknesses in reporting and analysis which needs to be addressed as part of the implementation of a new Institute.

**Q2. Do you agree with the suggested functions which should be included?  
Do you feel there are additional functions relevant to the proposed institute?**

Strongly agree      Agree      **Neither**      Disagree      Strongly disagree

Comments:

Quality 2020:

LTCANI would agree that Quality outcomes are based on safety, effectiveness and patient/client focus

### **Recommendation 8**

**We recommend the establishment of a small number of systems metrics that can be aggregated and disaggregated from the regional level down to individual service level for the Northern Ireland health and social care system. The measures should be those used in validated programmes in North America (where there is a much longer tradition of doing this) so that regular benchmarking can take place. We further recommend that a clinical leadership academy is established in Northern Ireland and that all clinical staff pass through it.**

The Report states that 'The Northern Ireland Health and Social Care system has no consistent method for the regular assessment of its performance on quality and safety at regional-level, Trust-level, clinical service-level, and individual doctor-level. This is in contrast to the best systems in the world. The Review Team is familiar with the Cleveland Clinic. That service operates by managing and rewarding performance based

on clinically-relevant metrics covering areas of safety, quality and patient experience. This is strongly linked to standard pathways of care where outcome is variable or where there are high risks in a process.'

**Q1. Do you agree that systems metrics should be introduced so that regular benchmarking can take place from regional level down to individual service level?**

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

The LTCANI agrees that meaningful measures and targets should be developed, but based on trends rather than data selected arbitrarily. It is important to include relevant condition specific health related outcomes in performance metrics as they are key to measuring the effectiveness of any health service and identifying where resources may be required to improve them. The systems should be safe and secure and facilitate extrapolation of meaningful data

Details of all metrics used must be transparent and publicly available.

It is important that data collected should enable NI to fully participate in all UK wide surveys and assessments. The collection and effective analysis of data can really improve outcomes for patients/users.

Some of our members have suggested that the performance of the health system would be improved using "real time" data, via proven methodologies leading to service improvement and innovation.

Other members would also comment that input of data should not impede clinical work and skew this resource; or create a culture of fear and suspicion within the system. Data in the form of statistics, benchmarking and action plans should be viewed as tools to assist performance management against SLAs with all providers.

We recognise that there will need to be a major culture shift in relation to this recommendation and the change management process around this will need to be carefully considered.

**Q2. Do you agree with the establishment of a Clinical Leadership Academy in Northern Ireland?**

Strongly agree      Agree      **Neither**      Disagree      Strongly disagree

Comments:

Consideration around the role of Northern Ireland Healthcare Leadership Forum needs to happen. LTCANI would encourage development of leadership at all levels within Health and Social Care to support an improved culture across, primarily to improve outcomes and accountability to patients/users. If we are aspiring to world class services and standards, this can not be achieved without leadership.



## Recommendation 9

**We recommend that a small Technology Hub is established to identify the best technological innovations that are enhancing the quality and safety of care around the world and to make proposals for adoption in Northern Ireland. It is important that this idea is developed carefully. The Technology Hub should not deal primarily with hardware and software companies that are selling products. The emphasis should be on identifying technologies that are in established use, delivering proven benefits, and are highly valued by management and clinical staff in the organisations concerned. They should be replicable at Northern Ireland-scale. The overall aim of this recommendation is to put the Northern Ireland health and social care system in a position where it has the best technology and innovation from all corners of the world and is recognised as the most advanced in Europe.**

The report states that ‘The potential for information and digital technology to revolutionise healthcare is enormous. Its impact on some of the longstanding quality and safety problems of health systems around the world is already becoming evident in leading edge organisations. These developments include: the electronic medical record, electronic prescribing systems for medication, automated monitoring of acutely ill patients, robotic surgery, smartphone applications to manage workload in hospitals at night, near-patient diagnostics in primary care, simulation training, incident reporting and analysis on mobile devices, extraction of real-time information to assess and monitor service performance, advanced telemedicine, and even smart kitchens and talking walls in dwellings adapted for people with dementia. There is no organised approach to seeking out and making maximum use of technology in the Northern Ireland care system. There is evidence of individual Trusts making their own way forward on some technological fronts, but this uncoordinated development is inappropriate - the size of Northern Ireland is such that there should be one clear, unified approach.’

**Q1. Do you agree that Northern Ireland should seek to put itself in a position where it has the best technology and innovation from all corners of the world and is recognised as the best in Europe? Should this include the development of a technology hub to identify the best technological innovations?**

Strongly agree

Agree

**Neither**

Disagree

Strongly disagree

Comments:

The LTCANI recognises the important role leading edge technology can have in supporting service improvements and outcomes for patients. All developments should be patient centred. We would point out that the voluntary and community sector in Northern Ireland have excellent examples of innovation in this area, and that this contribution needs to be recognised.

Northern Ireland is a leading member of the European Connected Health Alliance and ECH Alliance is based in Northern Ireland. The LTCANI would therefore welcome clarification about the existing E- Health Strategy and implementation.

## Recommendation 10

**We recommend a number of measures to strengthen the patient voice:**

- **more independence should be introduced into the complaints process; whilst all efforts should be made to resolve a complaint locally, patients or their families should be able to refer their complaint to an independent service. This would look again at the substance of the complaint, and use its good offices to bring the parties together to seek resolution. The Ombudsman would be the third stage and it is hoped that changes to legislation would allow his reports to be made public;**
- **the board of the Patients and Client Council should be reconstituted to include a higher proportion of current or former patients or clients of the Northern Ireland health and social care system;**
- **the Patients and Client Council should have a revised constitution making it more independent;**
- **the organisations representing patients and clients with chronic diseases in Northern Ireland should be given a more powerful and formal role within the commissioning process, the precise mechanism to be determined by the Department of Health, Social Services and Public Safety;**
- **one of the validated patient experience surveys used by the Centers for Medicare and Medicaid Services in the USA (with minor modification to the Northern Ireland context) to rate hospitals and allocate resources should be carried out annually in Northern Ireland; the resulting data should be used to improve services, and assess progress. Finally and importantly, the survey results should be used in the funding formula for resource allocation to organisations and as part of the remuneration of staff (the mechanisms to be devised and piloted by the Department of Health, Social Services, and Public Safety).**

The Report states that ‘In the last decade, policy-makers in health and social care systems around the world have given increasing emphasis to the role of patients and family members in the wider aspects of planning and delivering services. External reviews – such as the Berwick Report in England - have expressed concern that patients and families are not empowered in the system. Various approaches have been taken worldwide to address concerns like these. Sometimes this has been through system features such as choice and personally-held budgets, sometimes through greater engagement in fields like incident investigation, sometimes through user experience surveys and focus groups, and sometimes through direct involvement in the governance structures of institutions. In the USA, patient experience data now forms part of the way that hospitals are paid and in some it determines part of the remuneration of individuals. This change catalysed the centrality of patients to the healthcare system in swathes of North America. Observers say that the big difference was when dollars were linked to the voice of patients. Northern Ireland has done some good work in the field of patient engagement, in particular the requirement to involve patients and families in Serious Adverse Incident investigation, the 10,000 voices initiative, in the field of mental health and in many aspects of social care. Looked at in the round, though patients and families have a much weaker voice in shaping the delivery and improvement of care than is the case in the best healthcare systems of the world.’

The Minister has announced that a framework to strengthen the voice of patients at every level will be designed applying the best available worldwide evidence on measuring patient/client experience.

**Q1. If you are unhappy with the response of a care provider regarding your care, do you agree that the substance of it should be looked at by people who are genuinely independent?**

**Strongly agree**      Agree      Neither      Disagree      Strongly disagree

Comments:

It is the view of the LTCANI that an independent body would support the confidence of patients and service users in the process of complaints and arbitration.

We would also support more transparency around the findings of complaints and actions taken as a result.

**Q2. Do you agree with the proposed changes to the Patient and Client Council?**

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

The LTCANI supports any recommendation or initiative that strengthens the voice of patients in Northern Ireland, and notes with concern the view contained in the Report that the voice in NI is weaker than in other parts of the UK.

We support a Patient and Client Council with wider powers and “more teeth”. The independence of the Patient and Client Council is a vital issue.

**Q3. Do you agree that the organisations representing patients and clients with chronic diseases should be given a more powerful and formal role within the commissioning process? If so, do you have any comments on how this could be best achieved?**

**Strongly agree**      Agree      Neither      Disagree      Strongly disagree

Comments:

The LTCANI believe that organisations representing patients and clients with chronic diseases should have a stronger, formal role in commissioning.

We support the principles of co-design and partnering with patients and carers as “experts from experience”, and believe that this must be the future role of users within Health and Social Care in NI, including commissioning.

This will require a paradigm shift with true patient empowerment and the voice of patients not just captured, but listened to. There is a greater need for transparency

The LTCANI and our membership has a vital role already in articulating the patient experience and would seek a future where the voluntary and community sector is involved more effectively in supporting and representing people with long term conditions in the design and commissioning process.

**Q4. Do you agree that patient experience surveys should be used to rate hospitals and allocate resources accordingly?**

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

The LTCANI would suggest that patient experience metrics should be an integral part of the overall performance management framework of all commissioned services.

Surveys are one way of obtaining the feedback required to support both the rating of the quality of the patient experience but also in allocating resources.

It is our view that other methodologies can also be used e.g. depth interviews, to further support patient information, choice and the publication of results.



## General Comments

Please use the box below to insert any general comments you would like to make in relation to the recommendation from the Donaldson Report.

Comments:

In addition to the individual responses to each of the recommendations below, the Long Term Conditions Alliance Northern Ireland (LTCANI) believes the following overarching issues are also significant:

- a) The focus of the report is primarily on hospitals and the acute sector and highlights the need for a change in the role and relationship between acute and community sectors. The challenge of making this change happen will require more leverage and pressure for reform than has been previously successfully exercised.
- b) Given the focus on self-management and the experience to date of the implementation of Transforming Your Care, there is some scepticism about how seriously to take the recommendations. Radical change needs investment, planning and implementation expertise, which to date has not manifested itself in sufficient quantities.
- c) LTCANI has stressed the importance of leadership with the former Health Minister, & this is echoed by Donaldson who has specifically highlighted the lack of clarity around who exactly is in charge of our complex health & social care infrastructure. The recent reshuffle in Health Ministers, especially after the short tenure in the predecessor, does not provide reassurance of consistent political leadership either. The question of leadership is now more important than ever, in order to provide vision, direction and long term sustainable solutions which will meet the challenges facing us in the next 25 years.
- d) It was widely agreed that much of the rationale for Transforming Your Care (TYC) was that transformation of Health and Social Services was required rather than incremental change. The LTCANI calls for a statement from the Department on its position vis-à-vis the Health Service two years on from the implementation of TYC.
- e) LTCANI seeks clarification as to the overall positioning of the Donaldson review in the context of current health & social care policy & reform. The 'Right Time, Right Place' findings & recommendations appear to have expanded from the original remit 'to examine the arrangements for assuring & improving the quality & safety of care in NI, to assess their strengths & weaknesses, & to make proposals to strengthen them'. In widening its original remit from quality & safety, it is unclear whether the Donaldson review & its recommendations propose to be the principle driving strategic reform in our health & social care system going forward, or where it sits in the context of TYC. LTCANI recommends that the DHSSPS utilises 'The Right Time The Right Place' as the principle driver for change in our health & social care system.
- f) In general summary of the above, there is a feeling that strategic inertia is affecting the health service through weight of policies, reviews, strategies and

initiatives. There is a need for clarity on what the key priorities are and which programmes will be put into action, under which banner. There is a need for leadership to be shown, but this needs to be exercised outside the current administrative boundaries to promote greater innovation and creativity.

If the recommendations in the Donaldson report are to be progressed, we would expect this to be supported by a comprehensive Terms of Reference, which clearly defines the scope of the work as well as the roles & responsibilities of all stakeholders. We specifically seek clarity around leadership, accountability & responsibility roles such as who will sponsor the programme, lead on the implementation of the recommendations & be responsible for outcomes.

**Part B**  
**Equality Implications**

Section 75 of the Northern Ireland Act 1998 requires the Department to “have due regard” to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without. The Department is also required to “have regard” to the desirability of promoting good relations between persons of a different religious belief, political opinion or racial group.

The Department has also embarked on an equality screening exercise to determine if any of these recommendations are likely to have a differential impact on equality of opportunity for any of the Section 75 groups. We invite you to consider the recommendations from a section 75 perspective by considering and answering the questions below. Answering these questions will contribute to the completion of the Department's Screening template and the screening outcome.

**Q1.** Are the actions/proposals set out in this consultation document likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998? If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals.

Yes  No

Comments:

**Q2.** Are you aware of any indication or evidence – qualitative or quantitative – that the actions/proposals set out in this consultation document may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Yes  No

Comments:

**Q3.** Is there an opportunity to better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes  No

Comments:

**Q4.** Are there any aspects of these recommendations where potential human rights violations may occur?

Yes  No

Comments:

**Please return your response questionnaire.  
Responses must be received no later than 22 May 2015  
Thank you for your comments.**



## *Appendix 1*

### *FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS*

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

- the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided
- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature
- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: <http://www.informationcommissioner.gov.uk/>).

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